NICE guideline - Spasticity in children and young people with non-progressive brain disorders:

management of spasticity and co-existing motor disorders and their early musculoskeletal complications

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The problem with good science is...

- Need a good question
- Need a defined population
- Need a defined experiment
- Need to be able to reproduce the experiment
Going beyond the experiment

• Meaningful outcomes for the child and carers

• Wealth of work out there......which bits do we look at? Grading of evidence..

• Making recommendations from primary care to tertiary level services.
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Target population

• Non-progressive brain disorders
  – Cerebral palsy
  – Acquired brain injury
What is the remit?

Management of spasticity and co-existing motor disorders and their early musculoskeletal complications

- Too little
- Too much
- Can’t win!
What is spasticity?

VELOCITY DEPENDANT RESISTANCE
Co-existing motor disorders

Negative signs of the upper motor neurone syndrome

- Weakness
- Loss of coordination
- Poor selective motor control
- Dystonia
- Athetosis
- Chorea
Aims of the guideline

• Help healthcare professionals to select and use appropriate therapies for individual children or young people

• Parents and carers also need guidance on choosing the most appropriate therapy, and to ensure that the time, effort and their own resources are used to the best to enhance quality of life for the child or young person and their family.
Who is the guideline for

- Primary, community and secondary care healthcare professionals
- Commissioners
- Professionals working with children and young people or their families and carers in education or social services
- Children and their families/carers.
How the sections are structured

• Research question
• Evidence
• Studies we would have liked to have seen
• Health economics
• Guidance – section on principles of care
• Key priorities for implementation
• Further research questions
Examples of Key Priorities for implementation

- **Physical therapy (physiotherapy and occupational therapy)**
  Offer to refer children and young people to a physiotherapist who is a member of the local multidisciplinary child development team.

- **Orthopaedic surgery**
  Offer children and young people referral to an orthopaedic surgeon if there is clinical or radiological evidence of hip displacement or spinal deformity.
  Monitor children and young people to identify displacement of the hip and spinal deformity.
What was the data set?

• Physiotherapy 1970 onwards
• Not time set for other evidence

• Towards the end of the guideline development process, the searches were updated and re-executed to include evidence published and indexed in the databases before 8 August 2011.
Physical therapy

What is the effectiveness of physical therapy (physiotherapy and occupational therapy) interventions?
Strengthening

• Lack of evidence but felt that weakness was a part of the problem so strengthening would be useful

• Consensus is that muscle weakness contributes to loss of function or joint deformity
Stretching

• Brief passive stretching – any benefit would be short lived so don’t recommend it

• Poor evidence but consensus is that sustained low load stretch with casting or orthotics was more likely to be effective in maintaining soft tissue length and preventing or limiting deformity.

• Botulinum toxin and delayed casting may improve tolerability
Postural management

• No studies identified the effectiveness of postural Mx

• Consensus was that is played a role however

• More important in the more impaired the child
General therapy activity

• Paucity of evidence of effect of therapy on spasticity but the considered an essential component

• Strongest evidence for task-focused active use therapy – particularly in under 8s - ? Frequency and duration to maintain skills

• Deformity and lack of participation in those who lack access to therapy

• Physical therapy - essential to all treatments and extended role of the therapist
Orthoses

What is the effectiveness of orthotic interventions (for example, ankle-foot orthoses, knee splints, and upper limb orthoses) as compared to no orthoses to optimise movement and function, to prevent or treat contractures?
Orthoses

• Consider AFO for equinus gait

• Comment on how to choose between a fixed and hinged AFO

• An AFO should be worn for at least 6hrs day

• AFOs in walking and non-ambulant children

• No evidence for upper limb orthotics
TLSO (Spinal Brace)

- Absence of evidence that TLSO prevents surgery, may delay it – may be useful for posture management

- Lycra type orthoses – used increasingly despite mixed evidence regarding their efficacy – recommend more research
Oral drugs

What is the effectiveness of oral medications including baclofen, benzodiazepines (diazepam, nitrazepam, clonazepam), tizanidine, dantrolene, clonidine, trihexyphenidyl, tetrabenazine and levodopa?
Oral drugs – recommendations

• Diazepam
  – Short term
  – Spasms

• Baclofen
  – Long term use
Botulinum toxin

What is the effectiveness of the long-term use of intramuscular BoNT A or B in combination with other interventions (physiotherapy, occupational therapy or orthoses) as compared to other interventions at reducing spasticity, maintaining motor function and preventing secondary complications?
Botulinum toxin Guidance

- Benefits outweigh the possible side effects as long as there is a MDT assessment and close monitoring.

- Reassessment should be by the same individual who initially assessed the child.

- No recommendation on interval of injections

- Suggest guidance for injections results in better efficacy and tolerability
Intrathecal baclofen

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Test dose evidence

• Evidence is sparse but single doses can result in reduction in spasticity.

• Evidence that test doses can reduce pain and possibly improve ease of care

• There was no convincing evidence from these studies of change in function or change in dystonia.

• Nevertheless the GDG believed that it would be important to consider these outcomes when relevant to the individual patient undergoing ITB-T.
Recommendation

• Limitation in evidence but consensus is that CITB had the potential to alleviate spasticity and to produce clinically important change

• Members of the GDG with experience of using ITB were also persuaded that in properly selected patients, it could produce important benefits

• Practical recommendations
Orthopaedic surgery

• What is the effectiveness of orthopaedic surgery in preventing or treating musculoskeletal deformity?

• What is the effectiveness of SEMLS in managing musculoskeletal deformity?
Orthopaedics

Surgery can be beneficial in improving function, including mobility, reducing pain and increasing comfort, cosmetic improvements, and preventing deterioration.

Improvements in these areas can have a significant impact on a child or young person’s health related quality of life.
Hip surveillance guideline

- X-ray by 18 months in bilateral CP
- Those with poor prognosis for walking or diplegic CP using an walking aid, or delayed walking
- Repeat x-ray every 6 months if MP>15% or rate >10% per year
Selective dorsal Rhizotomy

![Illustration of brain and spinal cord before and after surgery showing reduced input from sensory fibers](image)

- Brain
- Flexibility
- Stiffness
- Spinal Cord
- Motor
- Sensory
- Muscle
- Before surgery

- Brain
- Surgically reduced input from sensory fibers
- Dorsal Root (Sensory)
- Ventral Root (Motor)
- Muscle
- After surgery

- Long tracts
- Spinal cord
- Dorsal horn
- Sensory neuron
- Dorsal root
- Tendon organ
- Muscle fiber
- Muscle spindle
- Motor neuron
- Ventral horn
- Ventral root
- Ventral root
Selective Dorsal Rhizotomy

- Already a NICE guidance paper on this

- What is the clinical effectiveness of SDR in children and young people with spasticity caused by a non-progressive brain disorder?

- Looked at 7 studies
SDR recommendation

• The GDG concluded that the evidence for a long-term or permanent reduction in spasticity after SDR was not strong, and that the evidence for a long-term improvement in gross motor function was even weaker

• Offer selective dorsal rhizotomy to improve walking ability only in the context of clinical research
Pre and post SDR

Should the guidelines tell us more explicitly the experiments we should be doing?
Summary

- Represents a lot of hard work in a very difficult subject
- Hopefully will standardize assessment and access to treatment across the country
- Emotion vs evidence – How will families start to dictate service provision