Intrathecal baclofen

General principles

Consider treatment with continuous pump-administered intrathecal baclofen in children and young people with spasticity if, despite the use of non-invasive treatments, spasticity or dystonia are causing difficulties with any of the following:

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

Be aware that children and young people who benefit from continuous pump-administered intrathecal baclofen typically have:

- moderate or severe motor function problems (Gross Motor Function Classification System (GMFCS) level III, IV or V)
- bilateral spasticity affecting upper and lower limbs.

Be aware of the following contraindications to treatment with continuous pump-administered intrathecal baclofen:

- the child or young person is too small to accommodate an infusion pump
- local or systemic intercurrent infection.

Be aware of the following potential contraindications to treatment with continuous pump-administered intrathecal baclofen:

- co-existing medical conditions (for example, uncontrolled epilepsy or coagulation disorders)
- a previous spinal fusion procedure
- malnutrition, which increases the risk of post-surgical complications (for example, infection or delayed healing)
- respiratory disorders with a risk of respiratory failure.

If continuous pump-administered intrathecal baclofen is indicated in a child or young person with spasticity in whom a spinal fusion procedure is likely to be necessary for scoliosis, implant the infusion pump before performing the spinal fusion.

When considering continuous pump-administered intrathecal baclofen, balance the benefits of reducing spasticity against the risk of doing so because spasticity sometimes supports function (for example, by compensating for muscle weakness). Discuss these possible adverse effects with the child or young person and their parents or carers.

When considering continuous pump-administered intrathecal baclofen, inform children and young people and their parents or carers verbally and in writing (or appropriate formats) about:

- the surgical procedure used to implant the pump
- the need for regular hospital follow-up visits
- the requirements for pump maintenance
- the risks associated with pump implantation, pump-related complications and adverse effects that might be associated with intrathecal baclofen infusion.

Intrathecal baclofen testing

Before making the final decision to implant the intrathecal baclofen pump, perform an intrathecal baclofen test to assess the therapeutic effect and to check for adverse effects.

Before intrathecal baclofen testing, inform children and young people and their parents or carers verbally and in writing (or appropriate formats) about:

- what the test will entail
- adverse effects that might occur with testing
- how the test might help to indicate the response to treatment with continuous pump-administered intrathecal baclofen, including whether:
    - the treatment goals are likely to be achieved
    - adverse effects might occur.

Before performing the intrathecal baclofen test, assess the following where relevant to the treatment goals:

- spasticity
- dystonia
- the presence of pain or muscle spasms
- postural difficulties, including head control
- functional difficulties
- difficulties with self-care (or ease of care by parents or carers).

If necessary, assess passive range of movement under general anaesthesia.

The test dose or doses of intrathecal baclofen should be administered using a catheter inserted under general anaesthesia.

Assess the response to intrathecal baclofen testing within 3–5 hours of administration. If the child or young person is still sedated from the general anaesthetic at this point, repeat the assessment later when they have recovered.

When deciding whether the response to intrathecal baclofen is satisfactory, assess the following where relevant to the treatment goals:

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

Discuss with the child or young person and their parents or carers their views on the response to the intrathecal baclofen test. This should include their assessment of the effect on self-care (or ease of care by parents or carers). Consider using a standardised questionnaire to document their feedback.

Intrathecal baclofen testing should be:

- performed in a specialist neurosurgical centre within the network that has the expertise to carry out the necessary assessments
- undertaken in an inpatient setting to support a reliable process for assessing safety and effectiveness.

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

Continuous pump-administered intrathecal baclofen

Before implanting the intrathecal baclofen pump, inform children and young people and their parents or carers, verbally and in writing (or appropriate formats), about:

- safe and effective management of continuous pump-administered intrathecal baclofen
- the effects of intrathecal baclofen, possible adverse effects, and symptoms and signs suggesting the dose is too low or too high
- the potential for pump-related complications
- the danger of stopping the continuous pump-administered intrathecal baclofen infusion suddenly
- the need to attend hospital for follow-up appointments, for example to refill and reprogram the infusion pump
- the importance of seeking advice from a healthcare professional with expertise in intrathecal baclofen before stopping the treatment.

Implant the infusion pump and start treatment with continuous pump-administered intrathecal baclofen within 3 months of a satisfactory response to intrathecal baclofen testing.

Support children and young people receiving treatment with continuous pump-administered intrathecal baclofen and their parents or carers by offering regular follow-up with the network team, and a consistent point of contact with the specialist neurosurgical centre.

Monitor the response to continuous pump-administered intrathecal baclofen. This monitoring should preferably be performed by the healthcare professionals in the specialist neurosurgical centre who performed the pre-implantation assessments.

When deciding whether the response to continuous pump-administered intrathecal baclofen is satisfactory, assess the following where relevant to the treatment goals:

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

Titrate the dose of intrathecal baclofen after pump implantation, if necessary, to optimise effectiveness.

If treatment with continuous pump-administered intrathecal baclofen does not result in a satisfactory response, check that there are no technical faults in the delivery system and that the catheter is correctly placed to deliver the drug to the intrathecal space. If no such problems are identified, consider reducing the dose gradually to determine whether spasticity and associated symptoms increase.

If continuous pump-administered intrathecal baclofen therapy is unsatisfactory, the specialist neurosurgical centre and other members of the network team should discuss removing the pump and alternative management options with the child or young person and their parents or carers.

As the infusion pump approaches the end of its expected lifespan, consider reducing the dose gradually to enable the child or young person and their parents or carers to decide whether or not to have a new pump implanted.