Communicating with children with cerebral palsy

Introduction
Children with cerebral palsy often struggle with communication. Their speech may be hard to understand if they experience difficulties with the production of sounds, due to poor control of breathing, tongue and vocal cords. They may also have difficulty understanding the spoken word. Children may have associated learning difficulties, which may be mild, moderate or severe, but may just be related to a specific area of learning. It is important to remember that children who are severely physically affected by cerebral palsy may have average or above average intelligence and understanding.

The right to effective communication
Communication is a basic human right, through which we control our existence, make friends and build relationships. It is the way in which we become independent, learn, make choices and express our feelings, thoughts and emotions. Communication is a two way process, relying on the exchange of ideas. People who cannot express themselves in conventional speech or the written word can become excluded from shared communication unless those around them are prepared to learn how to hear their ideas, wants and needs. A consistent complaint from patients with complex special needs and language and communication disorders is that healthcare providers tend to speak to their parents or carers rather than to them as individuals.

General tips to encourage good communication
• Review any notes available regarding the child’s cognitive ability and level of communication. Do not assume the child has learning difficulties even if their expression is indistinct or they are non-verbal
• Remember that conversations may take longer than usual
• Introduce yourself to the child
• Assess their response to your initial approach – they may make a gesture or verbal response
• Speak to both child and the parents or carers to establish how the child usually communicates and their level of involvement in decision making
• Ask if the child has a communication passport (see later)
• Even if the conversation is mainly with the parents or carers, involve the child in the conversation by frequent eye contact and use of their name
• Ask the child’s permission before any physical contact or examination, and explain the purpose and nature of the examination
• Establish how the child indicates ‘yes’ and ‘no’ and how they express discomfort
• Offer explanations and reassurance in appropriate words and phrases
• Children with cerebral palsy may have learning disabilities in addition to specific difficulties with both receptive and expressive communication
• Spoken communication:
  o Try not to talk too fast – it may take longer for a child with cerebral palsy to process the words they hear
○ Speak in short clear sentences
○ Use everyday words and literal language wherever possible and avoid jargon, abbreviations, acronyms, sarcasm or metaphor
○ Gestures and facial expressions will give visual clues about what you are saying
○ Ask questions one at a time and allow the child time to respond
○ Consider questions which require a yes/no answer if the child’s communication is very limited
  • Don’t pretend to understand the child’s responses if you haven’t – people can spot this immediately and find it insulting. Ask the child to repeat their answer, or invite the parent or carer to interpret.
  • Try to ensure that the child has understood the main idea of your message or ask the parent or carer to explain further
  • If the child uses an alternative or augmentative form of communication (see later), try to engage with this and share a conversation
  • Try not to be impatient, no matter how rushed you are
  • Try to see the individual behind the disability and ensure respect and dignity at all times

**Communication passports**
Some children with cerebral palsy may have a communication passport. This is a simple and practical guide to help people to communicate with a non-verbal child. It contains personal information about the child’s needs, including medical information and their like and dislikes, and is owned by the child. It values the child, gives them a voice and helps to give them some control. It can be very useful in helping new staff / strangers to gain a rapid understanding of the child's personal needs and usually contains positive problem-solving solutions to physical and communication issues. Communication passports are usually updated every six months to allow for progress and changes in circumstances.

**Augmentative and Alternative Communication (AAC)**
Augmentative and alternative communication is the term used to describe methods of communication which can be used to add to the more usual methods of speech and writing when these are impaired. AAC is particularly useful when there are physical difficulties with speech production rather than with cognition. AAC methods are classified as follows:
  • Unaided
    ○ Body language, facial expressions, gestures, signing
  • Aided
    ○ Low tech – writing, drawing, picture boards, symbols, objects
    ○ High tech – requiring a power source – computers, switches, voice output communication aids (VOCA)

There are a range of simple methods to enable non-verbal children to indicate ‘yes’ and ‘no’, for instance:
  • Looking up for ‘yes’ and down for ‘no’
  • Blinking their eyes once for ‘yes’ and twice for ‘no’
• A tight fist for ‘yes’ or an open hand for ‘no’
• Pointing at the words ‘yes’ and ‘no’ on printed cards
If a child has such a system, it can provide the basis for involving them in discussions about basic choices regarding their anaesthetic – for instance options for anaesthetic induction.
Parents and carers are usually keen to assist healthcare providers in communicating effectively with their child, and will be able to explain the form of AAC used at home and at school. Most systems are relatively intuitive, but require patience and enthusiasm to learn. In the limited time available during an anaesthetic assessment, it may only be possible to establish basic communication, but AAC may allow the child to express themselves on important issues including preferences to ensure comfortable positioning, mode of anaesthetic induction, and wants and needs including symptoms such as pain and nausea. AAC methods can also be used to help children to understand the unfamiliar procedures associated with hospital treatment, if verbal explanations are insufficient. One example is the use of a symbol system to create a time-line of a hospital visit, where each step in the process is represented by a symbol which is used as a prompt and a form of explanation. A suggested time-line for a day case admission is available from the Royal College of Anaesthetists website, in the approved leaflets section.

Assessment of pain
Patients with cerebral palsy may be unable to use the conventional pain rating scales, such as the visual analogue scale or the faces scale, due to difficulties in understanding or the physical difficulties of indicating their response. In addition, they may experience pain other than that caused directly by surgical trauma – for instance, they may experience muscle spasms which may cause intense pain if the lower limbs are restrained by a hip spica. In addition, they may have residual aches and pains from lying in an unusual position for some time on the operating table, no matter how carefully padding has been applied to accommodate flexion contractures and/or a degree of scoliosis. AAC methods may assist children in expressing the site and nature of any pain, or other associated symptoms – for instance a larger version of the faces scale or a set of pictures of parts of the body.
For children with profound learning difficulties or complex special needs, alternative behavioural pain scoring systems exist, including scales which are individualised to the patients own observed pain and non-pain behaviour. These are to be recommended where pain assessment and treatment are likely to be difficult, and parent or carer involvement is essential. References to papers outlining various strategies are given with Question 4 in the main text.

Parents
Parents are often exhausted and vulnerable and will expect to receive considerable support to manage their child while they are in hospital. Common complaints from parents of children with special needs include fundamental misunderstandings on the part of staff members about their child’s abilities and needs, lack of suitable facilities to allow moving and handling, bathing and
positioning, and inadequate explanations about the likely effects of surgery and
the procedures involved in the recovery period. Monitoring and alarms,
unexpected events, prolonged recovery times and transient deteriorations are all
difficult to assimilate without comprehensive explanation and reassurance.
Parents are unable to continue to act as their child’s main carer during a hospital
stay, but they often feel underused as a resource by healthcare professionals, in
terms of the assessment of their child. They understand the nuances of their
child’s behaviour and can interpret the expression of discomfort, pain, anxiety, or
other symptoms. Their feeling that something is amiss should be acknowledged
and acted upon, even if the child’s observations do not indicate a cause for alarm.
It is important for healthcare providers to take into account that parents are in a
difficult emotional situation, which will be increasingly stressful if they feel that
their child is being undervalued by inadequate attempts to communicate.

Further resources:
• Visit Scope, the cerebral palsy charity at: www.scope.org.uk
• More information on AAC: www.communicationmatters.org.uk
• Symbol time-line: http://www.rcoa.ac.uk/index.asp?PageID=1693