

## Involving and communicating with patients

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### Key points

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- We need to begin by understanding what makes communication 'effective'.
- There are a number of recognised barriers to communication which need to be addressed.
- Good communication strategies can be learned.
- Communication takes place within a social context.

### Health promotion points

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- It is very important to encourage parents to use objective, non-judgemental language with their children, so that children will realise it is their difficulties with continence and not they themselves that are the problem.
- Demonstrate and encourage use of positive language with both parents and children.

This chapter focuses on communicating with children and families, and on the interactions between children and their parents. The role of the health professional as communicator, facilitator, interpreter and teacher is explored.

The chapter draws on current, limited research, but it also makes use of anecdotal evidence and practical experience.

## **What is communication?**

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Communication can be defined as ‘information sharing’ and ‘exchanging ideas in an interactive manner’. Mullally (2002) defines the term as:

. . . the exchange of information between at least two people, usually accomplished by using verbal language, which can be spoken, written, word processed, typed, printed or displayed on a screen, or non-verbal, which transmits attitudes, values and beliefs relevant to the information exchanged.

Poor communication, on the other hand, can be summed up by the following widely available slogan:

I know you believe you understand what you think I said, but I am not sure you realise that what you heard is not what I meant.

Effective health promotion employs a range of strategies to persuade people to change their behaviour. ‘Persuasion’ being the key word here, it should be evident that sensitivity and tact are particularly important if you are working with children and young people who have a bladder or bowel problem. A sensitive and individualised programme of assessment and treatment is needed if the young person is to be motivated to become a partner in their own care. The approach should be patient-centred and should focus on the particular sensitivities and needs involved. It is vital that anyone involved in paediatric healthcare understands how to share information in an age-appropriate and respectful manner, starting at a point alongside the young people themselves. A positive, no-blame approach is necessary if children are to be able to overcome their feelings of helplessness (see also Chapter 12 by Melinda Edwards).

## **Getting to know your patient**

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### ***Initial contact***

Beginnings are important, and a first contact acknowledgement letter to the child’s family, accepting the referral, helps the child and family to become aware that their concerns and difficulties have been acknowledged and taken seriously. They can now take comfort from realising that help and support are about to become available to them. It is

simply good practice for all families to be offered the opportunity both to rearrange the appointment and to book a language interpreter in advance if English is not their first language.

### ***Communication during the assessment process***

As assessment of the child's problem will take place early in the course of the therapeutic relationship, it is particularly important that good communication underlies this. The importance of information sharing in an age-appropriate and respectful manner cannot be over-emphasised. Nor can the necessity of ensuring that the information given is sensitive to the individual needs of the child.

The assessment needs to be patient-focused, reflecting the young person's experience of life, to have achievable outcomes, and set attainable goals. It needs to be carried out in a way that acknowledges cultural diversity and ethnicity, recognising that approaches to toilet training or dealing with continence problems differ greatly from one country or culture to another. Children need structure, demystification of the problem, appropriate advice and consistent positive reinforcement if they are to be empowered to overcome their incontinence. Celebrating success is important to keep the sense of achievement alive. A non-judgemental manner is crucial, making the child and parents feel accepted whatever they look like, whoever they are. Trust and acceptance are the basis for establishing a helping relationship.

We need to understand that children and young people who suffer continence problems are likely to experience enormous embarrassment and shame, coupled with a sense of overwhelming failure. If they are not given support, they can suffer permanent, life-long consequences such as poor self-esteem, lack of confidence and other damaging consequences. A more detailed examination of the psychological consequences of incontinence is given in Chapter 12 by Melinda Edwards.

To help children and their parents feel at ease, it is a good idea to ensure they have information about what to expect *before* their first clinic visit. Children, and their parents too, are likely to be anxious and embarrassed, so it is important to ask questions in a way which can be clearly understood and won't prejudice the answers. Listening carefully to the child's answers will show him or her that you are genuinely interested in them as well as in their problem.

***Non-verbal communication***

Reading a child's non-verbal signals will help you make a thorough and holistic assessment. Body language can convey powerful messages. For example, excessive fidgeting or poor eye contact may demonstrate a high level of anxiety that is not revealed in what the child actually says. More extreme behavioural examples may include apparent lack of ability to hear, pulling clothes over the face, or walking away to play with toys, for example.

***Communication during the treatment process***

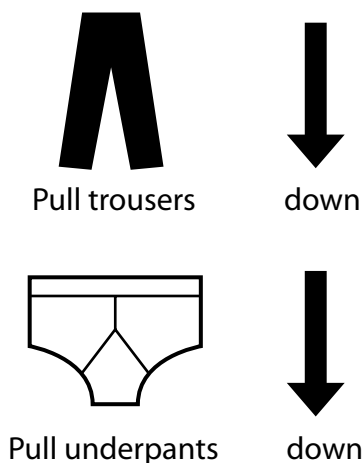
Treatment should reflect assessment, and needs to be easily incorporated into the young person's family context. Providing good information before the first clinic appointment can help to allay fears and cultivate expectations. Charting of fluid intake and recording episodes of wetting or soiling helps the family engage with the idea of tackling the problem. It can be very useful to let children themselves lead the way, by showing the professional their records and charts. This can give them a sense of ownership and taking control, while helping them to understand what information can be revealed about the cause of their problem. Written care plans can be integrated into the child's care pathway. Individual care pathways for the assessment and management of childhood enuresis can be shared documents which function as 'route maps' of the child's journey to completion of treatment. If agreements or contracts of agreed action plans are written up in the presence of the child and parents, and given to them to take away, this can help to motivate them between appointments. Motivation to engage in treatment is more important than the child's chronological age.

**Practical barriers**

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***Language problems***

Useful strategies to employ if the child or parents do not have English as their first language include the use of interpreters (if available), audiovisual aids, diagrams, pictures and drawings, play therapy and anatomical dolls or teddy bears. Alternatively, symbols such as those in Widgett (see Figure 2.1) may be useful.



**Figure 2.1** Step Chart using Widdgit symbols

### *Learning difficulties*

The term 'learning difficulty' is an umbrella term for a wide variety of genetic, social or specific medical conditions which result in a restricted capacity to learn. These may include the autistic spectrum, attention deficit disorder, and global developmental delay. Many children with problems such as these have other difficulties – such as hearing loss or visual impairment – which present a particular challenge to the process of communication (Cokerill 2002).

Both faecal and urinary incontinence have been found to be common in children with additional special needs (Butler and Price 2001). Every child is a complex individual, whose continence cannot be considered in isolation from their other problems. Developmental delay and other difficulties (such as dyspraxia or attention deficit disorder) will interfere with a child's ability to recognise the need to pass a bowel movement or urine.

The prevalence of continence problems in children with physical disabilities in the UK is not known (Brookes 1997). Figures for children with Down's syndrome, however, show attainment of continence to be delayed, but not drastically (Rogers 1998).

It should not be presumed, however, that children with learning difficulties are unable to achieve continence or a higher degree of control, nor that they are unable to become involved in decision-making. The social and family support available will have a major impact on a child's ability to cope with continence problems.