

Chronic physical illness and disability

Mental health problems in children and adolescents may be linked to physical illnesses, including diabetes mellitus, asthma, eczema, congenital heart disease and HIV infection. However, there is a closer link between mental health problems and disorders affecting the brain, such as epilepsy and cerebral palsy, than there is with other physical conditions.

12.1 Physical illness and mental health

Case 12.1

Lakshmi is a 9-year-old girl well known to the local primary healthcare professional because she has chronic asthma. The health professional has learned over the past 3 years since the diagnosis of asthma was made that understanding Lakshmi's mental health and the social conditions in which she lives has been really important in keeping her alive and able to go to school. Some of Lakshmi's asthma attacks come on when she has a cold or the flu or when she has been exposed to pollen in the spring. Some of her worst attacks are triggered by excitement and disappointment. Helping her parents to prevent Lakshmi getting too excited at the time of festivals and present-giving has reduced her attacks. A year ago, Lakshmi started to refuse to go to school because she was worried about having an attack there. The health professional was able to talk to the teachers to explain what should be done if Lakshmi had an attack in school and this reassured the teachers so that she was able to attend regularly. Lakshmi's family lives in an overcrowded shack in a poor part of the city. There is nothing that the health professional can do about the living conditions, but she was able to help her mother and father to stop smoking so that the air at home was less polluted and there was more money to spend on food. Now Lakshmi has started to be very disobedient and does not want to take the medication that seems to prevent the attacks. The health professional will have to try to understand this non-adherence with treatment and also help Lakshmi understand why it is important for her to take her medication regularly if it is to help.

Of course not all children who attend primary care clinics have such a rich set of links between their physical illness and their mental health and social circumstances as described in the case above, but many children have at least one of these features.

12.1.1 *Information about physical illness and mental health*

Chronic physical illness is common. About one in five children are affected by conditions such as asthma, eczema, diabetes, spinal deformities, heart conditions and tuberculosis. Children with a physical illness have about twice as many mental health problems as other

children in the population. Certain physical illnesses have a much higher rate of associated mental health problems. These include epilepsy and other conditions affecting brain function.

There is no particular type of mental health problem linked to physical illness, although children with illness affecting the brain have a particularly high rate of difficulties with activity, attention and concentration. Sometimes the mental health problems arise directly from the illness, for example a child with a brain tumour might be depressed on learning of his prognosis. Often mental health problems are triggered by stresses, such as parental mental illness, that might be experienced by all children regardless of whether they have a physical illness or not.

Cultural influences affect the way parents and children themselves see their illness. This has implications for treatment. For example, if the parents of a child with a curvature of the spine believe that their child has been bewitched, this will affect the way the health professional talks to them about the ways in which the child might be helped.

Chronic physical illness may have an effect on the self-esteem of children. They may think that they are not worth bothering about, that it would be better if they had not been born or, to the contrary, they may feel special and pleased that they get so much attention. All this will affect their likelihood of becoming, for example, depressed, anxious or aggressive. In addition, parents react in many different ways to having a child with a chronic physical illness. For example, some parents are brought closer together by having a shared problem to face and deal with. With other parents, the child's illness may lead to arguments, even to separation and divorce.

The care of a child with a physical illness is likely to involve extra expense, for example in buying medicines or taking time off work to bring the child to a health clinic or hospital. The health professional should bear this in mind when counselling parents. The lives of brothers and sisters of a child with a chronic illness are often affected. They may be very caring or resentful. This will have an impact on family life that parents may find it helpful to discuss.

Some children with acute or chronic physical problems may need admission to hospital, usually for short periods but sometimes for weeks at a time. In LAMI countries, virtually all children admitted to hospital are accompanied by an adult, usually a parent or other relative. Most children are upset, at least to some degree, by having to come into hospital. If possible, admissions should be avoided by investigating and treating children as out-patients.

12.1.2 Principles of mental healthcare in children with physical illness

- Try to be alert to the ways in which the mental health of children with a chronic illness may be affecting the illness and the approach you should take in assessment and management.
- Listen to all the concerns parents express about their child with a physical illness. Sometimes these concerns may not be about the illness itself but may be even more important than treating the illness.
- Before you talk to children and parents about what might be the cause of an illness and how it might be managed, always find out from them what their ideas are and what they have already tried.
- If at all possible, try to see both parents (if available) at least from time to time. This will help communication between the parents.
- If parents or children get upset when you see them, show them that you understand how they feel and are prepared to share their pain (e.g. 'I know how hard this is for you'), rather than changing rapidly to another subject.
- Try to learn about the child's social circumstances. For you, the child's problem will, rightly, come first. However, it helps to understand a mother's apparent disinterest in her

child's condition if you know that her main concern is for her husband to stop beating and sexually abusing her when he comes home drunk every night.

- Keep in mind that a large part of a child's life is spent in school. The signs of illness and behaviour in school may be very different from that at home. If possible, get to know the local school and keep in touch with teachers about children with a chronic physical illness. They may have very useful information to give you. With the parent's permission, you can provide information to them that may enable them to give the child a better experience in school.
- Try to help parents feel that they are doing a good job looking after their child. It is very easy for parents to feel that they are failures. Give praise wherever you can, even for care that seems to you rather minimal, especially if you have seen at least some improvement.
- As with children with a physical disability, know what is available locally that might help families with a child with a chronic illness. If there are other parents with a child with a similar problem, consider putting them in touch with each other so that there can be some mutual help and support.
- If parents and/or children are not following treatment instructions, try to understand why this is happening rather than just telling them off. Understanding sometimes leads to change, while telling off rarely produces adherence – more commonly it results in resentment and even less adherence.
- When children are admitted to hospital in LAMI countries, they are nearly always admitted with an accompanying adult, usually a parent or other relative. All the same, a hospital admission is likely to be an upsetting experience for the child. The following measures will help to reduce distress.
 - Parents should prepare young children for admission to hospital by telling them stories about other children admitted to hospital and reading such stories from books.
 - Parents should never threaten children with admission to hospital if they are naughty.
 - If an admission is planned, then the child might be able to visit the ward and meet the staff before being admitted so that it will not be so strange to him later on.
 - If an emergency admission is necessary, this will be easier if the parents have explained about hospitals to the child beforehand. Emergency admission is so common that parents should educate their children about hospitals in cases where hospitalisation is anticipated or may be necessary.
 - Children should be prepared for all unpleasant procedures in a way suitable for their age. Children should not be given procedures without any warning.
 - Nursing and medical staff should be trained in working with children and in understanding how children react to stress.
 - If possible, children should have nurses allocated to them so that they become familiar with two or three members of staff and learn to trust them.
 - The organisation of the ward routine should be child-centred and not arranged for the convenience of the staff.
 - As far as possible, the food provided should be what the child is familiar with.
- Working with very sick children is very stressful. This should be generally understood, and young, inexperienced staff should be encouraged to talk to their seniors about how they are feeling about their work.
- Parents should expect their children to be upset when they are discharged from hospital, however good the care has been. They should be prepared to give their children extra attention at this time.

12.2 Physical disability

Case 12.2

An 8-year-old boy, Dilip, was carried to the clinic by his mother to see the health professional because of an eye infection. Although the health professional thought she knew most of the people living in the community she served, she had never seen Dilip before. She had seen his mother but did not know of Dilip's existence. Dilip had been unable to move his legs from about the age of 18 months after contracting meningitis that had left him brain-damaged. It turned out that Dilip's mother was deeply ashamed of having a son with a disability. It had taken a lot of courage for her to walk to the clinic carrying her son in front of her neighbours, but she had been worried he would lose his sight so she had had to come. The health professional prescribed some drops for Dilip's eyes and reassured the mother that the infection would be cured in a short time. She talked to Dilip and found that he also seemed to have some learning problems. He had never been to school and had been looked after entirely at home. The health professional wondered whether she could do anything to help in addition to prescribing the eye drops.

12.2.1 Information about physical disability in children

Physical disability is relatively common in children living in LAMI countries. The exact frequency is not known, but in many areas about 2 in every 100 children have a disability severely affecting their movements. Physical disability may show itself in a variety of ways:

- impairment of movement
- visual impairment
- hearing impairment
- intellectual impairment, specific or general intellectual disability
- a combination of the above – this is common; for example, cerebral palsy may be accompanied by intellectual disability.

Although in high-income countries most physical disability is caused by genetic disease, in LAMI countries infection is the most common cause. Poliomyelitis, tuberculosis and meningitis are the most common infections producing physical disability. In some areas, HIV/AIDS is also a significant cause. Cerebral palsy or the inability to move one or more limbs as a result of brain damage is also relatively frequent. This may be due to a genetic disease, injury during pregnancy, at birth or early in life, head injuries or infection.

Parents often think that their child has a physical disability because of witchcraft or other causes related to their religious beliefs.

Infectious disease is linked to poverty and poor social conditions, so physical disability is more common among disadvantaged groups. Parents and other caregivers are often financially stretched, with very little support, either material or emotional.

A high proportion of children with physical disability do not go to school. They are also often excluded in other ways, socially isolated and stigmatised. This may be related to the shame their parents experience.

Children with a physical disability may receive poor healthcare and have low rates of immunisation. They may be neglected at home, with care passed on to elderly grandparents or servants who ill-treat them.

Children with a physical disability have a high rate of mental health problems, occurring at least twice as frequently as in children without such disabilities.

Access to aids that would make a great difference to their lives, such as wheelchairs, prostheses and hearing aids, is often limited. When support is available, it is more likely to be provided by charitable organisations than by the government.

All this should not obscure the fact that some children with a physical disability are well looked after, have good healthcare, have access to the aids they need, attend school and lead happy and fulfilled lives.

Now, given the information you have obtained, try to understand how the physical disability is affecting the life of this particular child. Then go on to work out a plan to help.

12.2.2 What the health professional can do to help children with a physical disability

To begin with, health professionals need to make their own observations as well as to find out from the parents and child the following.

- Is the child well cared for? Is there evidence of neglect or physical abuse such as bruising?
- Is the child getting good healthcare? Has the child been immunised?
- Is the child in school? If not, why not?
- Has the child access to aids that might make a difference to his quality of life, such as a wheelchair, prosthesis (artificial limb), hearing aid or spectacles?
- Is the mother getting help from her family or from the community?
- Is there a voluntary organisation that might be able to help with financial support, counselling or aids to daily living, such as handrails and ramps?
- Does the child have a mental health problem? Children with brain damage are particularly likely to have attention and concentration problems, but they may also have significant depressive feelings and anxiety, or behaviour problems.

Having assessed the situation, the health professional may be able to help in a number of ways.

- Carefully check all aspects of health and disability, as simple treatable problems are often easily missed in children with a disability. For example, treating constipation, providing appropriate spectacles, ensuring good dental health and good hearing, and treating epilepsy can often greatly improve a child's quality of life, even when only supportive treatment is available for the main disability.
- Give advice on nutrition and hygiene; without such information, it may be difficult for the parents to manage.
- If the child is not in school, check why this is and whether there is a way in which he might attend, even if only part time.
- Check on the health status of the child and, for example, ensure he is up to date on immunisations.
- If it seems as if the child's mobility or sensory abilities could be improved, put the parents in touch with a charitable foundation that could be helpful in the provision of aids or financial support.
- If the child has a mental health problem, give advice as suggested elsewhere in this manual, depending on the nature of the problem.
- Talking to influential people in the community about ways in which the parents might be helped to feel less stigmatised and more included in community life.
- Put the parents in touch with other parents who have a child with a physical disability so that they can find mutual support.

12.3 Hearing impairment

Case 12.3

Rahul was a 7-year-old boy who was brought to the health professional by his father, who said his son was always in trouble at school for being naughty and not paying attention. The health professional talked to Rahul and noticed that the boy seemed to be paying close attention to her lips when she spoke. She turned the boy round and asked him in a quiet voice to put his finger on his nose. The boy did not move. She then turned the boy to face her and made the same request. The boy did as he was told. What should the health professional do?

12.3.1 Information about children with poor hearing

Hearing impairment in a child may be mild to severe, depending on the amount (measured in decibels) of hearing loss. Deafness can be caused by:

- a problem of conduction of sound through the external (outer) or middle ear: this usually produces mild to moderate deafness. It is most commonly due to wax blocking the outer ear and chronic middle-ear effusion – serous otitis media (infection in the middle ear or ‘glue ear’);
- sensorineural damage: the nerves carrying impulses from the ear to the brain may be affected by genetic conditions or by damage resulting from viral infection of the fetus, especially by cytomegalovirus or rubella;
- damage to the cochlea (the inner ear where sounds are turned into electrical impulses that go to the brain): this can happen after a child has had meningitis and can also be due to drugs such as antimalarials and aminoglycosides, as well as persistent loud noise.

The most important effect of hearing impairment is on language development (see Section 4.2). Even mild hearing loss may result in delayed language development. Poor language development may lead to learning and reading difficulties.

Behaviour may also be affected. Children who cannot understand instructions because they cannot hear them are likely to become frustrated. This may result in:

- temper tantrums and disobedience
- problems of attention and distractibility (which may seem like ADHD, although rarely children may have both conditions)
- emotional problems with anxiety or depression
- social difficulties in mixing with other children.

12.3.2 Finding out about children with hearing impairment

Children born with poor hearing need to be identified as soon as possible after birth. It is possible to diagnose hearing loss accurately in babies shortly after birth, but this requires expensive equipment. Such equipment (otoacoustic emissions and automated auditory brain stem response) will not be readily available to most health professionals working in primary care. In a small number of centres in LAMI countries, all babies are screened using such equipment, sometimes in association with the local immunisation programme.

Without such equipment it is possible to obtain a reasonably good idea whether a child aged between 7 and 9 months has hearing loss by asking the mother whether the infant turns his head in the direction of speech or noises and whether he reacts with a startle response to sounds such as clapping behind his ears. The health professional can try making a quiet noise, with, for example, a rattle, behind the child’s head when the child’s attention is engaged

elsewhere and observing whether the child's head turns. However, even if the child turns its head, it may have done so for other reasons and still be deaf. If there is any doubt about the child's hearing, the child should be observed and retested when a little older. In cases of doubt, if at all possible the child should be referred for more detailed testing. If the mother expresses any concerns about her child's hearing, they should be taken very seriously. Parents are usually accurate when they suspect deafness.

With older children, aged 3 years or more, a more accurate diagnosis can be made even without expensive equipment, if the child does not have significant intellectual disability. The health professional should cover their mouth with a sheet of paper and taking care to look only at the child's eyes, give a simple command such as 'Show me your nose'. A normal child should be able to respond accurately and quickly at the lowest voice level when the examiner is about a metre away. A child who does not turn his head to a whisper behind him is likely to have mild hearing impairment. Lack of response to a normal voice means that there is probably moderate impairment. A child who does not respond to a loud voice probably has severe impairment.

If a child is deaf, examination of the child's eardrum may show the ear canal to be full of hard wax, a dull yellow eardrum if there is fluid behind it or a red eardrum if there is infection. A child who has had many ear infections may have a perforation (hole) in the eardrum, although these examinations need some practice and skill. Most conductive losses are mild or moderate. Children with sensorineural deafness more often have severe hearing loss. In all children with developmental, behaviour or emotional problems, the possibility of hearing loss should be considered. If there is any possibility of hearing impairment, this should be investigated with the best available equipment.

It is particularly difficult to diagnose or rule out deafness in some children with ASD as they are unresponsive to sounds most of the time. They are, however, very likely to pay attention and even become agitated when they are exposed to unfamiliar sounds. Some children with ASD, especially those for whom congenital rubella is responsible, are likely to have an associated hearing impairment.

Sometimes children with only moderate hearing problems have the greatest behaviour and emotional problems because the hearing difficulties have gone unnoticed – they know others are talking to them or possibly about them but cannot communicate this and can become very upset or appear disobedient.

Now, given the information you have obtained, try to understand how this child's hearing problem has arisen and is affecting his life. Then go on to work out a plan to help.

12.3.3 *Helping children with hearing impairment*

If, from the information provided by the family and from observation, it seems likely that the child does have a hearing impairment, then if at all possible the child should be referred for more expert diagnosis and advice on treatment. If no expert advice is available, and it is not possible for the child to be fitted with a hearing aid, then the following measures should be taken.

- 1 Treat the cause. This is not likely to be possible with sensorineural deafness, but an infection in the middle ear may be treatable with antibiotics or simple surgical procedures if someone with specialist surgical expertise is available in the area. Wax in the external ear can be gently and carefully removed. This is best done by putting 2 or 3 drops of warm vegetable oil in the ear daily for about 2 weeks.
- 2 Make family members and school teachers aware of the hearing loss. If mild or moderate hearing loss is present, they will need to speak more clearly and ensure that the child can

- see them easily when they are talking. Background noise should be kept to a minimum. In severe hearing impairment, they will need to develop sign language with the child.
- 3 Any associated developmental (especially language), behaviour and emotional problems should be managed as described in the relevant sections.
 - 4 Children whose language is delayed because of mild or moderate hearing impairment should be helped to communicate using every possible means. Further, it should not be assumed that because their language is delayed they lack intelligence. Their abilities in manual tasks not involving language should be noted and encouraged.

Now write down what the health professional can do to help Rahul.

12.4 Visual impairment

Case 12.4

Ajit is 2 years old when his mother brings him to the clinic because he does not seem to understand simple requests like her other children did at his age. She has not brought him to the clinic before. The health professional notices not only that Ajit's development is more like that of a 1-year-old, but that he does not seem to look around or notice anything that is going on around him. What should the health professional do about his possible visual problem?

12.4.1 Information about children with limited sight or lack of sight

Visual problems in children are often present from birth or develop in early childhood. Some are caused by genetic defects, as a result of damage to the baby's brain around the time of birth or because of an infection picked up in the womb or shortly after birth. The most common causes of blindness are vitamin A deficiency, measles, conjunctivitis in the newborn, congenital cataract, and retinopathy of prematurity. If a baby is born blind, it is sometimes only recognised several weeks after birth when it is noticed that his eyes do not follow a moving object such as a face, or the baby is very late to smile in response to the mother's face. Most, but by no means all, children with visual problems that have been present from birth also have some degree of intellectual disability. They are often slow in their motor, language and social development. Although onchocerciasis or 'river blindness' and trachoma are common causes of blindness in adults, visual problems are not usual in children with these infections.

Children who are blind usually have roving eye movements and do not appear to focus on anything. Children with poor sight often have a squint or lazy eye where the eyes do not move together so that the child may be seen to be looking with only one eye. Older children with visual problems (nystagmus, paralytic squints) may also look at things at an unusual angle. Severe visual problems in children are also associated with:

- various habits or mannerisms not seen in other children, such as rocking, eye pressing, repetitive noises and flapping their hands in front of their eyes
- a high rate of behaviour and emotional problems, especially anxiety disorders.

Some of the additional difficulties in children with visual impairment from birth are caused by physical damage or poor function of the brain or visual pathways. However, some difficulties are environmental and open to change.

- Lack of appropriate stimulation. The usual types of stimulation provided to children will not help the development of a child with visual impairment. Stimulation and games involving touch and sound need to be encouraged.

- Depression in other family members, especially the mother who may be very upset and possibly blames herself for her child's condition.

Later in childhood, it may become clear that a child's reading problem is caused by short- or long-sightedness. The child may be holding a book very close to his eyes or may only be able to watch the television if sitting very close to the screen.

Vitamin A deficiency is common in areas where diets are poor. Children can be affected from 1 year of age – the first signs are difficulty seeing in the dark (night blindness) and white spots on the sclera (whites of the eyes). Vitamin A supplementation for every baby and young child is important to help prevent this form of blindness in areas where this is a problem.

Measles can cause scarring of the cornea, especially in children with vitamin A deficiency. It is important to ensure all children are immunised against measles and any child with measles is correctly treated and has their eyes examined for corneal ulcers.

12.4.2 *Finding out about children with visual impairment*

- The baby may be brought to the health clinic because the mother suspects that her child cannot see. The baby may not seem to notice objects or be slow to smile or startle and seem surprised when the mouth is touched. The eyes of a baby that is blind often move rapidly from side to side.
- Visual impairment may be confirmed by passing a finger or a light in front of the baby and observing whether the eyes follow it. The baby may fail to blink when a hand is moved rapidly towards the face as if to strike it.
- As blindness is often caused by a genetic defect, babies suspected of being blind should be carefully examined for the possible presence of other genetic problems such as deafness and heart defects.
- Babies identified as visually impaired need careful developmental assessment (see Section 4.1) as they are likely to be delayed in other aspects of their development.
- A baby suspected of visual impairment needs referral to a specialist centre if one is available.
- A child over 1 year who has a squint should be referred to a specialist if one is available. The child may need spectacles and some children may be helped by an operation on the eye muscles to help the eyes move together.
- When an older child needs to hold a book close to their eyes or to get near to the television to watch programmes, the child's eyes will need testing. The child should go to the local optician, if available, to get prescription spectacles.
- Children with significant long sight, some of whom may have a squint, may find reading or studying tiring.
- A quick and easy way to check for eye-sight problems is by using the pinhole test. Punch a small hole in a paper card and ask the child to read while looking through the pinhole. If the child can see better through the pinhole, it is suggestive of problems with refraction. Note that children will often be able to see easily for most simple vision tests, so if it is possible, the child should have their eyes checked by an optician/optometrist.

Now, given the information you have obtained, try to understand how this child's visual problem has arisen and is affecting his life. Then go on to work out a plan to help.

12.4.3 *Helping babies and children who are visually impaired*

Babies who are blind or severely visually impaired need as much non-visual experience as possible. It is important to let them learn about the world by using their other senses,

putting objects into their hands, and making sure they recognise objects by their feel and smell. Babies who cannot see their mothers and other family members are very likely to find separation from them more difficult. Babies and young children should be reassured when left alone, even for brief periods.

Family members should be encouraged to talk to babies who are visually impaired about things they cannot see, about what is happening to them and around them. Particular attention should be given to the encouragement of language development using other ways (see Section 15.4).

Children with visual impairment who develop anxiety problems should be treated as described in Section 7.3.3.

In older children with learning difficulties, vision should always be tested to check whether there is a need for spectacles.

What can the health professional do to help Ajit's visual problems?

12.5 Cerebral palsy

Case 12.5

Abhi is a 7-year-old boy brought to the clinic by his mother because he is not eating properly. The health professional has known Abhi since he was 6 months old. To begin with, he had developed normally, but after a few months his mother noticed that when he kicked his legs his right leg did not move as much as his left. He did not seem to use his right arm when he held things. The health professional had tested the power on his left side and found it was normal but his right arm and leg were definitely weak. Abhi was diagnosed with congenital hemiplegia. This is a type of cerebral palsy present from birth. It was not known why Abhi had this problem but his mother had had a small bleed when she was 7 months pregnant and it may have been that the left side of his brain had been deprived of oxygen and been damaged. Generally, Abhi was making good progress. He had been slow to walk but now was walking well, although with an obvious limp. He could even run without falling over. His speech had developed normally. He was a friendly boy.

Why was he not eating properly? It turned out that he was being teased at school where he was called 'Hoppy' by other boys because of the way he walked. At playtime when the boys chose sides to play football, Abhi was never chosen until right at the end, and then no one wanted him on their side. He was coming home miserable every afternoon and not wanting to eat his supper. What could the health professional do to help?

12.5.1 Information about cerebral palsy

Cerebral palsy is a condition where the part of the brain controlling movement is damaged. Cerebral palsy is congenital. The brain is abnormal: either it has not developed properly or it was damaged during pregnancy or during birth. There are various types of cerebral palsy:

- quadriplegia: all four limbs are weak
- diplegia or paraplegia: both legs are weak, but not the arms
- hemiplegia: one side of the body is weak
- ataxia: balance is poor and movements unsteady
- dyskinesia: involuntary movements, especially writhing (athetoid) movements, are present.

Many children with cerebral palsy were born prematurely. Sometimes the premature birth occurred because the brain had not developed normally but sometimes part of the brain was damaged during a difficult birth or by a bleed into the brain shortly after birth. The damage to the brain that is responsible for the weakness may cause other problems.

- Low intelligence. Often, but by no means always, present. It is especially likely to occur with diplegia and quadriplegia. Sometimes children with cerebral palsy may be thought to have low intelligence because they have great difficulty making themselves understood. If one helps them to communicate and takes trouble to understand them, it may turn out that they have much higher intelligence than seemed likely. Children with cerebral palsy are often much brighter in some ways than in others.
- Problems with perception. The child may have difficulty telling the difference between shapes, causing delay in learning to read. They may have difficulty finding their way about because they cannot differentiate right from left.
- Coordination of movement. The child may be clumsy either because of weakness or because the part of the brain controlling movement is damaged.
- Feeding problems. The child may have coordination problems with swallowing, making it difficult for them to eat. This means they often put on weight slowly after birth.

Children with cerebral palsy are more likely than other children to have emotional and behaviour problems. They are especially likely to have problems with attention and concentration. The emotional and behaviour problems may occur either because of brain damage or because they face unusual stresses, such as learning difficulties, teasing and humiliation. They may be excluded from activities in which other children take part. This may result in low self-esteem and depression.

The presence of a child with cerebral palsy may cause tensions in the family, with parents disagreeing on how best to manage the child. Brothers and sisters may feel left out. However, there are often positive aspects to having a child with a physical disability in the family. Parents may be drawn closer together, and brothers and sisters may learn that children who are 'different' may still be lovable and make a great contribution to family life.

12.5.2 Finding out more about children with cerebral palsy

- Find out the extent of the weakness. What parts of the body are affected and which parts are working well?
- Is the child being given the opportunity to move the weak parts of the body as much as possible? Are the limbs that are very weak being moved regularly so that the joints do not stiffen up?
- How is the child communicating? Can the child's communication be improved?
- Is the child being educated as well as possible? If he has difficulty getting to school, can arrangements be made to help him to get there?
- Is the child being excluded from having friendships with other children? Can more be done to help him to mix with others of his age?
- Does the child have any behaviour or emotional problems? If so, are these receiving attention as suggested in the relevant sections of this book?
- How is the family coping? Can the parents talk to each other about the problems caused by having a child with cerebral palsy? Are other children able to discuss how they feel about having a brother or sister with a disability? What do they see as the positive sides of this situation?
- What do the parents know about the reasons why their child has cerebral palsy? Are they feeling guilty about the disability, thinking they had something to do with causing it?

Now, given the information you have obtained, try to understand how the cerebral palsy is affecting the life of this particular child. Then go on to work out a plan to help.

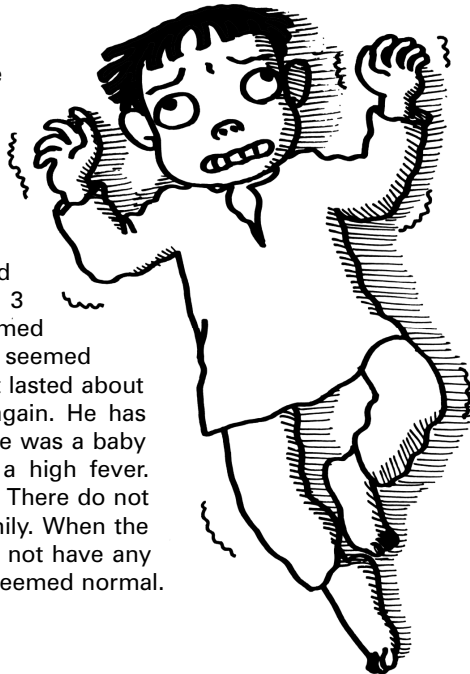
12.5.3 *Helping children with cerebral palsy*

- Try to develop a good relationship with both the child and the parents so that they trust you.
- Have a discussion with the child about his life, taking into account his ability to communicate.
- After checking weakness and power in the limbs, make sure the weak limbs are being regularly exercised and moved. This will prevent the joints from stiffening up.
- If physiotherapy and/or speech therapy are available locally, make sure that the parents are put in touch with these professionals for further advice. Speech and language therapists may be helpful in providing advice about feeding problems, especially in young children.
- If the child is having problems in school such as learning difficulties, being bullied or difficulties in making friends, contact the school to see whether more help can be provided.
- If the child has an emotional or behaviour problem or difficulties in attention or concentration, make sure that the child and parents are receiving appropriate help (see relevant sections of this book).
- Discuss with the parents their views about the reasons their child has cerebral palsy. Help them to express what may well be inappropriate feelings of guilt.
- Discuss with the parents how they see their child's future. It may be difficult for the parents to make plans for the future, but usually they will appreciate the opportunity to discuss this.

12.6 Seizures/fits (epilepsy)

Case 12.6

Samir is a 12-year-old boy brought to the clinic by his mother because he has had two seizures. These came on without warning. He had said, 'Mum, I don't feel well' and then a few moments later he fell to the ground with his arms and legs making regular, jerky movements. He did not answer to his name and had noisy breathing. The seizure lasted about 3 minutes, after which Samir gradually seemed to 'wake up'. He got up from the floor and seemed dazed. At this point he had a headache that lasted about an hour. Then he was perfectly all right again. He has not had any fits like this before but when he was a baby he had attacks of shaking when he had a high fever. Nobody else in the family has had seizures. There do not seem to be any unusual stresses in the family. When the health professional examined Samir, he did not have any weakness of his face, arms or legs and he seemed normal. What should the health professional do?



12.6.1 Information about seizures/fits

There are two main types of seizure (also referred to as fits or attacks):

- 1 epileptic seizures
- 2 non-epileptic seizures.

Epileptic seizures

In an epileptic seizure there is a sudden discharge of electricity in the brain. This may affect:

- the whole of the brain (generalised seizure), or
- part of the brain (partial seizure).

Reasons for epileptic seizures include:

- family members with epilepsy, particularly febrile convulsions – this suggests a genetic cause;
- pre-existing brain damage or dysfunction – children with developmental problems such as severe intellectual disability, cerebral palsy or autism are more likely to have epilepsy. The brain may have been damaged in the past by a head injury, meningitis or cerebral malaria. Often there is no identifiable condition or illness, occurring in children who have a genetic vulnerability to seizures;
- epileptic attacks that may be triggered by exposure to bright, flashing lights;
- symptomatic seizures that may occur as a result of a brain tumour, an infection in the brain such as meningitis, malaria, tuberculosis, sleeping sickness or tapeworm, or low blood sugar level, especially in a child with diabetes who has taken too much insulin.

In many societies it is believed that a person with fits/seizures is bewitched or is inhabited by evil spirits.

Most children who develop epilepsy need medication on a long-term basis, but they can lead normal lives, go to school and study like other children.

Children with epilepsy have an increased tendency to show behaviour and emotional disorders. These can be caused by the epileptic trigger, by the seizures themselves or by anxiety and the discrimination related to the diagnosis of epilepsy. It may also be caused by normal every day stresses. Most children with epilepsy, however, do not have behaviour or emotional disorders.

Generalised epileptic seizure

When the whole of the brain is affected (generalised epileptic seizure), the child or adolescent may show some or all of the following signs:

- usually has little warning but may sense that an attack is coming on
- falls to the ground, sometimes after a brief scream or cry
- jerky movements of the arms and legs
- eyeballs may roll upwards
- may go pale or blue because of the lack of oxygen
- is unconscious and does not respond to his name
- may bite his tongue
- may lose control of the bladder and pass urine
- comes round slowly and has a period of confusion or headache, lasting anything from a few minutes to a few hours
- the attack usually lasts a few minutes but may go on for as long as several hours (status epilepticus).

With other types of generalised seizure, the most common indicator is momentary loss of consciousness with staring of the eyes, blinking and, very occasionally, facial twitching. In the classroom, affected children may stop what they are doing, stare vacantly for a brief period and then resume the same activity as before without realising anything has happened. These are called absence attacks or *petit mal* and may occur on their own or alongside generalised epileptic seizures.

Partial epileptic seizures

Partial seizures present in a variety of ways, depending on where the electrical activity is occurring in the brain. The child is likely to get a warning – an aura – that a seizure is coming. This aura may be a smell or taste, or an unusual sensation often felt in the abdomen. This may be followed by a feeling of fear, tightness of the chest, hallucinations or odd automatic behaviour, such as smacking of the lips. Some partial seizures may cause jerking or weakness of just one part or side of the body (face or limb) and may then sometimes spread to become a more generalised seizure. This can last for a few minutes up to as long as a few hours (partial continuous epilepsy). The child may respond to his name and even carry out requests but is clearly not completely conscious. The attack may be followed by a headache

Fainting

Another type of attack that may be mistaken for a fit/seizure is a faint. In a faint, a child feels dizzy and unsteady. The child may fall to the floor but will not lose consciousness except perhaps for a moment or so. If the child sits or lies down he immediately begins to feel better. There are usually no jerky movements or other signs of an epileptic seizure. These episodes may follow a temper tantrum or after a sudden surprise. Occasional faints are not a sign of illness and do not require any special treatment. However, children who are ill or dehydrated or hungry are more likely to faint.

Non-epileptic seizures

Non-epileptic seizures occur both in children who have epileptic seizures and in those without. They are usually brought on by stress. In non-epileptic seizures the child:

- may show a variety of attacks, often different from each other
- may fall to the floor
- may show movements that appear purposeful
- may appear to be unconscious but will often respond to questions or to his name
- will not change colour, pass urine or harm themselves
- will have normal reaction of the pupils to a bright light.

Some infants and young children up to the age of about 4 years have fits/seizures whenever they have a high fever. These fits are called ‘febrile convulsions’. When they occur frequently they need the same first aid as for any generalised fit and the child should be undressed and allowed to cool, but not be allowed to get too cold. Paracetamol should be given as soon as possible to reduce the fever. Most children with febrile convulsions do not go on to develop epileptic seizures of the type described above, but a minority do.

12.6.2 Finding out more about children with seizures

The first important task when a child or adolescent comes to you with a seizure is to work out what type of seizure it is. You will need to know:

- whether the attack seemed to have been triggered by anything
- exactly what the attack looked like

- what, if any, warning the child had
- whether the child was unconscious, partially conscious or completely conscious during the attack
- how long the attack lasted
- what happened after the attack.

Given this information, you should be able to work out whether the child has had a generalised epileptic seizure, a partial seizure, a non-epileptic seizure or possibly more than one type of attack.

If the child has either a generalised or partial form of epilepsy you will need to decide whether there is a physical cause. Does the child have a temperature or other signs of an infection? Are there signs of meningitis, tuberculosis, sleeping sickness, etc.? A physical examination of the arms and legs to see whether there is any weakness may be helpful. At this point if there is someone with more expertise available, you should refer for further investigation, especially if an underlying illness is suspected or the fits are frequent.

If the child's fits/seizures are apparently non-epileptic and he does not have epileptic seizures, talk to the child and parents about the stresses the child may be experiencing. Remember that generalised or partial fits/seizures may very occasionally also be brought on by stress.

Now, using the information you have obtained from the child with epilepsy or another type of seizure and the family member(s) you have seen, try to understand what has happened and decide what is the best course of action.

12.6.3 *Helping a child with seizures*

The steps below should be followed if you see the child in a fit or are recommending to parents what to do when the child has a fit.

- 1 Turn the child onto one side.
- 2 If necessary, remove him from danger and place some soft clothing under his head.
- 3 Leave the child alone to recover; in particular, do not try to force anything into his mouth, do not try to restrain him and do not force him to take a drink.
- 4 If the seizure goes on for more than 5 minutes, put a diazepam suppository (0.5 mg/kg) into the child's rectum.
- 5 If the seizure goes on for more than 10 minutes, insert another diazepam suppository.
- 6 If the child has an underlying cause for the epilepsy, such as meningitis, tuberculosis, tapeworm or sleeping sickness, then this will need treatment. In the case of meningitis, the need for treatment will be urgent.

A child who has had more than two or three seizures will need medication. Where there is an identifiable underlying cause, treatment will usually be needed for both the underlying cause and the fits if they are recurrent.

Medication (anticonvulsants) for fits/seizures

- Medication will reduce or even stop seizures that have been happening repeatedly.
- Some children may need to take medication for the rest of their lives.
- You should use the anticonvulsants recommended on the basis of efficacy and cost.
- Only prescribe one anticonvulsant at a time. That way you will be able to know which medication is causing improvement/side-effects.
- Remember, all anticonvulsants may have side-effects, especially drowsiness and difficulties concentrating, or occasionally behaviour problems such as hyperactivity.

- If the side-effects are severe on the dose of medication needed to stop the fits completely, it may be better to reduce the dose a little and accept that the child may have very occasional fits.

Note that if a child with fits/seizures is showing unusual behaviour between attacks, this may be the result of abnormal brain activity that is not producing a full-blown epileptic attack. It may also be due to an underlying physical or mental health problem. Further investigation including, if possible, an electroencephalogram should be carried out.

12.6.4 *Advice to children and parents of children with epilepsy*

Children with epilepsy who do not have another disability can lead a normal life, go to school, learn well and later on get a job, marry and have children.

Teenagers with epilepsy should try to lead a healthy lifestyle, drinking alcohol only occasionally, taking part in a normal level of exercise and having regular meals.

Children with epilepsy should not swim unaccompanied because of the very small risk of having a fit in the water and drowning.

12.6.5 *Community education*

Health professionals should take every opportunity to reduce stigma in the community in which they work. Often the most severe disability experienced by a child with epilepsy is not caused by the illness but by the social isolation imposed by other children, other parents and the community. Health professionals should educate the community that epilepsy is not caused by black magic or evil spirits and has nothing to do with supernatural forces. Some parents will not let their children go to school or play with a child with epilepsy because they are worried their children will 'catch' it. Epilepsy is not contagious and cannot be passed on from one child to another like an infection. It is a disorder of the brain.

Now make a list of the ways in which the health professional might be able to help Samir.

12.7 Diabetes mellitus

Case 12.7

Pranav is a 14-year-old boy brought by his mother to a health clinic on the outskirts of the city. About 6 months ago he was diagnosed with diabetes in a specialised clinic at the main city hospital. He had been referred to the city hospital by the health professional to whom he had now returned. Six months ago he had been suffering from thirst, excessive drinking and loss of weight. His blood and urine had been examined and found to show sugar levels much above normal. At the hospital he had been put on medication and told to lose weight and do more exercise. He had been given a glucometer to measure his blood sugar once a day. At the time he was diagnosed, Pranav was very overweight. Over the past 6 months he had not kept to his diet and had indeed put on weight rather than lost it. He had been taking the medication he had been prescribed but this was expensive, costing about a fifth of the family income. His mother left the use of the glucometer to him but she knew he was not using it regularly. She wanted to go back to the specialist clinic, but the fares to the city hospital were too expensive for more than one person to go and Pranav's mother did not think it was a good idea for Pranav to go by himself. So she had brought him to the health professional who had first made the diagnosis. Pranav had not wanted to come as he thought he would be told off. What can the health professional do?

12.7.1 *Information about diabetes mellitus*

Diabetes mellitus is a disease caused by insulin failure. Insulin is a hormone that regulates blood sugar levels, making sure they do not fall too low or rise too high. There are two types of diabetes:

- 1 type 1 diabetes – the cells producing insulin are destroyed and so cannot produce insulin. This condition is acute, very serious and if left untreated may result in a coma and then death over a few days or weeks;
- 2 type 2 diabetes – cells produce insulin but the body does not respond to the hormone, so it is ineffective. This (insulin-resistant) type is closely linked to obesity. It is much more chronic in its course.

Until the 1990s, children and adolescents virtually only had type 1 diabetes. Now, because of the increase in the rate of obesity in many middle-income countries, type 2 diabetes is increasing in frequency.

The increase in the rate of obesity has been caused by teenagers doing less exercise, together with an increase in calorie intake/the amount of food they eat (see Section 6.2).

12.7.2 *Finding out more about children with diabetes mellitus*

The diagnosis of diabetes mellitus is usually fairly easy to make. Excessive thirst, increased urination and loss of weight are the main presenting symptoms in both types, but the course of type 1 diabetes is much more rapid. Patients with either type 1 or type 2 diabetes may present with recurrent infections.

It is important to make the diagnosis promptly. Increased thirst may be mistaken as a symptom of anxiety and the diagnosis missed for this reason. A raised sugar level in a simple urine test will make the diagnosis highly probable. Missing a diagnosis of type 1 diabetes can result in a fatal outcome.

Occasionally it is difficult to decide whether an adolescent has type 1 or type 2 diabetes. Most, but not all of those with type 2 diabetes are seriously overweight, while type 1 is not linked to any particular body size. Blood tests are necessary to distinguish between the two.

Assessment should involve judging how well the child and family can cope with the treatment necessary.

Now, given the information you have obtained, try to understand whether the diabetes is being well treated and how it is affecting the life of this particular child. Then go on to work out a plan to help.

12.7.3 *Helping children with diabetes mellitus*

Treatment of both types of diabetes involves first of all education about the condition and its treatment. In type 2 diabetes, the importance of increasing exercise and reducing food intake needs to be stressed from the start.

If the child has type 2 diabetes, he will need insulin injections. In type 2 diabetes, oral medication can be tried first, although insulin injection may be required. The child, together with his parents, needs to be taught how to use a glucometer and, if necessary, how to change the amount of insulin or dose of medication accordingly. A specialist nurse or doctor can do this.

There are various ways of delivering insulin. All at the moment require injections either with a needle or an insulin pen.

Inadequately treated diabetes results in the development of many complications. It can reduce vision, affect kidney function and nerves, and lead to ulceration in the legs. The latter is usually seen later on in life in people who have had diabetes for at least 10 years. It is really important that diabetes mellitus is treated as well as possible so that these complications can at least be delayed.

Now, given the information you have obtained, try to understand how this particular child with diabetes is affected in everyday life. Then go on to work out a plan to help.

12.7.4 *Helping the mental health of children with diabetes mellitus*

- Prevention: the health professional should use every opportunity she can to alert parents and children to the dangers of being overweight.
- Practical advice on how to exercise more and how to reduce calorie intake is much more helpful than vague encouragement. Here are some tips.
 - First, ask the teenager what ideas he has for increasing exercise and reducing food intake. Build on these ideas rather than imposing your own ideas, although you may have some new suggestions that the child and family have not thought of.
 - The best exercise is that taken as part of daily life, not as a special activity. Encourage walking or cycling instead of taking a bus to school or when going shopping.
 - Talking to teachers about making regular physical exercise and competitive games a more important part of the curriculum is worthwhile.
 - Avoiding snacking is especially important for weight loss. However, snacking is often an important part of teenage life. Try to help the adolescent to snack on a bottle of water and very low-calorie foods when with friends.
 - Changes in the pattern of exercise and in dietary habits are never easy but are easier if the whole family tries to change at the same time. This is often necessary as if a teenager is overweight, the chances that the parents and siblings are overweight is substantial.
- Keeping in touch with a specialist clinic may be very difficult for a child and family. By using email or telephone, the health professional in a clinic some distance away may be able to help to keep the family in touch with specialist expertise.
- The health professional might put the child and family in touch with other young people with the same condition. A small group of teenagers, some of whom have diabetes and some who are seriously overweight, might be a source of mutual support.
- Non-adherence with treatment is a common problem in teenagers with diabetes mellitus. It may arise from:
 - poor explanation to the teenager about the importance of adherence and the likelihood of complications if the treatment programme is not followed – further explanations may be necessary;
 - a poor relationship between the child and the parents leading to the child using non-adherence as a weapon against his own parents – this will need discussion with both parents and with the child;
 - misery/sadness/depression in the young person leading to low self-esteem and to not caring what happens (see Section 7.7.4);
 - other associated behaviour or emotional problems (see relevant sections for advice).
- Some young people rebel against diabetes and subsequently have a condition that is very difficult to control. These cases need expert, specialist help if at all possible.

Now make a list of the ways in which the health professional might be able to help Pranav.

12.8 HIV/AIDS

Case 12.8

Shasti is a 9-year-old girl brought to the clinic by her grandmother with whom she lives in a small town in South Africa. Both of Shasti's parents died of AIDS before she was 4 years old. Shasti can hardly remember them because they were too ill to look after her even before they died. Shasti was born HIV negative, but her mother breastfed her and she became HIV positive at about 18 months. She was immediately put on antiretroviral therapy and has been on it ever since. Her outlook is, her grandmother has been told, quite good. She may live well into adult life if she keeps taking the antiretrovirals. However, she is becoming uncooperative. Further, the grandmother is concerned about what will happen when Shasti enters puberty. Girls of 13 and 14 are often sexually active in this part of South Africa. Her grandmother thinks that Shasti does not know that she is HIV positive. At the moment Shasti is a normal, healthy girl. What should she be told? How can the health professional help?

12.8.1 Information about psychosocial aspects of HIV/AIDS

Acquired immunodeficiency syndrome (AIDS) is the group of infectious and neurological diseases which people with human immunodeficiency virus (HIV) develop if they are not treated, and from which they die. HIV/AIDS infections are most common in African countries, especially in southern Africa. They do occur nearly everywhere else in the world but much less frequently.

Nearly all HIV infection is passed on during sexual intercourse. It is also transmitted by infected blood during blood transfusion and by infected needles used by drug users. Most children with HIV have been infected in fetal life because the virus was in their mother's bloodstream. A smaller number are infected because the virus was in their mother's breast milk. A very small number are infected as a result of sexual abuse. The false belief that intercourse with a virgin can cure a man with AIDS has led to an additional number of girls being infected.

Untreated, most children with HIV at birth die by the age of 5 years. Treated with antiretroviral therapy, most will survive well into adult life. Although the number of children with HIV treated with antiretroviral therapy has increased, there are still a number of infected children who are not treated. It is really important that children receiving antiretroviral therapy take it regularly if they are to benefit from the treatment. This is often very difficult for carers who are likely to be struggling with a number of other stresses.

HIV infection can be passed on during sexual intercourse even by people who are receiving antiretroviral therapy. People who are on antiretroviral therapy need to use condoms when having intercourse to avoid passing on the infection.

Parents with AIDS often have difficulty looking after their children properly because they are easily tired and may be in pain. If their brain is infected they may become disabled with dementia or other neurological disorders. Children with HIV whose parents die may be resented because they are seen as a burden. Many children with HIV infection are orphaned in early life, are looked after by relatives or in institutions, or live in child-headed households.

Children with HIV for whom treatment is not available show:

- feeding problems
- failure to thrive
- repeated infections
- slow speech development
- if the child survives long enough, gradual deterioration of intelligence
- increased rates of behaviour and emotional problems.

Children with HIV are often discriminated against even in parts of the world where the disease is common. Parents and grandparents may feel guilt and shame about the condition. Many children with HIV infection have not been told of their diagnosis to protect them from painful news about their parents and themselves. This puts those with whom they have intercourse later in life at considerable risk of developing the infection.

Families with a child with HIV are likely to be living in poverty.

In many places where HIV is prevalent there are clinics available to counsel children, adolescents and adults with this condition. Pregnant women are in particular need of counselling. These clinics also counsel carers who are looking after children whose parents have died from HIV.

12.8.2 *Finding out more about children with HIV/AIDS*

- Find out about the social circumstances in which the child is living. Is the child living with the parents or were they unable to look after the child? Who is living with and looking after the child?
- Is the child being well looked after or is he being neglected because his presence is resented as an additional burden, or because there are no adults looking after him?
- Is the child receiving antiretroviral therapy? If not, can this be obtained? If the child is receiving it, is it being taken regularly? It is worth asking the child why he is taking this medicine.
- If the child is not receiving antiretroviral therapy regularly, why is this? Is the child being resistant, are the carers being negligent in this respect or are there difficulties in obtaining the medication?
- What has the child been told? Does the child know about his condition and its implications for later life? If not, why has the child not been told?
- Does the child have any behaviour or emotional problems?
- Is the child attending school regularly? If not, is this because the carers have unrealistic ideas about other children at school catching the disease? Or is it because they are ashamed and do not want the family to be humiliated? Or is it because they cannot afford the school fees?
- In the case of a teenage girl, is she sexually active? If so, is she using contraception?
- Has the family been put in touch with the local HIV counselling service?

Now, using the information you have obtained from the child with HIV/AIDS and the family member(s) you have seen, try to understand what has happened and decide what is best to do.

12.8.3 *Helping children with HIV/AIDS*

- Discuss the care of the child with whoever is looking after him. Note any problems arising from shame and guilt over the cause of the child's condition. Make sure the carers (parents or others who have taken over the parental role) realise you are sympathetic to them and understand how they feel. Make it clear that you do not blame them for anything that has happened. It is just your job to help as much as you can.
- If the child is receiving antiretroviral therapy, check that this is being taken regularly. If there are problems with adherence, then take steps as suggested in Chapter 17. Note that it may be very hard for carers to ensure adherence if they have other stresses to cope with. If the child is not receiving antiretroviral therapy, find out whether this can be made available to him.
- Identify any problems in development the child may have and offer advice on how to promote development (see Section 15.4).

- If the child is not attending school regularly, find out why this is and see whether you can offer advice to improve school attendance.
- In the case of a sexually active teenage girl not using contraception, make sure the girl is given and has access to contraceptive advice.
- Identify any behaviour or emotional problems the child may have and offer management along the lines suggested in the relevant sections elsewhere in this manual.
- Help the carers to discuss the child's HIV status with the child as well as its implications for later life. Put the carers in touch with the local HIV counselling service if there is one.

Now make a list of the ways in which the health professional might be able to help Shasti.

12.9 Sickle cell disease

Case 12.9

Nelson is a 9-year-old boy with known sickle cell disease who was brought to the health clinic with acute pain in his legs and shoulders. He was crying with the pain which he had had many times before. The health professional gave him some tablets for pain relief and then enquired about his life at home and school. It turned out that he was missing a great deal of school, sometimes because of the painful episodes but often because his mother kept him at home just in case he had another attack. What should the health professional do?

12.9.1 Information about sickle cell disease

This is a disorder of the blood caused by a defect in haemoglobin. The defect causes the red blood cells to clump together and block small blood vessels. This results in a reduction of oxygen supply to the tissue, producing acute pain lasting a few hours to several days. Episodes of pain can be triggered by infection, cold or dehydration, but sometimes there is no obvious trigger. The frequency of pain is very variable. The condition is an autosomal recessive genetic blood disorder. Both parents are carriers of the gene but are unaffected. If both parents are carriers, there is a one in four risk of their having a child with sickle cell disease. The child may have anaemia and require occasional blood transfusions. The condition occurs all over the world but mostly in sub-Saharan Africa.

If it is possible for children to take folic acid as a supplement and penicillin from 3 months of age this will prevent pneumococcal infection to which children with sickle cell disease are prone. This needs to be taken for at least the first 5 years, but preferably on a lifelong basis. Children need to be well hydrated, especially when in hot environments or when exercising.

Treatment of the condition mainly consists of managing the painful episodes with analgesics such as paracetamol and anti-inflammatory agents; sometimes opioids will be needed. The child should also be given fluids by mouth.

The painful episodes affect both family and school life, with numerous school absences. Affected children should be encouraged to take a full part in school life. They may be anxious between episodes about when the next attack will occur. With good medical management, children with this condition can survive into late adulthood.

Parents should bring a child with this condition back to the health professional if the child runs a high fever, becomes very pale or develops breathing difficulties.

12.9.2 Finding out about children with sickle cell disease

The diagnosis requires laboratory facilities which are available in places where the condition is endemic. Blood samples should be sent away if the condition is suspected and there are no such facilities available locally.

- Does the child have anaemia? If so, he may need a blood transfusion.
- Is the child receiving appropriate pain management when painful episodes occur? Most pain can be managed at home.
- Does the child have any behaviour or emotional problems? In particular, is he so anxious between attacks that his ability to attend school is affected?
- What is the attitude of the parent(s)? Do they ensure that the child gets appropriate pain management? Are they so anxious between attacks that they are unnecessarily preventing the child from leading as normal a life as possible?
- Do the teachers know about the child's medical problem? Are they well informed about what to do when the child has a painful crisis?

Now, using the information you have obtained from the child with sickle cell disease and the family member(s) you have seen, try to understand how the condition is being managed and decide what the best course of action is.

12.9.3 *Helping children with sickle cell disease*

In most areas where sickle cell disease is widespread there is a community-based pain management service available. This service will also be able to carry out blood tests, check whether the child has anaemia and perform blood transfusions if necessary.

The health professional responsible needs to be familiar with the best means of pain management, using analgesics and how to manage other common complications such as infection, pain arising from the spleen and acute chest conditions.

If the assessment has revealed that the child's life is more limited than really needs to be the case, the health professional needs to see the parents and child both together and separately to counsel them on how the child can be helped to lead a more normal life. The health professional should make contact with the child's teachers to ensure they are also involved in helping the child to lead as normal a life as possible.

The genetics of the condition need to be discussed with the parents (and eventually with the child) to make sure that they are aware of the risks of having another child with the condition. If appropriate, they should be given effective contraceptive advice.

As the child gets older, he will need to be able to discuss his condition so that he can gradually take over responsibility for his own healthcare.

Now describe what the health professional might be able to do to help Nelson.

12.10 Mental health aspects of life-threatening illness

Case 12.10

Manasa is a 10-year-old girl brought to the health professional in a clinic in a poor rural area by her mother, with weakness, breathlessness, severe loss of weight and loss of appetite. She has had a chronic cough and breathlessness for the past 2 years. A diagnosis of tuberculosis was made a year ago and Manasa was put on anti-tuberculosis drugs. These had only been taken irregularly and her condition had gradually worsened. It was now clear that Manasa was terminally ill. It had already been explained to the parents that this was a chronic illness, and that if she did not take the tablets, Manasa would die before she reached adult life. Now her chest condition seems worse and her mother had noticed she has lost a great deal of weight. The health professional, from her previous experience, thinks that Manasa probably only has a few weeks to live. Both Manasa and her mother look very anxious. What should the health professional do?

12.10.1 *Information about life-threatening illness*

In poor areas of LAMI countries, most deaths in childhood are caused by a combination of malnutrition and infectious disease and occur in the first 2–3 years of life, although it is also common later in childhood.

The five most common causes of childhood deaths are pneumonia, diarrhoeal diseases, malaria, measles and malnutrition, the last being an underlying cause in more than half the deaths. Tuberculosis is also a very common cause of death and AIDS is another significant cause in many parts of southern Africa. In infants, birth asphyxia is a common cause of death.

In contrast, in high-income countries and in areas of LAMI countries where nutrition is adequate, most childhood deaths occur in the first year of life from genetic disorders such as congenital heart disease and other congenital malformations. In later childhood and adolescence, most life-threatening illness in high-income countries and affluent areas of LAMI countries arises from cancer, cystic fibrosis and congenital malformations. The most common cancer is acute lymphoblastic leukaemia, for which highly specialist, expensive treatments are effective.

Mental health problems in life-threatening illnesses are similar to those in chronic illnesses that are not life-threatening (see Section 12.1.2), but there are additional issues. These will be summarised here.

When children and adolescents enter the terminal phase of an illness, health professionals such as doctors and nurses often see their main role as prolonging life. This is the case even when it is clear that the quality of life will be very poor. Many health professionals find it difficult to accept that perhaps a more important task is to help make the last few weeks/months as comfortable and meaningful to the child and family as possible. The presence of a life-threatening illness will always have a marked impact on the lives of parents and of the child.

Nearly all families in LAMI countries with a child with a terminal illness will view the illness as having religious meaning. They are likely to visit their temple, mosque or church asking for divine intervention. When the child dies, they will continue to believe that the child's spirit lives on, for which they are likely to pray and consult with their local priests.

As with other chronic illnesses, a life-threatening disorder may put stress on the parents' relationship, resulting in arguments and quarrels. Such a stress may, however, also bring parents closer together as they face a common threat.

A terminal illness may add financial burdens to the family budget, perhaps because of the need for medication or travelling to hospital appointments. Such expenditure on one child may make other children in the family resentful. The lives of brothers and sisters of the child with a chronic illness will, of course, often be affected in other ways.

Parents usually wish to protect their children against the knowledge of the fatal nature of their illness. However, most children are aware of the seriousness of their condition, although many do not talk about it because they wish to protect their parents from distress.

12.10.2 *Finding out more about the child with a chronic life-threatening illness*

- If at all possible, some time should be spent alone with the parent(s) and some time alone with the child.
- Make sure that, as far as resources permit, the child's illness is being treated appropriately, especially as far as relief of distressing symptoms, such as pain and breathlessness, are concerned.
- Find out whether the parents have a realistic idea of the length of life that can be expected. Check how much they think the child knows about the likely outcome.
- If there are genetic implications of the child's condition, are the parents aware of these?

For example, parents with a child with sickle cell disease have a one in four chance of having another child with the same disorder.

- Ask about the effect the illness is having on the child's life as well as on the lives of other members of the family.
- Ask about the religious practices that the family observes.
- Ask about any financial implications of the illness and whether the family can manage on their resources.
- If the child is still at school, check whether he is having any difficulties getting there. Is the child being bullied at school? Are the teachers well informed about the nature of the child's illness?
- Are the parents being appropriately protective of the child? Is the child being allowed to do as much as one might reasonably expect given the nature of his illness? Is he being overprotected? Is he being rejected and very much left to fend for himself?

12.10.3 Promoting the mental health of children with chronic life-threatening illness

Ensure the parents are well informed of the genetic implications of their child's condition and that he is being treated appropriately with the best available symptom management. Be aware that it is desirable to use sufficient medication to relieve symptoms even if the medication might shorten life.

Encourage communication about the illness within the family and between the parents and the school. If at all possible, see both parents together so that any disagreements between them can be discussed.

Health professionals are likely to share the same beliefs of their patients concerning the religious meaning of the terminal illness of a child and the afterlife. If the health professional is from a different culture and does not share the same beliefs, she should not discourage these beliefs as they are usually a source of great comfort. In addition, she should encourage the family to use all the community supports available. Close family and friends, priests or ministers of religion and traditional healers may all provide such support.

If appropriate, arrange to see the parents after the child has died to enable them to express their feelings about what has happened. Encourage them to talk with their other children about what has happened, so that the child who has died can be talked about in the family without anxiety or embarrassment.

Now make a list of the ways in which the health professional might be able to help Manasa.