

Sick children in the family

Information and guidance for parents
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Introduction

In our work with sick children, we have often met parents who feel they are alone. They meet little understanding from people who are not involved and cannot imagine what it is like living with a sick child in the family. Many have little support from people around them, who do not see how hard going day to day life is. The child may need forms of treatment that are very trying for the parents, treatment which requires a high level of expertise shared by a small number of hands. It may, therefore, also be difficult for parents to get the information and support they need to help them through the critical phases of their child's illness.

This book is intended to relay some of the knowledge we have acquired through our contact with sick children and their families, so that it can be of help to others in similar situations.

We hope parents will recognise themselves in our descriptions. This may normalise the overwhelming and often frightening feelings that may arise, as «it's normal to think like that».

Parents are the most important providers of support and care for children there are. When they are well-informed, they become more secure in their role as parents. Information can also help to mobilise the network surrounding the family.

Some people will probably prefer to dip into this book, or look up the sections they particularly want to read about. We have therefore described some situations several times, from a slightly different angle according to the circumstances of illness we are discussing.

We have focused very little in this book on illnesses which are minor and of short duration. Our emphasis will be on situations where children develop acute, chronic and/or life-threatening illnesses.

There may be many people who may feel that we have concentrated on the negative aspects, the strains of having sick children in the family, and they may feel

that we have overlooked or covered up the fact that there are many positive consequences of having a sick child. A child who has an illness is equally valuable as a healthy one. And it is important to point out that everyone will not experience all the problems we have brought up in this book. All the same, we have focused on the problems, because they are what we want to do something about.

1. The framework around the child and the family

The child's place in the family and society

Family patterns change from one generation to the next, and children today have a different position in the family than formerly. Parents choose to a large extent how many children they want to have and when they want to have them. Children are their parents pride and joy, and they have a great deal of their parents' time, involvement and feelings invested in them. It is an extremely vulnerable situation when the life and health of these children are threatened.

Great progress has been made in medicine during the last few decades, and infant mortality has been drastically reduced. This has led to a strong and often unrealistic belief that medical treatment will always be able to save people from most diseases. This sense of protection, a feeling of invulnerability, is severely shaken when a child becomes seriously and perhaps terminally ill.

Different family patterns

A family's reaction to a child becoming ill and the way they deal with the situation, depends on their whole life situation. The extent to which help and support are available is of great significance for the way families cope in a stressful life situation. The family situation is, therefore, decisive for how they attain mastery of the tasks confronting them. On the whole, this book makes the presumption that the parents are living together, or if not, that they are sharing responsibility for the children. If the mother or father has sole responsibility as parent, the question of relief and support becomes especially important. Isolation and loneliness can often become a problem for these very small families.

For those whose extended family is small or who have moved away from their original home area, there will be less participation from others. This



makes them more vulnerable. The creation of new families after a break-up can provide new resources, as there are then more people to involve. But if new relationships bring about conflicts, the situation can become very complicated.

People from other cultures can feel uncertain and poorly understood when they meet the Norwegian health service. Existential questions and traditions of co-operation become extremely important in connection with serious illness. Rituals and ceremonies can be of great significance for a family's ability to master the situation. If the support services are unfamiliar with the traditions of other cultures, these families access to an important source of support may be limited.

A short description of different types of illness

Different illness present different symptom pictures and patterns of reaction. They may also in fact have different status both in the health service and in the rest of society. This is significant for the way the child and the parents are met and the support they receive.

To give an overview, we will describe some groups of illnesses to illustrate this. This can, however, only be an incomplete categorisation, and is not sufficient to describe the situation of the individual child and the individual family. We have chosen to concentrate on four categories:

Acute, life-threatening illnesses

Examples of acute, life-threatening illnesses are serious infections, meningitis or anaphylactic shock. Acute injuries and accidents are also included in this group. Characteristic for these situations is that they occur without previous warning, the circumstances can be dramatic and there is no time to prepare oneself for the situation. Relatives often feel extremely helpless, and the reactions to acute crises have particular characteristics.

Illnesses which affect new-born children

The reason for focusing separately on illnesses which affect newly born children is that there are particular burdens in connection with this situation, which are difficult to compare with others. These children are born ill, they are born as «patients», and know no other reality. This can have an effect on the bonding process between the parents and the child. It may also be difficult to «interpret» the child because it is impossible to distinguish between what is connected to the child's personality and way of being and what is the result of the illness.

Chronic conditions

Chronic conditions, illnesses which one does not recover from, or which will in any case last for several years, will have a marked effect on the everyday life of the family. Certain aspects of the family's life will have to be altered and adapted to the needs of the sick child.

Chronic complaints make the child's development of skills, self-image and independence more challenging, and the same is true for the child's social adaptation. Examples of this kind of condition are: diabetes, asthma, allergies, rheumatic illnesses, epilepsy and certain heart conditions.

Chronic, life-threatening illnesses

A number of chronic illnesses can essentially be both serious and terminal. However, medical treatment may be able to extend a child's life considerably, and many can live an almost normal life or become completely healthy. In other cases, there may be an overshadowing threat or the certainty that the outcome will be death. This is a tremendous additional burden which intensifies the challenges of everyday life for the family, because they will periodically have to deal with grief and great uncertainty. Examples of this kind of condition are: cancer, certain heart conditions, lung diseases like cystic fibrosis, a number of muscular and neurological illnesses and HIV.

In situations of this kind, the child and the parents may swing from a positive, optimistic attitude to hopelessness and fear of the child dying. There may be periods when it seems difficult to relate in a realistic way to both the hope of cure and the possibility of death.

This division does not give a correct picture of every condition. Some may find the division artificial because they feel that the illness their child is suffering from fits into several of these divisions. Many will have been through an acute and a critical phase before the illness became chronic, or chronic illnesses may have periods which are acute. And conditions which only rarely lead to complications or death, may be experienced as a threat and cause anxiety in both the child and the parents. We are aware of this, but we have chosen this presentation for the sake of clarity.

The way the illness starts can affect the way it progresses

Insidious diseases

Some illnesses develop over time. The child may have had vague symptoms for a long while. Many will have been to the doctor one or more times before the disease is confirmed and diagnosed.

Progressive, fatal diseases

Some illnesses begin with vague and diffuse symptoms, which do not at first seem alarming. It is only as the illness progresses that it is possible to make a final diagnosis. There is a large group of muscular diseases belonging to this category. Many of these illnesses are extremely serious, with a fairly certain terminal outcome. Some of these children become slowly and gradually more ill before they enter into the last, terminal phase. Others are in relatively good form for long periods, but acute, life-threatening crises can suddenly flare up.

Sick children without a definite diagnosis

Although the world of medicine has increasingly better possibilities for making subtle diagnoses, it still also happens that children are sick and no exact diagnosis can be given. The child may receive a group diagnosis (muscular disease, immune system disease, metabolism disorders, etc.).

The challenges of growing up

From birth and through all the stages of growing up, physical development is determined by the challenges of attaining mastery over tasks which will equip the child for life. The child should develop in such a way as to be able to live and enjoy life to the full in his family and the society he is to grow up in and become a part of.

Children's developmental tasks

Children's development actually takes place in every aspect of the child's life. The child learns from and about the people around her and her surroundings through movement, play, observation, exploration, imitation (learning through models), trial and error, guidance and interaction. The child is affected by her surroundings and her surroundings are affected by her in this process.

Right from birth, the child uses all his senses to study his surroundings. This development takes place in the earliest years of childhood in close interaction with adult people who take care of the child. The acquisition of an ever increasing number of physical skills enables the child to explore ever greater areas. The development of speech opens up the possibility of easier interaction with other people. This extends the child's social radius, and other children become important in the child's life. Through spending time together with other children, social skills and rules for interaction are acquired. This interaction will demand everything the child has learnt of motor skills, intellectual understanding as well as social interaction. Other adults take on important roles in the child's life in kindergarten and school. From the time of starting school, greater demands are put on the child's intellectual abilities, and she is now capable of taking responsibility for limited areas of her life with the support of adult guidance. Friends become more important in the child's life and become important reference points. The child gains a clearer picture of who she is - she has a greater sense of identity. The process of emotional maturation, which runs parallel, becomes clearer as a result of the experiences the child makes.

The child's sense of self-worth and a positive self-image develop from the experiences he has in interaction with other people, and how he attains mastery over the challenges he meets.

Once a child enters into the teenage years, the foundation should have been laid for a process of breaking away from her parents to gather headway. Now the child is moving in the direction of more self-reliance, self-determination and independence. An adult identity grows through this development, in other words, the young person perceives her qualities as being stable whatever the situation. Young

people need to gain experiences in many social connections and to choose their social group. Belonging to a youth group is essentially on the basis of similarity. Being different can therefore be a threatening experience. Other challenges young people are faced with are choices in connection with further education and direction of a future career, bearing in mind considerations about economic independence.

How is a child's development disturbed by illness?

There are certain lines of development in children that we know from experience can be inhibited or disrupted if a child becomes ill. An illness which limits a child's range of physical activities, will affect his motor development and level of activity. Motor control is a source of joy, contentment, experiences and a positive self-image - and is of significance for other areas of development. A further consequence of physical skills being reduced, is that the possibilities for playing with other children may be limited. Hospital admissions and treatment can also restrict a child's possibilities for spending time with other children.

It is through contact with other children that social skills are learnt, insight into the interests of other children is gained, and feedback on

The situation is not that healthy children develop «more» than chronically sick children. But chronically sick children explore other areas and other experiences than healthy children.

what is acceptable behaviour and appearance is given. These qualities are promoted and adapted in this interaction. If a child loses much of this contact at the critical ages when these things are to be learnt, they may become quite helpless in their interaction with other children. We have descriptions from kindergartens, where four to five year olds get on very well in the staff room, talking to the adults. They have learnt to

«communicate» in a different way from their peers, through all the adult contact they have had at the hospital and with their parents. When they are with the group of children, they are more helpless, because they have a limited idea of what is acceptable behaviour, the rules in use and what the other children are talking about. They may, for example, demand a lot of attention without taking enough consideration of the others. Younger children may find it difficult to understand what makes being together with other children difficult. The others are just «silly».

By school-starting age and upwards, children have usually reached a level of maturity which helps them to see themselves more clearly in relation to others. Their sense of identity is stronger, and they are less self-centred. Some sick children in this age group describe themselves as more immature in some respects than their peers. There are some things they cannot join in with and they are strongly attached to their



parents. On the other hand, they have advanced far ahead of their peers in other areas of maturity and life experience.

Being together with other children gives a feeling of belonging and the sense of meaning something for other people. Important parts of the child's sense of identity and self-image are formed together with other children. When she becomes a young person and adult, the child will have to have learnt to get on with her peers independently of her parents. Dependence on parents is a natural consequence of chronic illness, because parents are a necessary source of sympathy, a buffer and support for their children. The anxiety a sick child and her parents can feel, may become so strong that being separated may become threatening. Parents want to protect their child the whole time, the child feels insecure without the parents' protection. This can inhibit the extent of the child's contact and the time he spends with other children, which he needs in terms of development. This dependence can be particularly unfortunate in the teenage years. Young people need to break away from their parents in order to gain experiences which enable them to function as adult, independent people.

The psychological burdens of being chronically ill can cause concentration problems and difficulties at school. If this is not dealt with properly and at an early stage, the child may end up being behind with his school subjects for a long time.

3. Normal crisis reactions when a child becomes sick

Some normal, immediate reactions in parents, the sick child and her siblings follow here. Reactions which develop over time, when the illness has taken on a chronic character, are described more closely in the section «The characteristics of various reactions - and advice on different types of illness».

The period before the diagnosis is made

Parents may become very uneasy and anxious if the child's illness has developed gradually and no exact diagnosis has been made during this period. One moment they are worried that something is wrong, and the next they are reassured that everything is normal. The mother and the father may experience the situation differently; one may think the child looks perfectly healthy, and may minimise suspicions of there being anything abnormal. Parents may reproach each other for being «hysterical» or for being «blind». In some cases, parents consult a doctor, perhaps several times, who does not confirm their anxiety, and this can make them quite distressed as they feel they are not being taken seriously, while the child's illness continues to develop.

Parents' immediate reactions

Parents may feel «relief» once a diagnosis has been made if the child has had symptoms for a long time. They are relieved because their anxiety has been taken seriously, their observations have been given importance, but most of all because a diagnosis means that whatever treatment is available can be started.

In cases where the child is given a collective diagnosis (muscular disease, immune system disease), the situation may all the same feel very insecure. Parents know that an exact diagnosis may be needed for the illness to be treated, and may therefore be anxious that treatment will be delayed, cancelled, experimental, faltering - or actually incorrect.

Other parents experience the diagnosis as a shock. «It can't be true», «There must be a mistake», «He must have looked at the wrong samples!» They cannot believe what they are told and protest that it cannot be true. Very many describe a feeling of unreality. One mother related that to begin with she went round, waiting to be woken up from a nightmare. She was part of a «drama» which did not really affect her. «The first months were like living in a vacuum. Nothing apart from my child meant anything to me,» said another mother.

This feeling of unreality can explain why parents can seem calm and collected, «they took it very well». This is a part of the reaction of shock; the body and the mind protect themselves by letting the truth sink in gradually. Parents may be shocked over their reactions in that they do not react more forcefully. Others show strong reactions, crying, despair and terror. One father related that hearing that his child had a life-threatening disease was like being hit by a train.

If the illness does not involve any danger for the child's life, it may be the worries about how they will overcome all the challenges involved in the illness and the treatment and the ways in which their lives will be affected by all this, that is the most prominent concern.

Many feel anger and reproach towards others: «Why didn't they listen to us?». Or they feel guilty and blame themselves: «We should have gone to the doctor before», «What have we/I done wrong?».

Some parents can have strong physical reactions of shock, like nausea/vomiting, violent palpitations or the feeling that they are going to faint.

Problems concentrating, remembering things and taking in information can be very troubling to begin with. There may be many questions, the health service personnel may give a lot of information, but parents feel they have a limited capacity to take it all in.

The child's and siblings' immediate reactions

The youngest children are in a way protected in that they do not understand the implications of the illness they have developed. But this also means that many things will seem overwhelming and frightening because it is difficult to reassure them with explanations. First of all, they will react to changes in their parents and to whatever they experience at the hospital. They may express fear, anger and they may protest against examinations and treatment. Others will remain quiet and say little.

Older children can react with shock, disbelief and protest. They may also describe a feeling of unreality about what is going on. They are waiting for someone to come and tell them it is not true. Afterwards, some children explain that they did not react at all because they did not understand what was going on. Others conceal their reactions out of consideration for their parents. Older children often become anxious about how the illness will affect their lives, and prevent them from being with friends. They may ask very concrete and practical questions, which illustrate this. «Will I be able to play football?», «Will I be able to go to school camp?» «I didn't understand what the word the doctor said meant, but I suddenly got such a tummy ache that I had to run to the toilet», said one eleven year old girl, after she had been told she had a chronic illness.

Siblings are often the last members of the family to learn of the illness. In addition to the crisis reaction described above, many siblings are worried and afraid because they are not together with their

parents. Although a hospital ward can be both unfamiliar and frightening, it can often reduce their anxiety if they can be together with their parents and the sick child. Then they have more of a feeling of control and they can see what is going on. Siblings who have stayed at home have later related the fantasies they had because they did not see the illness with their own eyes.

Anticipatory grief

Parents of a child who has developed a life-threatening illness, may find that they start mourning for their child. This may start immediately after the diagnosis has been made and is called «anticipatory grief». Parents start thinking ahead to the funeral, they imagine and formulate death notices or they imagine themselves mourning. Afterwards they may feel guilty for having had these thoughts, and they may wonder if they actually want their child to die?

This is an expression of enormous fear of experiencing the very thing they are most afraid of - that their child will die. These painful and frightening imaginations are an attempt to prepare themselves for the worst. We have experienced many times that parents find these thoughts so unacceptable that they have not shared them with anyone, not even their spouse. It is not until we have brought up the subject that they have been able to talk about this.

4: The characteristics of various reactions - and advice on different types of illness

4. The characteristics of various reactions — and advice on different types of illness

Acute, life-threatening illness

Many children are admitted to hospital every year as a result of serious accidents or sudden, life-threatening illness. The admission may be dramatic, and there is not much time to prepare the child or his siblings. The child may be unconscious, and the parents and siblings can be left with strong and terrifying sensory impressions.

Both parents and children respond to acute crises with crisis reactions. The child's reaction is based on several factors. One is her own perception of the seriousness of the situation and the extent to which she is able to appreciate how ill she is. Another factor is the experience the child has of her parents. If they are calming and reassuring, this will rub off on her. Likewise, a nervous, anxious atmosphere will do the same. Other important factors are the initial impressions of the hospital, the hospital staff and the treatment, and the extent to which the child is in pain, discomfort or finds the situation frightening.

The most usual immediate reaction is unreality, the situation resembles a bad dream. The child may be expecting everything to be over any minute, and reacts with disbelief or denial. This sense of unreality will often be followed by fear and anxiety. Some acutely ill children can show strong stress and crisis reactions. Young children may not talk until the situation becomes normalised or becomes clearer. Other children react by clinging, crying and protest.

When a child is struck down by acute illness, the parents will also experience a feeling of unreality. A strong sense of being outside oneself is common. Parents often say that they act instinctively or find strengths within themselves they had not known they had, so that they are able to carry out the practical tasks the situation demands of them. For example, they can remember the number to the doctor or the ambulance and ring them or they start resuscitation. Many are surprised that they are not overwhelmed by their emotions, and that they can feel quite «empty» or stunned. It is not unusual to feel that time stands still or passes very slowly.

Once the most dramatic phase has passed, and others have taken over responsibility or help has arrived, some people will experience strong reactions. These may be physical, like shaking, shivering and nausea. Some also experience stronger psychological reactions like anxiety and unrest, violent crying, restlessness or jumpiness. However, the feeling of unreality may last for days, even when stronger secondary reactions also present themselves.

Siblings tend to show the same crisis reactions as the sick child and the parents. They often have to piece together the events by themselves, without the help of adults, as most of their capacity is being used on the sick child. Siblings may be left with very strong impressions, because they are often spectators with no useful role to play. This can be very frightening.

The more long-term reactions will depend on the way the illness develops. If the child survives without permanent disability, things will probably return to normal after a relatively short period of time - on the surface at least. However, some children and parents find that the episode leaves a mark. The sensory impressions may have become fixed in their minds and return as troubling and painful memories afterwards. It is like being constantly drawn back to the terrible and dramatic episode, and this may make it difficult to move on. Sleep may be disturbed and concentration weakened, as a result of this episode being relived, or because thoughts about what could have happened allow no peace of mind. Sometimes a sensation, a little glimpse, a sound, a smell which may not be registered consciously, leads to a reliving of feelings from the acute situation.

Another normal secondary reaction in adults and children is a feeling of increased vulnerability. Most people have assumptions about the world which make it secure and predictable. The fact that one of our children is struck down by an acute, serious illness, is not a part of what most of us expect to happen. These things happen to other people. Once the unthinkable has happened, a feeling of vulnerability may arise, a sense of catastrophe which leads to anxiety and disquiet that other distressing things may also happen. Some people go round waiting for the next thing, for «if this could happen, anything could happen».

When a child becomes so critically ill that there is little likelihood of recovery, the relatives are struck by intense pain and grief. It can be difficult to stand seeing the child in pain, even though they want to cling to the hope that the illness will turn and everything will be all right. In these situations, relatives sometimes feel that the staff or others are thinking «it would be best if he/she no longer had to suffer». Relatives may feel this themselves - «the child must be relieved of his/her suffering». But these are often taboo thoughts which may lead to feelings of guilt.

Advice on acute, life-threatening illnesses

It can be difficult in a critical situation to think of and do the right things to take care of the child's psychological needs. The situation may make it impossible to prepare the child for what is going to happen.

Children who are under heavy medication or are unconscious, may be able to hear sounds and conversations without being able to show it. The rule should be that if the child is present when medical information is being given, it should be directed to the child in language

the child can understand. Information which is not suitable for or directed to the child, can be given to the relatives outside the sick room. The child's hearing may function well even though he is heavily medicated. (For further advice on how parents can provide support for their child in hospital, you are referred to the chapter: «When the child has to go to hospital»).

In order that children who have been acutely and critically ill shall regain control over their situation and feel that they have an overview over what has happened, it is important to spend time on the event afterwards. This also applies to siblings. Children need the help of adults to process what they have experienced. They are able to perceive and understand more than adults are willing to admit. If they have overheard adults talking about how serious the situation is, or have experienced their parents' anxiety in other ways, confusion and mistrust will develop if this is later denied or minimised. Explanations must therefore be truthful and attention must be directed to the way the child experienced and thought about the events. This should not be like an interrogation, but a gentle talk with the child to find out what she has understood, so that further information can be based on this.

Adults need to go through the events together with the child step by step and fill in the gaps in the child's information so that he gains a complete overview. Children also need explanations of what they do not understand. If the adults are not able to explain, the child can be reassured if you try to establish exactly what is unclear. A definite «I don't know» is better than woolly evasions. The events become connected to each other when they are gone through in this way; having this kind of overview helps the child to grasp what has happened and the events become more real.

Many children are helped by the explanation being made more vivid with drawings or dolls. The events can be connected together on a piece of drawing paper: «first this happened» and «then we came here» etc.. This makes both talking and understanding easier. There may have been sounds or sensory impressions which have been frightening and which the child needs to have explained and to process. If you notice that the child becomes anxious, or wants to avoid a particular theme, they can be helped by their parents giving examples, trying to guess what the child has thought of or reacted to, or the parents can tell them about their own reactions. In this way, parents can show empathy which makes the situation less anxious for the child.

Some feel that the adults require something of them, that they have to talk about something they do not even feel able to express in words within themselves. A different occasion at a later time, different circumstances, greater openness on the part of the parents and greater control on the part of the child are all factors which make the child more secure and receptive. No child should be forced. It is the responsibility of the adults to be available, to take the initiative, to adapt the circumstances and motivate.

It can often be useful to use photographs to help the child go over the events. We therefore advise parents to take pictures of the child in intensive care. Many parents and children have good experience of this, although they may have been reluctant to take pictures during the critical phase. The pictures contribute to sick children, their siblings and parents having the possibility to remember and process events afterwards. Pictures link before and after together so that the child can experience continuity in his life.

It is routine in some hospitals to write a «journal» for the patients. Continual entries are made here about the state of the patient, what is being done, who has come to visit, and other important things they think the patient would like to know. This initiative has been appreciated by patients.

If it is feasible, it can be very positive to take the child on a return visit to the ward once she has become better. This enables the child to review what happened and often stimulates questions which can help revive memories.

Children also need to be given the opportunity to discuss their fear that the event can happen again or that other people in the family may suddenly become ill. It is often the parents themselves who have to take the initiative to reassure children about this. If there really is a danger of the situation happening again, this should not be denied, but strategies should also be made for how this will be dealt with. For example, a plan of action can be made, telephone numbers to the hospital or doctor who is familiar with the child's condition can be readily available, or clear guidelines can be set for how to get help if a new, acute situation arises.

Children who have experienced a frightening situation will often need more closeness and care afterwards than they did before. Many also need to be allowed to be more dependent for a while. They may feel most secure when they are near Mummy or Daddy, especially when they are going to sleep.

It is important for the adults also to get over the event so that later problems are prevented. Having the opportunity to describe what happened in detail, and in addition the thoughts and feelings they had, is a useful method. If there is no one to share the experience with, many people have found it beneficial to write down what happened. It is important for adults as well to link the events together so that they have an overview. Contact with other people who were present, ancillary workers or people who treated the child in hospital may be able to provide important pieces of information and reduce the thoughts which otherwise demand so much energy.

If the child stays in intensive care for several days, or there is the danger that the child may die, siblings should be taken to the hospital so that the relationship between them is taken care of. This is important for all parties. Healthy siblings can be good medicine.

To sum up, we would like to say that it is important to spend time processing the acute, critical events. By talking through what has happened in detail with the children and explaining what has

happened and why, children, parents and siblings gain a better grasp of the events. Once they become more real and surveyable, they are easier to get over. Give your children care, closeness and time so that their feelings can be calmed.

When the child is born as a patient; illness in the neonatal period

The emotional reactions to having a sick new born child are the same as the reactions which have been described earlier for other acute conditions. But there are some particular factors which are relevant and they will be mentioned separately here. During the course of the pregnancy and birth, all parents wonder if their child will be healthy and normal. Some parents have been very worried about this, others do not think much about the possibility of something being wrong. Some parents know already before the birth that there is something wrong with the child, but they do not know what or how serious the illness or damage is.

When a child is born with an illness, malformation of other damage, the joy of having a child becomes mixed with sorrow that she is not as the parents had hoped. Many parents feel they have little opportunity to process this grief. As far as people around them are concerned, the most important thing is that the child survives, while the parents are grieving over not having had a healthy child.

Some children are deeply wanted and longed for by their parents, others come more as an inconvenience and some are directly unwanted. This affects the way parents react when their child is born ill. Parents may feel ambivalent, may reject the child, or may feel guilt because they had not been looking forward to getting him. Some feel that the illness is a punishment because they were not looking forward to him, or that it is a consequence of this.

Having a new born, sick child means a very particular start to the establishment of a new family. If the child has to be in hospital, the parents and child do not have the normal good framework around the start of their life together that they would wish. It is harder to feel the peace and quiet to be close, to cuddle the baby and get to know her. It is not easy to feel secure in the new role as parents, at the same time as they are trying to relate to the illness. Hospitals have a large staff who work shifts, unfamiliar routines and at times frightening methods of treatment. The intensive care units for new born babies are very intense, and it is difficult to find the correct balance between necessary stimulation of the child and unfortunate over-stimulation with noise, lights kept on all night, tests and treatment. The mother may be tired after the pregnancy and breast feeding may be difficult.

If there is danger of the child dying, the parents may be afraid of becoming too attached to him, and want to avoid the vulnerability of loving a child they know they are going to lose. Some people want, therefore, to protect themselves from this pain by spending less time

with the child. Parents can feel guilty about having thought this, or if the child dies, they may feel guilty because they have had little contact with the child.

Feelings of guilt can also be connected to parents taking responsibility for the child having developed the disease or damage. They may focus on things they have or have not done themselves or they may reproach others, in the health service for example, or at their place of work. The question of heredity may also intensify feelings of guilt, or lead to reproaches between parents - «it's in your family».

A mother and father will often react differently to getting a sick child. This difference can be quite noticeable when there is illness in the new born period. The mother has been through a pregnancy and is connected more closely to the child. It is she who has physically, psychologically and socially prepared herself to stay at home to begin with. So her role is suddenly turned upside down, in addition to the insecurity and emotional reactions she has. Fathers have often said that they wanted to support the mother at this time and many suppress their own reactions. Some also say that they need time to bond with a newly born child and feel that the mother has a head start. These differing reactions have also led to misunderstandings between the mother and the father, or that they reproach one another.

Advice on illness in the neonatal period

The mother and father should come to the neonatal/intensive care unit to see and to make contact with their child as soon as possible. It is important to bring the child's siblings also. Contact between siblings and the new born child is very significant and their worries and need for information must be taken into consideration.

It is very positive if pictures can be taken of the whole family together. This can help to recreate the new born period, both for the child when he grows up and for the parents and siblings.

Close contact with the child is also positive. If the child can be taken out of the incubator or her bed, it is important that she can be held in her mother's, father's or a sibling's arms.

It is important to be aware of the risk of over-stimulating the newly born child; the child does not need long periods of contact and stimulation. Avoid putting objects with sharp edges on top of the incubator, they make too much noise for the child.

If the family and the staff use the child's name, this will help give the child an identity. It will also give a sense of closeness and reality to the perception of this new little person.

It is important that the people around the family are kept well informed about the state of the child, so that they understand the situation the parent and siblings are in. This can prevent a sense of isolation in relation to others, who may find the situation difficult because they do not know the child either.

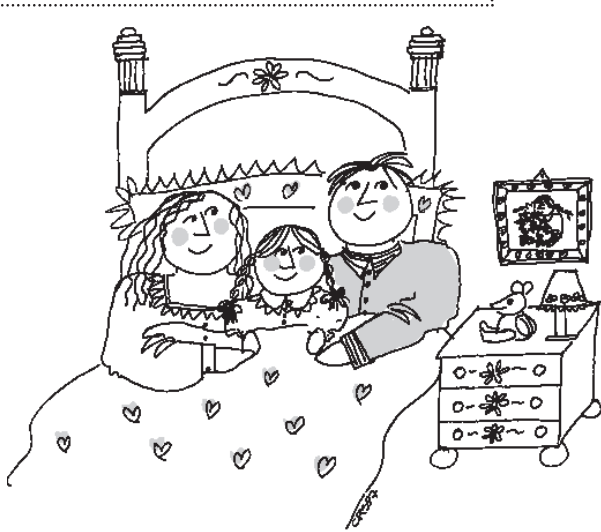
Chronic illnesses

The child's reactions

The child needs to be able to recognise himself in others and to be understood. Sick children often do not have anyone they know who is in the same position, and they may feel lonely. This is not because they are physically lonely, but because they do not have anyone they can share their experiences with. Children who do not have others they can compare themselves with, can feel that they are different. «Nobody else feels the way I do.»

Alterations in the child's appearance can make the child embarrassed and afraid of being teased. There are many examples of children not wanting to take part in gym or swimming lessons because they do not want others to see the changes in their body (from eczema, for example, or operation scars).

Children who have to be careful because of an illness and cannot put their body to same sort of challenges as their peers, may feel that their body



has let them down. The experience of not being in control and the insecurity that then arises, may make some children anxious. Parents often observe that children are cautious in their play and activities and withdraw from children who are active; they tend to avoid challenges and ask a lot of questions about illness. It can be a great burden for the child if she is just a spectator when she is together with her peers. Contact with other children can be a constant reminder that she is unable to achieve on the same lines as the others. A girl in 6th grade wanted absolutely to be driven to school. It emerged that she was the only one who could not cycle. The others said they would wait for her, but that did not help. She felt excluded when she could not be the same as her friends. When children experience this, they may cry, become quieter or less active. Some may become bad-tempered and angry.

Many children are afraid and worried because they have to look out for symptoms. They may also be anxious about symptoms which come suddenly or which are a sign of the illness getting worse.

When children are sad or worried about being ill, this takes energy and attention away from tasks the child is facing. It is not unusual for children with these sorts of burdens to develop school and concentration problems. In addition, absence from school, treatment, lack of energy – as direct consequences of the child's illness - can interfere

with the child's ability to concentrate and his performance at school.

Thoughts and difficult feelings are often more pronounced in the evening. The demands of the following day may seem very great and insurmountable, and it can be difficult to get to sleep.

Children who are feeling anxious and insecure, find that the immediate proximity of their parents relieves these unpleasant feelings. They may protest about being separated even for a short time. Some parents may not be able to go to get the post without this leading to screams and protests.

Some children have unstable or swinging moods. They may start crying very easily or be angry and bad-tempered. Some parents find that it is just a trifle that causes tears and anger. Many explain this, with great empathy, by the fact that the child feels things are very difficult and need a little «excuse» to express this. The real reason for the outburst of feelings is not always known. On other occasions, the reactions are clearly connected to the concrete situation the child is in. This may be despair about something that cannot be allowed because of the illness. Some medication makes children anxious and angry.

Children and young people may be aware of the fact that the illness they are suffering from is a strain on the family. Some will therefore feel guilty about being ill and think of themselves as a burden for their parents and siblings. A thirteen year old girl told that the most difficult thing for her was her bad conscience about her mother being so sad.

Some children react to illness by becoming more immature and dependent. They fall back on levels of mastery that are typical of younger children; this is called regression. Children who have stopped using nappies or sucking their thumb, may start wetting themselves or revert to their thumb again. Other children become more dependent on their parents' help with things they used to be able to manage themselves.

In other areas, children who are sick can be more mature than their peers. Living with a chronic condition, means that they become familiar with and experience circumstances which other children do not. They may therefore develop a greater ability to imagine how others are, and may become more socially responsible.

Chronic illness in children puts the physical body and health into focus in such a way as they become insecure and anxious. This can be seen in some children by the development of physical symptoms which do not have any physical cause. As they are afraid of things getting worse or an attack coming, they are very conscious of conditions in their body. A «pain» they otherwise would not have noticed, makes them worried. Muscular tension, headaches and tummy aches are physical problems which may have a psychological explanation.

Even in cases where the illness and treatment remain unchanged over time, there may be phases with strong and varying reactions from the child. They may be sad, angry or anxious, they may develop concentration problems and may become more dependent even though outwardly nothing has changed. One reason may be that the

child has become tired, sad and fed up with the illness and the demands it makes. The motivation for lasting out can be reduced for periods of time. Another reason may be that the child is facing new developmental challenges which require new skills; they understand more and the illness becomes significant in a different way. The development from childhood to youth can become particularly obvious in many ways. The limitations of the illness can be felt especially strongly in the teenage years, when it is difficult to be different, and belonging to a group outside the family becomes more important. The development of independence and the process of breaking away from parents becomes more complicated if the illness or treatment involves the parents a great deal, and the young person is dependent on them. All chronic illness can lead to a particularly close relationship of dependence between children and their parents.

The parents' reactions

The parents' reaction to a child developing a chronic illness is usually one of loss. Parents describe a great sense of grief and pain on behalf of their child. Whatever the child has to put up with or go without, becomes the parents' sorrow. And parents will often also be worrying about the future. Even though the illness is not fatal or is one which rarely leads to complications, parents can be afraid, anxious and insecure.

When children become ill and cannot live as happy and carefree a life as their parents would wish, this is often accompanied by a feeling of injustice. Why does it have to be my child? This feeling can lead to anger and bitterness.

As they try to understand why their child has got a chronic complaint, parents often search through the pregnancy, birth, environment and diet for clues. Alternatively they wonder if the illness may be hereditary. This may lead to reproaches to themselves or to each other. The explanations from experts cannot always prevent this happening. Some people feel guilty because they feel the illness could have been prevented.

There is often a great deal of uncertainty in connection with illness - about which treatment is best, how and when the symptoms will reappear, if the illness will change its character and what the future will bring. Uncertainty may be one of the characteristics of certain diseases. This is a great burden for many people. Uncertainty can be destructive because it is so difficult to master. Some people manage to cling to the positive possibilities, others feel it is safest to imagine the worst so that they are prepared. In any case this is a very energy-demanding feeling to master.

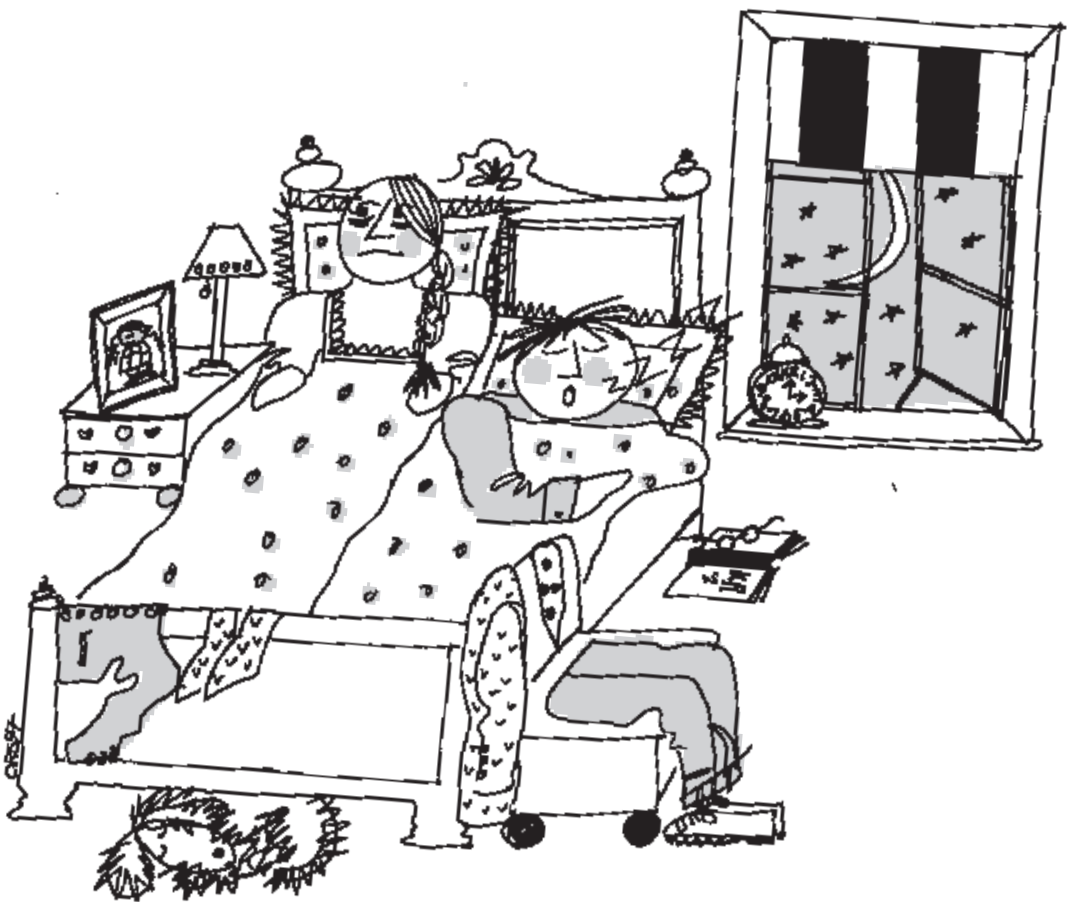
Many parents develop periodical sleeping problems. When all is quiet around them, it is not so easy to keep gloomy thoughts, fear and anxieties at a distance.

Increased vulnerability is a commonly described reaction to becoming a victim to negative events. Many people live in a kind of protected belief that «it won't happen to us», negative factors are not

part of our expectations of the future. When expectations are dashed by illness actually striking, this results in many people feeling vulnerable to new negative events. Some people wait for the next catastrophe, become anxious for the child who is sick, for their other children, for their spouse or themselves.

Chronic illness in the family places great demands on the parents. As they strive to fulfil the child's needs and get everyday life to function, many feel that they cannot do enough. They should be in at least two places at the same time, should have more time for each individual child, should have more energy and put in more effort at work. There are in other word many sources of a guilty conscience.

Some illnesses require a great deal of effort on the part of the parents, and the parents have a strong need to protect, help and support their children. In many families with chronically ill children, this takes place at the cost of the parents' time and energy. Poor or insufficient sleep at night, the demands of being careful and alert all the time with regard to the child and the illness, care and treatment, drain parents of their energy. Usual consequences of this are anger and bad-tempered, unstable and fluctuating moods. It is not unusual for us to see parents with symptoms of being burnt out. They are exhausted, depressed and resigned, and it becomes harder and harder to become recharged with energy again.



The siblings' reactions

The siblings of a chronically sick child are a much overlooked and forgotten group. Their development has to continue as normal - parallel with the challenges the family is facing.

Siblings may feel sorry that the illness limits the activities the family can be involved in and perhaps most important: their parents have little time and energy for them. Some siblings find that the rest of the family and friends are also more interested in the child who is ill, and overlook them. When parents have less time and attention to give siblings, this can lead to considerable jealousy and a feeling of being loved less than the child who is sick. This is a great burden for children. Even older children who understand that the sick child needs more time and support, can suffer from jealousy and envy. However, it can be difficult to admit to these thoughts, and they may be expressed in different ways. Some are angry with their sibling or parents and can respond by shouting, quarrelling, teasing or hitting. Others can express their sense of unfairness more directly. Somewhat older children may also be sad for their brother or sister because they can see that he or she is having such a difficult time.

Siblings who perceive that their parents are anxious or worried, that the illness is changing or becoming more frightening, may become afraid or anxious themselves. Outwardly, these children can be observed to become more immature, dependent and clinging, and that they protest about being separated from their parents. Some become angry or difficult.

Anxiety in many siblings can be traced back to them having experienced changes in the atmosphere at home without being given any explanation. Information may be withheld from siblings because the adults do not think they will register that anything is different. Children with a sick brother or sister are often very sensitive to the atmosphere around the events at home. Many register a change. Unless they are given a good explanation, they will have to work one out on the basis of what they observe and previous experience. This can be very unfortunate and can create great anxiety.

Poorer concentration at school cannot always be connected to outer circumstances, but can occur as a reaction to long-term strain.

We sometimes see that psychological strain causes physical reactions like headaches, tummy aches and muscular tension. It is not unusual for the doctor who is treating the sick child to have to take a look at a sibling because they are complaining of symptoms of physical illness. The vulnerability we have described as being a result of illness hitting the family, is also experienced by siblings. They may be worried that they will get the same illness because they are siblings, live in the same house, etc.. Anxiety about other illnesses is not unusual either.

If siblings start behaving differently, become withdrawn or become more hot-tempered, it may mean that they are finding the situation difficult. Siblings are periodically the family's «outer face» and may have to deal with thoughtless questions and hurtful comments. If they

have not been given a good explanation and do not know how to deal with other people's reactions, this may be distressing and make them afraid. For some age groups, having a sick sibling can be rather embarrassing and it may make them feel foolish with regard to their friends, so they do not want this to be focused on.

Being closely related to a child with special needs also gives siblings experiences that help them to develop. Many siblings are more mature than their peers. They are more empathetic and some people describe them as making contact more easily with others who have difficulties.

The consequences for family interaction

In addition to illness being a strain for each individual family member, it also challenges the relationship between them. Ordinary families with small children are often balancing on a tight rope when it comes to time and energy, especially if both parents are working outside the home. Chronic illness makes the jigsaw puzzle almost impossible. Some parents work like «nurses», apart from the fact that there are no evening or night duty nurses to relieve them! Parents who have a lot of their time tied up in care and treatment will find that their social network shrinks. The amount of time and energy they have for recreational activities and social life will be very limited. In some cases, the illness will also reduce the possibility of one or both parents being in full-time employment. This may again have negative consequences for the family's economy. Some illnesses mean that one or both parents have to spend time at a hospital or another institution. This separation interferes severely with the way a family functions together and solves everyday tasks. The interaction in the family is further affected by the way each individual reacts to and gains mastery over the illness that has affected the family. If a lot of time and attention is directed to the sick child, this will affect the amount of adult time the parents have by themselves and together, the amount of time they have with the child's siblings as well as affecting the way the family functions as a whole.

Bringing up children

Chronic illness in a family cuts right into its everyday routines. Many parents find that it becomes difficult to bring up their children and maintain rules. The parents are tired, have no energy and have a guilty conscience about not being able to do enough, and it becomes difficult to be consistent. The desire to compensate for what the child is missing out on, can often lead to giving in to the child's wishes, even when they are unreasonable. The child's anger and despair which is expressed when he is guided or stopped from doing something, may intensify the symptoms of the illness, and parents want to avoid this kind of situation. Some children learn to use their illness and their parents' uncertainty to get their own way. Examples of rules and routines which can easily slip out of use are: bedtimes, mealtimes, presents and rewards as well as the kind of behaviour that is tolerated. Many parents let their children delay their bedtime, for example, because after a long day they are so tired that they do not have the

energy to take up the struggle to get the children to bed. The day may have been so demanding that they do not feel the children have had enough attention and want to give them «a bit extra» in the evening. Then the nice evening together ends up not being a positive experience because both parents and children are tired and bad tempered.

We know that many parents have periods when they feel unsure about bringing up their children and would like to discuss this with experts or other parents in the same situation.

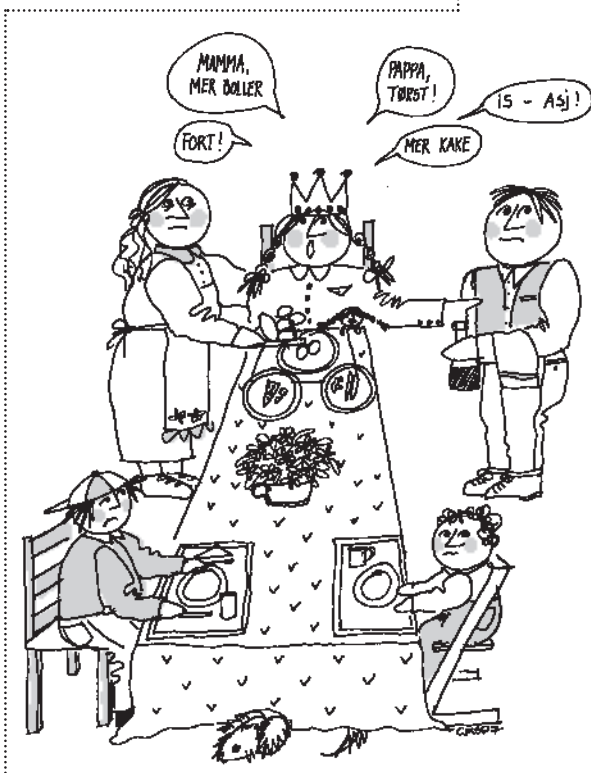
The consequences for the parents' relationship as a couple

Many young people become parents at a time when they have not settled down in a home and with an established job. Some are still

studying, and even the relationship between the parents may be new and untested. Tolerance and the ability to co-operate needs to be developed, and the relationship is in many ways put to hard tests when a child in the family is ill.

It is not unusual for the father and the mother to have different emotional reactions to a child being chronically sick. Many women worry more than men and spend more time dwelling on questions, thoughts and worries about the illness and the child. They also find it easier to talk about their thoughts, feelings and reactions; they cry more and seek more support from others. Men often process their situation by keeping busy. Many men say that this helps them keep the difficult thoughts and feelings at a distance. «Many terraces and garages have been built by the fathers of sick children,» as one father said at a meeting of parents of sick children. Another difference that can be observed is that mothers worry more about things in anticipation than fathers do. These differences in reaction can be difficult to tackle if they are not met with understanding. A father who feels that the mother is worrying about something that has not yet arisen, may reproach her for being pessimistic. Likewise, a mother may reproach her husband for taking things too lightly, for running away and she may be angry with him for not being able to talk about things that are difficult.

The parents' sex life is also affected when there is illness in the family. Lack of energy, little sleep, children who need attention at



night all tend to lower the desire for intimate contact between parents. The differences in the needs of men and women also become more obvious. The man finds a sense of closeness through sexual activity, the woman need to feel close to the man before she feels like sex with him. She finds this sense of closeness through talking with him or through him sharing her home life and helping her.

There are also differences between the sexes in the way home life is organised. It is often the woman who first gives up her own time and spends most of her time with the children and the family. It is also usually mothers who give up their careers to take care of sick children. She has the main responsibility for the treatment and taking the child to the hospital. This pattern reinforces her ties to the home because she «knows most about it». The father can be an «assistant» whom neither the mother or the children are quite confident in. Some fathers feel that the mother does not give them a chance. They would like to take more responsibility, but feel that she wants to be involved to control that things are done properly. The mother has fewer impulses from «outside» than the man. This can reinforce a sex role pattern and division of work that the couple had not imagined, and which can cause conflicts between them. Lack of sleep and energy can also contribute to disagreements and their ability to co-operate will be put to the test.

When their precious time is to be allocated, their relationship as a couple often comes far down on the list of priorities. Their role as parents takes all their time, and there is little time for them to be friends, lovers and to take care of their social life outside the home.

The relationship with the extended family and friends

When a child becomes ill, many families feel they have a lot of support, interest and care from their extended families and friends to begin with. Some families become very disappointed when all this fades as the illness becomes chronic and a part of the family's everyday life. Many parents find that other people who have not experienced anything similar themselves, may have a very limited ability to understand what the family is going through. Unfortunately, many families meet a lack of initiative and understanding, as well as inconsiderate comments from their extended family, friends, neighbours and colleagues. The experience of people around withdrawing from the situation or minimising the strain and worries the family are under may be hurtful and a direct burden. One mother told her group of friends how worried she was about her son's illness. She was met with the following comment: «You mustn't take such a gloomy view of everything».

However, there are exceptions. Some families have people who are close to them and who can give them support, and they find this is a great strength and a real help, both for the family as a unit and for the individual family members.

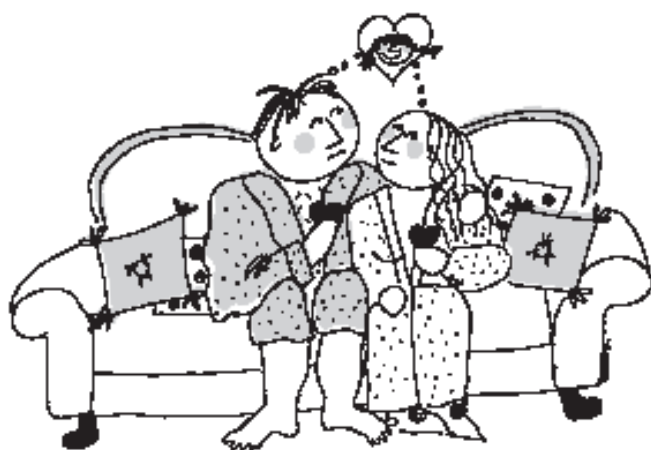
Another, not unusual characteristic of those who are on the outside of the situation is that they want to help by giving advice and making recommendations. They have themselves tried this or that in similar

situations, or they have read about or heard of other hospitals, other doctors or alternative treatment which they encourage the family to try. This can at times be felt as pressure.

The parents of chronically sick children also have varying experiences with the leadership or their colleagues at work. They may meet anything from really understanding support to suspicion, inconsideration and direct criticism.

When the illness becomes life-threatening

When, in addition to being chronic, an illness is also life-threatening, many of the reactions we have described earlier are intensified for the parents, the child herself and her siblings. Grief for everything the child cannot experience in life and the years he may not have, becomes more prominent. This often results in anxiety about the unknown and a stronger dependence on the parents. The child may become filled with pessimism about the future which seems to be characterised by uncertainty and hopelessness.



Families have to relate to a large range of feelings when they have a child with a

chronic, life-threatening illness. Some of the feelings may seem contradictory - the parents have to think ahead, plan so that the child can develop in every area, have duties, be given sanctions, establish relationships with friends, but also for the fact that they may lose the child.

Some illnesses are such that they may get better with good treatment and if the child is lucky. But the child may also die. In the case of other conditions, it may be fairly certain that the child will not recover, but no one is able to say when the illness will develop into the terminal phase.

Any changes in the child's condition will affect everyone in the family, even though the situation is not seriously acute on this occasion. The level of preparedness for «it is happening now» is high. Some people have described it as going around with a constant knot of anxiety and grief in their chest. They do not always feel it, but it is there.

Advice to families with chronically sick children

Many parents are surprised at the enormous amount of stress they manage to live with. Some put it like this: «If we'd known beforehand, we'd have said that we couldn't do it.» Or: «It's as well we don't know what the future holds for us, or we'd have given up.» «I don't know where we got our strength from.» This shows how people find resources they did not know they had before the situation demands it of them. The way each individual family copes with life with a sick child depends on the qualities and resources each individual family member has, how the family works together at the starting point, the family's situation at the onset of the illness and their access to help and support from others. Different families will therefore solve the challenges they face in different ways. All the same, we can see that the experiences one family makes can be useful for others. Many parents look for the opportunity to exchange experiences with families in similar situations. Here we will pass on the knowledge and insight which has been given by families we have had contact with, as well as the research which can add to what we know.

How can the child be helped with thoughts, feelings and reactions?

Sick children need information about their illness and the treatment they have to be given. If this information is adapted to the child's age and stage of development, even young children can understand enough for this to be a useful tool for gaining mastery over the stresses they have to cope with. Providing children with information is a process which has to extend over time, and where one often needs the help of concrete objects, like dolls, drawings, books and brochures. The information should be truthful and easy to understand, and should reduce anxiety and confusion. We advise that children should be told how serious the illness is, even when it can be fatal. It is easier for the family to talk together and have an open and supportive dialogue when everyone has been informed in the same way. Keeping important information from children makes everyone more guarded, anxious and cautious. This could be compared with how the parents would feel if they felt that the doctors knew something about the child's illness which they would not tell them. When children know what is wrong with them, it is easier to accept why they need treatment or have to be careful.

Our experience is that adults are not able to assess what their children are able to understand, what they are worried about and how they will react in a difficult situation. Children often protect their parents by not showing what they are feeling because they can see that their parents are finding things difficult themselves. This partly explains why the feelings and reactions to illness are not talked about in some families. Parents can feel unsure of how they can best help their children when they can see that they are having a difficult time.

If children and young people have the chance to express their thoughts and feelings, the sensation of being alone becomes less. The child may well cry, get upset and angry in reaction to being ill. But this must be accepted and confirmed as being acceptable and normal, so that the child himself can be helped to understand why he is feeling this way. Children can be given consolation and support: «We are also unhappy that it has to be like this». Both children and adults seek to find understanding in others. This has an immediate effect because the child instantly feels less sad and afraid. In the long term, this is an essential contribution to processing the situation they are in.

Another problem is that parents may wait until the child or young person takes the initiative to talk about what they are thinking. Our experience is that if the sole responsibility is handed over to the children, probably nothing will be said. Children and young people are reluctant to reveal their personal thoughts and feelings. They may be afraid of making a fool of themselves, being laughed at or not being understood. Our view is, therefore, that it is the adults' responsibility to help children by taking the initiative and providing an open atmosphere where it is acceptable and natural to bring up difficult, personal themes. Children soon notice if there are themes they cannot bring up in the family. Parents who stimulate openness, are asked the most questions by their children. If children get used to being able to ask questions, this will give a better guarantee that they will find the exact answer to what they were wondering about. An open atmosphere in the family can be achieved by bringing up different themes for discussion on a regular basis, and by the parents themselves being open. Parents thus become models for the way difficult feelings and thoughts can be mastered. This can be done without the children ending up as the parents' comforters.

It is important that children are allowed to express themselves in their own terms according to their age, sex and situation. The youngest children need concrete help to express their feelings because they have not developed the necessary language to talk in this way. Children process their experiences and express what they understand, think and feel through play. This can be actively made use of with young children in a difficult situation. Difficult feelings like anger, anxiety and sorrow can be expressed through play. Another example of a concrete method is drawing. Feelings can be drawn into a drawing of «me». Some children feel sadness in their eyes because they want to cry, others in their throat, their chest or their stomach. Many children like to recognise themselves in others. So books about children or animals, where the child can identify with someone in a similar situation, can be very helpful.

Some children can be reached by making up a story together about them. One approach is to let the story develop through the child's choice of theme and content. The adult can also take a more direct role and can suggest that the story is about someone who is sad, afraid, angry or sick. They can go on to focus on social situations where the events describe what it is like being with friends, being at school or

meeting an unexpected challenge. The child can describe and discuss herself through the figures in the story, without it being too close. It can be easier to describe Peter in the story, dreading going to school the next day or worrying about visiting the hospital, than talking about herself in the same situation. This can be a starting point for exploring what children are thinking; they can express their feelings, and the solution can be discussed. If Peter is sad today, they can together ask the question why. Could it be because the others are outside playing football and he cannot join in? By commenting on this, the child gets the feeling that the reaction is completely understandable and reasonable: «Of course he's sad when he can see the others and can't join in himself.» Sometimes this can be enough to give the child support and understanding. Other times, the story can be developed to see if strategies can be devised which can help Peter.

Older children communicate their inner world more easily with the help of language. All the same, many children and young people resist this. When adults ask them questions about what they are thinking or feeling, the answer is often «nothing» or «I'm fine». Questions often make young people close up. They do not want to disclose their feelings unless the other person meets them half-way.

Sometimes the adults must take responsibility for talking with children and young people who are finding things difficult. The situation may seem more secure if the adult talks more to them. The adults can describe some of their feelings or try to tell them in a considerate way how they imagine it is like to be in the child's situation. The conversation will be coloured by where it takes place. Many parents have good experience of taking part in some kind of activity with the child. Going for a walk or doing a chore together can also provide a good, secure framework for talking together. Some of the best talks take place sitting on the child's bed in at bedtime.

The methods we have suggested using with younger children can also be used, with small adjustments, with older children. These concrete aids provide a concrete focus outside the child. There is more distance to the feelings and thoughts being expressed. As well as considering the age of the child, the sex of the child is also important when adults are trying to help him or her express his or her feelings. Many boys prefer concrete aids or another form of activity when they confide in someone. Girls tend to find it easier to talk directly about personal themes.

Guidance on talking with young people follows the same principles for younger children. It is, however, important to be aware of what this age group are concerned with and what can be difficult in their situation. This may be something that singles them out from others or something they cannot take part in. It is important here that the young person does not feel exposed. So the adult can gain an important means of approach if the young person feels she is understood.

Children and young people who are ill may feel other people invade their lives because they need so much help and support. They may need to keep something for themselves. The more dependent a

child or young person is, the more difficult it is to regulate the extent of closeness in contact with other people. Therefore it is important that the adult is sensitive and respects the young person's need to regulate the distance to his own feelings. It is the adult's responsibility to be available, to take initiative and set the scene so that conversations take place on the child's terms. Expect conversations to be short. Furthermore, it is important to accept and respect the child if he does not want to communicate.

How can a sick child's developmental tasks be supported?

In the introduction we indicated that there are important developmental tasks which can be interfered with or inhibited by chronic illness and its treatment. The skills a child develops are built one on top of the other. Before the child can go on to the next stage of development, the tasks of the previous stage must have been learnt. Even if the children get behind in some areas of development, due to adverse circumstances, they usually catch up again when things return to normal. In cases of chronic illness, we must direct our attention to the measures that can be taken to promote development and which can substitute for some of the elements the child is missing out on because of his illness or treatment.

When a child is ill, the people around her tend to focus on the things she is unable to master and all the limitations of her illness. This starts when the first indications of the illness appear, and continue throughout the stages of clarification, diagnosis, and treatment. Our experience is that the absolutely most important measure for stimulating the child's development is to look at the child as a whole, including the aspects of the child that are healthy and the things the child masters. Parents do not usually see a child's development in the terms of a problem, as this is something that «takes care of itself». When children are ill, this natural progression is interfered with, as the illness limits the ways in which the child can use herself in the ways appropriate for her age. Parents can try to find out what their child should be exploring and experiencing at the age level he or she is at. A concrete example is a four to five year old who spends a lot of time in hospital or at home and little time with children of her own age. The challenge is then to find ways for this child to spend time with other children of the same age, so that she can gain some of the same experiences despite the limitations of her illness. There may be special educational services which can bring playmates home to her or this can be arranged at the hospital.

In some cases, children lose skills they had before the illness developed. Our experience is that it can be useful to see if there are any activities which can help to replace these lost skills. A ten year old boy who cannot play football the way 90 percent of other boys in the class do, must be given the possibility of interaction with others in a situation where he is challenged and feels he can master a task. For example, chess, music or bridge can be a good alternative to sport for some children. And team sports and tournaments can also be carried out from a sick bed!

A positive self image is gradually built up, partly from the experiences the child makes. Children and young people who compare themselves with others and only see their own inadequacies, do not develop a positive self image. We show our attitudes to the child through our expectations. A child who is over-protected, does not have demands put on her and is not challenged, receives an indirect signal that we do not have confidence in her. Chronically sick children often cannot manage to do everything exactly the same as other children. But this does not mean that they cannot do anything. The chal-

The challenge is to give sick children the possibilities to explore and experience as far as possible the same things as healthy children of the same age.

lenge is to find something the child can strive for but which their parents, teachers and other people looking after them know they can manage. This is the case at home, in the kindergarten and at school. Maybe a bit of help is needed to get started, some children may be unsure of themselves, but once the task has been mastered, this will help to build up the child's self confidence.

One line of development we have mentioned before is the child's increasing independence and breaking away from his parents. Other children and adults become important in the child's life, and there are more and more tasks that they should master on their own. If a child is ill, it may be difficult to leave him in the care of others, because the parents need to be in control. Both parents and children may protest if they have to be away from each other because they are so dependent on each other. If the child is consciously, but gradually and carefully trained to be away from his parents in secure surroundings, this will be beneficial both in the long and short term.

A thread running through all the advice we give is to try to achieve a life for your child that is as normal as possible, at the same time as you take into consideration the special needs the illness brings about. It is difficult to find the balance between the child being taken into consideration and feeling that they are someone special the whole time.

Despite a life situation which has been well adapted to give the child good developmental possibilities, many will feel sad about all that is different in their life. Accepting oneself and one's life situation if illness and treatment limit life to a great extent, is a hard task. Therefore, hand in hand with these more active problem-solving tasks, support must be given to the child's inner, emotional world which we have discussed at an earlier point in this book.

Support for siblings

When everyday life is hectic and demanding, siblings often slide into the background. In our work with families with chronically sick children, attention has often been forcibly drawn to the siblings' situation because stress on them gains consequences for the whole family, or because the siblings gain symptoms of psychological or social malad-

justment. Many of the problems siblings develop are possible to prevent from the start.

There are many similarities in the guidance we give to parents on how to give support to the sick child and the child's siblings. Siblings need information about the illness and its treatment along the same lines as the rest of the family. Many of the siblings we have been in contact with, feel the need for current and continual information. They feel they are given good information when the diagnosis is made, but that they are not kept informed afterwards. The age and developmental level of the siblings must be taken into consideration when information about the illness and treatment are to be given. The same concrete methods, the use of which was described above can be useful for talking with siblings.

Siblings also have to adapt to a very difficult situation, and need help to express their thoughts and feelings. We have presented several suggestions for how adults can help sick children with their difficult reactions. These methods can likewise be very helpful for the child's siblings.

Siblings need to be with their family in difficult periods. As far as possible, sending them away from the family to other people who can care for them, should be avoided. It is better to have help with child care in the home. When admission to hospital is unavoidable, many siblings would like to visit regularly if they are given the chance.

It is unquestionable that more attention is periodically directed to the sick child. Older siblings can often accept this if they are given good explanations. All the same, their parents need to give them first priority sometimes. A lot of quarrelling, fuss and jealousy can be avoided if siblings also feel they have their parents genuine attention. Sometimes siblings describe that their parents «spend time with them» but their thoughts are elsewhere. Many parents have good experience of allocating time alone with a sibling. This can be arranged in advance so that they can look forward to it when the situation is difficult otherwise. This time alone can be spent in many ways. Many take the opportunity to do something fun together, or something they do not normally get the opportunity to do. Other times having a good chat about the sibling's everyday life or how she is feeling is needed.

For long periods of time, the part of family life that deals with the siblings' school day and recreational activities is overlooked. Siblings are often the family's representatives outside and they have to deal with all the questions and comments they meet. This can be hard. Parents should be aware that older siblings can keep their difficulties to themselves because they seem insignificant in relation to everything the sick child is experiencing.

Jealousy because the parents are giving most attention to the sick child is the most distressing reaction. But envy of the sick child because he or she gets more presents and attention from others also can also be clearly felt. Parents are usually very careful not to differentiate between their children in terms of the money, presents or experiences they are given. However, grandparents, extended family,

neighbours and friends are not always equally considerate. In such cases, parents can point out to these others what the rules are for presents (when, where and what would be appreciated), and that the siblings would also like to be shown some interest.

Regular contact with the siblings' kindergarten or school also has a positive preventative effect. Both the teachers and the other pupils need to know how the sick child is getting on. And if the siblings develop problems at school or in kindergarten, early intervention can prevent these developing further.

Support for parents

When parents prioritise who is going to get their precious time, they often put themselves right at the bottom of the list. This is in spite of the fact that recreation away from responsibility and hard work is extremely important for the adults in the family to be able to build up their energy reserves. There are many things parents know are important but do not have the energy to do anything about. When a person is under strain over a long period of time, the exhaustion will gradually be noticed less because they become used to being tired and worn out. It can be compared with walking with a heavy rucksack. After a while you become numb and the weight of the rucksack is not noticed until it is taken off. The strain on the body is just as great. Other people have compared the situation with a marathon where the finishing line is constantly being moved. The parents of chronically ill children have to go on, and they have to adopt the strategy of taking breaks and sitting down for a rest to reduce the strain. When you are tired and demands are being made on you, it is easier to continue, because organising help and relief requires that extra little effort you are too tired to make. We want to emphasise the importance of thinking about how backup help can be found. It may seem hard at the time, but it will give results in the long term.

We have previously mentioned the importance of children being able to express their thoughts and feelings. The same must be emphasised in relation to the parents, because this can help the parents' strain both in the short and the long term. It is of the greatest importance that they find someone they can share their grief, anxiety, despair and worry with. If the parents are living together, the spouse can be an important person to talk with. If one of the parents is living alone with responsibility for the child, this support must be sought among family and friends or within the professional services.

The relationship between the parents is often hard put to the test when a child is chronically ill. If the parents' relationship as a couple is weakened and becomes problematic, this will again have consequences for how the rest of the family functions. Parents have shown that the secret is to keep an open dialogue. If the parents can manage to communicate some of their inner feelings to each other, it is easier to maintain closeness and the feeling of belonging together. As has been mentioned previously, it is not unusual for parents to react differently to living with a chronically ill child in the family. Misunderstandings

and reproaches are lessened if they understand the way the other is thinking and reacting, even though they may not experience things in the same way themselves.

The division of work between the parents when it comes to treatment, attention and care of the child is set at an early stage of the illness. The parent who is given information, is trained by health service staff and takes the child to the hospital, is the one who will be responsible at home. It is therefore very important that both parents take part right from the beginning, so that both have the same starting point. The whole family will be better off if several people can share the tasks and take responsibility for treatment and care.

Time for each other will not turn up by itself, but must be planned. This could well be short chats which the parents put aside time for in their everyday lives, and where disturbances like television, the telephone and newspapers are «kept at bay». The parents of chronically sick children are more mother and father than man and woman. Some parents find that their sex lives become less active or problematic because they are so tired, worried or because there are conflicts between them. There may be differences between the partners in their need for sex.

Spending time alone, away from children and duties can have a stimulating effect on the relationship. Sometimes it may be necessary to decide to do something even though you do not feel like it in advance. The experience may all the same be positive both for you personally and for your relationship. Meeting as partners, lovers and not just as parents can bring more life to the relationship. This may seem artificial, but many have experienced that unless they plan actively, they will not prioritise putting aside time to be together.

Strengthening family interaction

Changes have to be made in the family to adapt to the new situation of having a sick child. But at the same time it is important to maintain the usual routines and rules the family had from before.

As we have already emphasised, open and truthful communication between the family members is essential for the family to adapt to the situation. This openness includes information about the illness itself as well as a dialogue about how the situation affects each individual. People are very different when it comes to how easily they can talk about personal and sensitive themes. Having an open atmosphere does not demand long revealing conversations, but that everyone gives the others a little glimpse of what they are thinking and feeling and that reactions are explained. An open atmosphere eases the emotional processing for each individual. The sense of togetherness and belonging in a family is strengthened when its members feel their situation is understood and they can recognise themselves in others. When people live closely together, they interpret each other's behaviour in order to understand each other better. Misinterpretations and misunderstandings can arise because different feelings can be expressed in the same way. When a father is sad and becomes quiet

and serious, he may well be perceived as bad-tempered by the others. Children are particularly vulnerable if they are not given explanations of why adults are behaving in the way they are. Children often explain other people's behaviour as being a consequence of something they have done themselves. If a mother is tired and sad and then gets a bit cross, the children may think this is because of them. An example of an open dialogue would be the mother telling her children that she is telling them off because she is sad about Kari being ill and she is tired because she did not sleep well last night. It is not anything the children have done wrong. Short messages like this are very important in a family that is living under pressure.

Saying no and being strict is difficult when children are ill. The same feeling may extend to siblings because the parents have a guilty conscience about not being able to do enough. If a child has a life-threatening illness, the situation is particularly painful and full of despair. Fear of the child dying, and the feelings of guilt parents can experience when they have been strict, make bringing up the child very complicated. Children have a need for rules and routines as a framework around their lives. This makes things clear, predictable, and secure. When the familiar framework around the child breaks down, they have to find out where the new framework is themselves. This requires an effort on the child's part and she has to test out her parents afresh. If the parents are definite and consistent when they guide their child in this new situation, the child will not have to find this out on her own. If parents remain as they were, this reduces the insecurity a new life situation often brings about. All the same, rules have to be adapted to new situations. Right from an early age, children are able to adapt to different rules being valid in different situations. So bedtimes, mealtimes and rewards may be different at hospital than they are at home. If it is explained to children that this is the case now, when we get home everything will go back to normal, they can adjust to this. The parents have to show that this is the way it is. Children will not usually come and ask to go to bed at 19.00 if they have been up until 21.00 in hospital every evening for several weeks!

Another common problem with bringing up sick children and their siblings is the behaviour that is to be tolerated. When strong emotional expressions of anger and despair affect other people, animals or material things, this is difficult. Parents must be understanding about the feeling, but should not accept the form of expression it is given. This difference is important and must be communicated to the child. If the action is just stopped, the child may feel that the feeling is also unacceptable. Parents can find out together with their child what could be more appropriate means of expression. Talking to parents about the things that are difficult, can often ease the pressure.

The strategies families we have been in contact with have taught us for living in the best possible way with chronic illness, is very similar to what research shows. The ability to take one day at a time and to live as normal a life as possible are often mentioned as the most important factors. Furthermore, the feeling of being together, sharing

chores, openness and good forms of conflict solving in the family are essential. Social support, backup help and ensuring positive experiences are made the most of when the opportunity arises, are also often mentioned. Finally we would like to point out the importance of daring to keep up hope. Some people find this difficult because then they become so vulnerable to disappointments. It feels more secure to be prepared for the worst eventualities. Parents who have experienced the worst have shown us that it is impossible to prepare oneself for this.

Contact with the kindergarten, school and the child's friends.

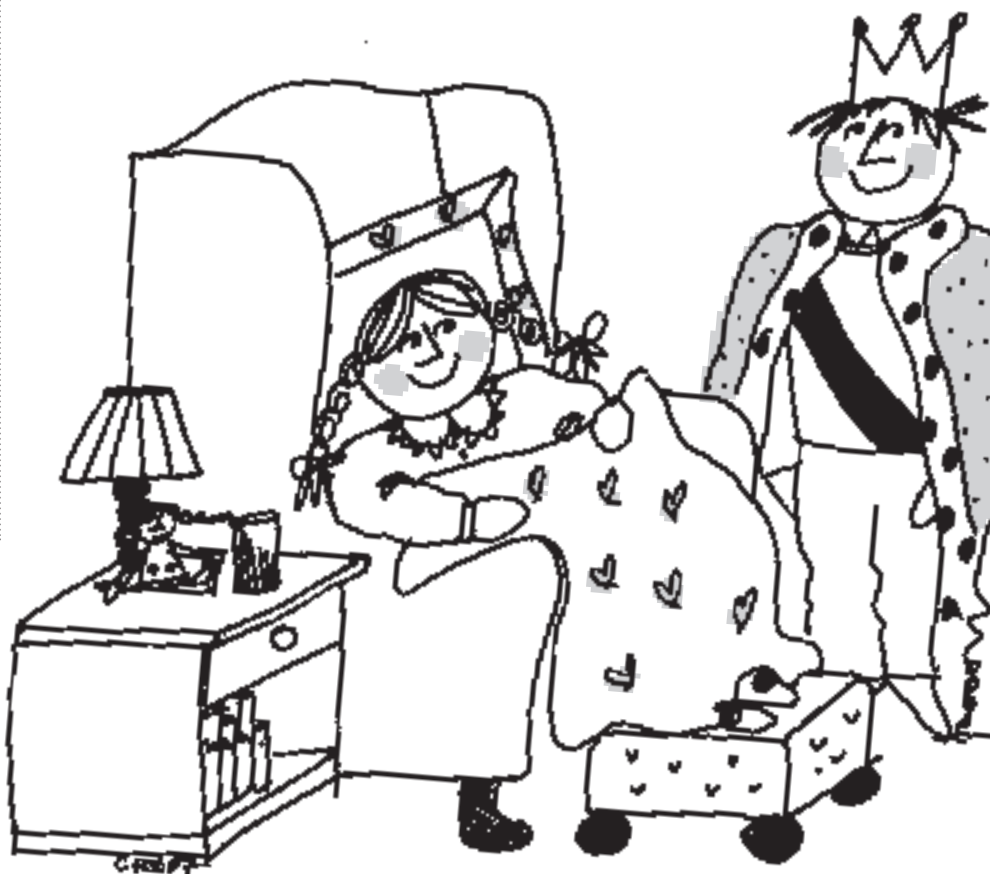
The kindergarten and school are very central arenas in the child's life for learning and development in all areas. The child will get on better if his sense of belonging to this important network is maintained. It is therefore important that the kindergarten and school are involved right from the start. The most important condition for successful co-operation between the family, school/kindergarten and the hospital is that good information is given to the head teachers of the kindergarten/school, the teaching staff and to the child's and his siblings' fellow pupils. It is advantageous if the hospital staff or the primary health service can help the family with this. We only have positive experience of fellow pupils being given concrete, thorough and truthful information about the diagnosis, treatment and the consequences this has for the child. In this way they can become the sick child's ally and protect her from the other pupils in the school/kindergarten if this should be necessary. It is an important duty of the school to adapt its teaching to the needs of the sick child, whether this is at school, at home or at hospital. The same is true of the educational programme in the kindergarten. Siblings may also need to have their teaching specially adapted during difficult periods. In addition to learning and the development of subject based knowledge, there is also an important social life and physical activities at school or kindergarten. These can therefore make it possible to achieve better adaptation in many of the most important areas of the child's life. This can also be done when the sick child is not able to attend school or kindergarten. One of the problems of being in hospital or at home for a long time is the separation from friends and the weakened sense of belonging. Through co-operation between the kindergarten/school, the hospital and the family, the sense of belonging together can be maintained between the child and her friends. By means of letter writing, cassette or video recordings, the school or kindergarten can keep the child up to date with everyday life there. This gives the child a feeling of belonging. Being remembered is a good feeling! Listening to a cassette recording from the morning gathering in the kindergarten, where the child's name is mentioned and greetings are sent, is good to listen to when you are lying in bed in hospital. In a similar way, the child can tell the people in her home environment about her days.

It is also important that friends have the opportunity to visit the child wherever he is. Adults can come along and help to make the visit a positive experience for everyone.

The parents' relationship to their friends and colleagues

«It's in times of hardship you learn who you're real friends are». This is a saying many parents of sick children recognise the meaning of. Or as one mother said: «We learnt to differentiate between real friends and pretend friends.» Parents often find that their friends divide into those who withdraw and those who really try to support them.

It is often the parents themselves who take the first initiative to tell friends, neighbours and colleagues about the situation. And as the illness progresses, they still have to be active and take the initiative towards their group of friends although it «should» have been the other way round. Friends, neighbours and colleagues may feel helpless and not know what to do. It is difficult for others to imagine what the family's situation is like. Parents often understand this, but it can still be hurtful and in the end exhausting to be active and understanding all the time. This is perhaps the most important reason why many find the best support in other parents who are in the same situation and whom they come into contact with at the hospital or through



parent associations. They feel «normal» together with them, they find understanding both for what they say and for what they do not say. Many parents associations are actively involved in putting families who are in the same situation in contact with each other. We would like to point out the importance of keeping contact with friends and recreational groups because this contact helps to maintain normal life both for the adults and for the children. If it is possible to involve those who are closest right from the start, this can increase their understanding and their ability to empathise with the difficult situation. But we constantly come across parents who have to be indulgent to be able to maintain good family and neighbourhood relationships.

Sometimes the people around are felt to be a burden because they minimise the severity of the situation and the parents' worries. Or they may have good suggestions about how to bring up the child/children or about treatment which is impracticable or against the wishes of the parents. Parents have different ways of dealing with this. Some overlook it, others explain why they do not want this kind of interference. Some become unsure of themselves, hurt and withdraw so as to avoid social contact.

For many families with sick children, the possibility of being able to manage the situation is completely dependent on employers and colleagues realising the importance of flexible arrangements with regard to working hours, and the work load and level of responsibility. Going to work can be of great positive significance, but it may also be a decisive factor that working hours and work loads are reduced or adapted to the situation.



5. When the child has to go to hospital

Tremendous improvements have been made during the last twenty to twenty five years for children who have to go to hospital. A hospital admission does not need to be the traumatic experience it used to be when parents were not allowed to stay with their child. All the same, hospital admission and treatment is a great challenge. There are major upheavals both for the sick child and for the family. To some extent, the strains will be different for the child, the parents and for any siblings.

The situation for the sick child and the parents

Staying at hospital means a period of separation from the familiar, great challenges, strange routines and meeting new health service staff. The child may have pain and discomfort to relate to. He may feel great longing for the rest of his family, his friends and his school or kindergarten if he has to spend a long time in hospital. School children feel a strong affinity with their school and their friends. It is distressing if this relationship is weakened, and many children will feel sorry that they cannot take part in everything the others are experiencing. Maybe their best friend will find someone else to play with?

It is decisive for children to have their parents or other close people with them for support. Children who have had to spend a lot of time alone in hospital, without this kind of support, can be affected by this later, with anxiety and insecurity.

When their child has to go into hospital, parents are challenged both by the practical difficulties and by their emotional reactions. They have to arrange to be with the child. They may need to organise someone to look after the other children in the family and have a guilty conscience about neglecting them. Neither is it a matter of course for parents to be given sick leave because their child is ill. (This is a matter of evaluation, and depends on the child either being in a critical phase of a chronic, serious illness or that the presence of the parents is necessary for the child's treatment.)

Parents are also anxious for their child. The illness can make a deep impression on them and they may be affected by this. At the same time they need to empathise with the child and to support and console her. Caught up, as they are, in these practical and emotional strains, the parents are the child's most important support. They usually have to ignore their own needs for emotional release, to protect the child, or they may not have adult people who have the time or energy to listen to their worries.

Seeing other sick children in the ward and sharing other parents' worries may also become a burden. Admissions for investigation and treatment often involve a lot of waiting - waiting for the doctor, for information, waiting for the results of tests, and waiting for treatment.

This can become extremely irritating for those who have to spend a lot of time in hospital.

The high tempo in the wards and the heavy work load of the hospital staff can lead to parents feeling that they have to stay with their children the whole time to make sure they get the necessary attention and treatment. It may be difficult to find time to eat, and even more difficult to find the opportunity for recreation and relaxation. Many parents feel they have to take on the role of nursing and watching over their child at the same time as they may feel alienated and superfluous.

Parents are often very loyal and understanding towards the hospital staff as they can see that they have stressful working day. However, there can sometimes be good reason to criticise circumstances around the treatment or care of the child. Many parents are reluctant to make criticisms because they are afraid this will have a negative rebound effect on their child or themselves.

Although looking after your child in hospital does not usually involve heavy, physical work, it still demands a lot of energy, and parents can become extremely tired because of the tremendous worries they have. Parents are concerned that their children should eat, should do their school work, and it is of course very important that medicines should be taken exactly as the doctor has stated. When children are not in good form, feel unwell, sad or afraid, co-operation on these things can be difficult. The parents' encouragement can seem nagging. There are very many parents indeed who go home from hospital totally exhausted, even though they «haven't done anything, and have just been sitting in a chair» as some put it.

The psychological strain of being in hospital as the parent of a chronically sick child is underestimated.

Parents who have several children feel especially that they are under conflicting pressures - should they be in the hospital with the sick child, or should they be at home with the healthy children? Where there are two parents, the tasks are usually divided. This means that the parents seldom have shared experiences, which may again affect the communication between them. It can be difficult to express one's experiences to the other, whether one is at home and unsure how things are with the sick child, or one is at the hospital under all the strain this involves.

There can be many reasons why information about the illness and its treatment can cause problems between the people giving the treatment and the parents. During the period of investigation and diagnosis, there is a great stream of information. The hospital staff usually think that the family is being given all the information they need during this period. However, the parents' capacity to take in information is limited in this time of crisis. The parents' levels of concentration and memory are reduced as a result of the enormous psychological strains they are under. Once the strongest feelings of shock have subsided somewhat, the parents gain more of an overview.

At the same time, they become hungry for information because the real situation is dawning on them, and the need to know what this situation is, and what can be done, makes them more able to involve themselves in explanations about the illness. At this point, the people responsible for the treatment feel they have given the most relevant information and do not take the initiative to new rounds of information. So it is then up to the parents to ask questions and request more information. Parents may feel unsure about asking questions for many reasons. They may be afraid of asking stupid questions, they may be afraid of the answers they may be given, or they may be worried about taking too much of the doctor's time when they can see how busy it is in the ward. Most questions come up after the doctor's visit. The fact that the hospital staff have seen many children with similar illnesses, means that they take some things so much for granted that they are not mentioned. It is easy to forget that the situation is completely new for every family and they all need the same basic explanations and information.

Information and explanations take time, and that is one commodity there is often a shortage of in a hospital ward.

Parents and children can become confused when they receive different answers to the same question from different doctors and nurses. Parents who spend a lot of time in hospital in connection with the treatment of their child, often notice that procedures are followed differently.

It is precisely information and explanations about the illness and its treatment that are very important tools for attaining mastery of the situation for parents and children. This reduces anxiety, the feeling of helplessness and gives them a feeling of being in control of the situation.

Young people in hospital are a particularly vulnerable group. The role they have to take on themselves as patient is in direct conflict with the developmental tasks they are facing. The psychological strain of being in hospital leads to increased dependence on their parents whom they are in the process of breaking away from. Independence and autonomy, which young people need to develop, are not sufficiently fostered in the hospital system. The patient role leads unavoidably to becoming dependent on others. This period is also sensitive because of the focus on the body which the illness brings about. The young person's body is steadily changing and developing, changes which he is trying to become familiar with and accept, and this body is to be examined and observed by other people. It is not always possible to respect the young person's modesty. Many young people feel they are treated as though they were younger than they are, when they are ill. Being away from their friends and girlfriend/boyfriend is also particularly painful and problematic at this age. They need to feel they are a part of things and are the same as everyone else.

Siblings of a child in hospital

Just as it is a challenge for parents when a child is admitted to hospital, so it is also for the siblings. They be given a greater responsibility for practical tasks, or they may have to manage more on their own with less assistance from their parents. They frequently have to suppress or postpone their own needs. Plans the family has made have to be changed at short notice because of hospital admission or changes in the symptom picture.

We have met siblings who have experienced their sick brother or sister being taken into hospital very suddenly and have been very frightened of experiencing the same thing again. They describe their fear every time some one knocks on the classroom door - it may be some bad news for them, or they may become afraid when they see an ambulance.

Advice for when a child has to go to hospital

When we start to look at ways of improving the situation for children in hospital and their parents, it is easy to feel hopeless because the shortage of resources is so obvious. All the same, we would like to present some experiences that have been of help to families we have met. These are areas families feel they have had some influence on and which have contributed to the stay in hospital being easier.

Creating security around children in hospital requires effort from several quarters. First and foremost it is being close to their parents that makes children feel secure. If parents feel secure, this will wipe off onto the children. Parents who are worried and uncertain in a hospital situation, signal this to their children. A primary condition for parents to feel comfortable in the hospital is that the staff have a positive attitude to the parents being there. The nurses and the people giving the treatment can show parents through their attitude that they are important in this connection.

Information and discussions with the hospital staff

Information is also decisive. When children know that they are being kept informed all the time, that they will be given explanations and will be prepared for what they have to go through, the feeling of insecurity is reduced. Information and explanations must be adapted to the child's age and level of maturity.

Questions and answers about the illness are easier to remember if they are written down. It can be a useful habit to have paper and pen handy so that questions can be written down when they arise. The most important points in the information the doctors give can also be advantageous to write down. Then you can go through this later and discuss points which are unclear with each other. This also motivates the person giving the information to be more clear and precise. It is the practice in some hospital wards for a nurse to write notes from important talks between the doctor and the family. This is a good

practice because anything that is not taken in or remembered during the talk, can be looked at again when there is more peace and quiet.

No questions are stupid. It can be very helpful for the staff to be asked questions because then it is easier for them to give adequate and appropriate help. If all the questions that have arisen require more time than is available in the doctor's round, it is reasonable to ask for an extra meeting with the doctor. There will be less rush and the necessary dialogue between the parents/child and the doctor will be easier.

Many parents are unsure whether the child should be present at meetings with the doctor. It is difficult to give absolute advice on this, but these guidelines may be useful:

The child will usually have understood that something important is going to happen and that this revolves around him. He picks up the signals from what is going on around him and from his own body. If the parents are called in to talk to the doctor without the child, this may cause fantasies which are even more dramatic and negative than the actual situation, and the child may become very anxious. These arguments state the case for children being present when important



information is to be given. The child's presence gives an important and clear signal that information about him is not being kept back.

There are, however, some conditions for setting the limit of whether the child should be there or not, which are more important than the child's age.

It is important that the parents are able to give the child support in this situation. If the information and the shock it will cause are of such a nature that it is uncertain how the parents will tackle it, one must consider whether it would be better to inform the child at a later stage. However, if the alternative is that the child is left waiting to hear something she knows is serious and concerns her, this may be worse than seeing her parents' strong reactions. It is therefore important that there are always adults present who can support the child if the parents are unable, whether this is a member of the staff or another member of the family.

Another very important point in this information process is that the doctor addresses the child directly in a simple enough way for the child to be able to understand. If the parents ask questions the child does not understand, these should be «translated» for him. It is impor-

tant to check that the child has understood what has been said. One should also try to avoid the child developing worries as far into the future as the parents often have. There may be quite different things that concern them. If parents ask questions or express worry about what may happen some way into the future, this can be too much for the child to take in. They should wait with these questions until the situation and the consequences here and now are clearer for the child. Parents may be able to ask some questions without the child being present because this is their need for information and not the child's. The child must of course be given the same information when he is ready for it or when it is appropriate. Giving children information is a difficult but necessary process. While children need to be given information in suitable portions, they should not be constantly left waiting for the next piece of bad news. They must be told about the main threads and the most impor-



tant consequences straight away. But it may not be best for them to listen to all the «ifs» and «buts» which the parents may want to discuss at the beginning. They must be reassured all the time that they will immediately be told everything to do with them and everything that people know. It is not a good thing if «everyone else» knows something important about the child before she does herself.

Pain and discomfort

When children are so young that it is impossible to give them verbal explanations, the environment must be made straightforward. Young children remember connections in situations where something hurts, is frightening or uncomfortable. If, for example, painful examinations are carried out when the child is in bed, the child will have unpleasant associations with bed. It is therefore a good idea to follow definite procedures and short rituals when babies and young children are going to undergo something unpleasant. This enables the child to recognise and distinguish the unpleasant situation, but he can otherwise feel secure. Children who are in a confusing or unpredictable situation, can never quite relax or feel secure because they do not know when the next pain or discomfort will occur. Even if the child is so young that he does not understand the words, gentle explanations and verbal preparations from the parents can have a calming effect. Talk to your child about what is going to happen before it takes place, even if the child does not understand. The intonation and the expression in your voice will be perceived all the same. What we mean by procedures and rituals is everything that is said and done before an examination or treatment which causes discomfort. The same is repeated every time so that the child recognises it. The parents say the same things and put the child in the same place. This should not be a place the child will have a cosy time, eat, sleep or play later. It could be in a treatment room, on a particular chair or another set place.

Many parents are unsure whether they should stay with their child in situations which are painful or unpleasant. They are afraid the child will associate them with this, or that the child will feel that they accept or are behind what is happening. All experience and research from this area shows, however, that it is important for parents to be present, and that they can hold the child. If the parents are not there, the child's feeling of insecurity about being deserted and alone will intensify the pain. What is important when the parents are holding the child is that their attention is directed to her and they talk reassuringly to her. Once the examination is over, it is a good idea to finish up with the same word each time. The child will gradually come to recognise this as meaning «finished».

Older children who have to undergo pain and discomfort can be prepared verbally. If the child has been given a good explanation in advance, this can have a motivating effect, and the parents and the people carrying out the treatment can refer to this when they talk to the child. It is important that you do not tell a child that an examination is not going to hurt when you know it will.

Children have shown us techniques which can help them in the situation itself. An essential key word here is the experience of being in control. Within a certain framework, they are allowed to take part in decision making, like which arm or finger will be pricked, where they shall sit or that they can count to ten or another pre-arranged number. Sometimes we see children introduce their own negotiation rituals which put off whatever it is they are worried about, so that large parts of the day are wasted thinking about it, talking about it and dreading it. In cases like this, the adults must intervene and help the child to get it over with. When the child is in this situation, he is helped by adults who are reassuring, encouraging, supportive and who give praise. Children are easily distracted. During painful or unpleasant procedures, they can be distracted by activities, blowing soap bubbles, being read to from an exciting book, drawn into an exciting conversation about something he is interested in, or listening to a story. With professional help, a child can be taught his own strategies for mastering the situation by distracting himself or taking control over the sensation of pain. Some families choose to give their children a little token present after they have been through something unpleasant. These may be stars or stickers, which are a reward in themselves, or points which can be saved up over a period of time for something bigger or an activity. This might be something good to eat, or it could be a cosy time together or time spent reading together.

Many children who are chronically ill, have to undergo tests and treatment for long periods or continuously. No matter how good everyone is at motivating, supporting and rewarding, the child will protest. This is almost completely unavoidable with teenagers. Boycotting the treatment of their illness may become part of their rebellion. Besides, young people's fear of being different and their need for excitement may lead to them being careless with treatment which is important. Parents may feel quite at a loss and full of despair at such times. The whole thing may become a power struggle. Anger and aggression may be a healthy reaction and an understandable protest towards what has happened to them. However, the child's protests may lead to the treatment being undermined. In these cases, it may be a good idea to consider whether the doctor or other health service personnel should have a talk with the child or young person, instead of the parents having full responsibility. The conflict this struggle can lead to between the young person and her parents can tie the situation into an unnecessarily tight knot.

Backup help for parents

Parents tend to give all their time and attention to the sick child without thinking about themselves and their own needs. This is understandable, they do not have the conscience to leave the child. It is particularly painful when the child protests and is anxious. The busy atmosphere in the hospital also makes it difficult to ask someone to come and sit with the child. However it can be a good thing for the child to learn that other adults can also give secure and good support.

The child becomes vulnerable if he can only feel secure together with his parents. We have met children who have associated feeling secure in hospital with only one of his parents, so that he protests when the other one is to take him. This often happens for practical reasons because it was the one parent who always took him when he was first ill. So the child thought, for example, that it was only his mother who had an overview and could be in control at the hospital and he did not feel so safe with his father. Children need to experience that there are several adults they can trust and feel secure with.

If the child is anxious or makes a protest, the situation may be helped by letting her gradually get used to being with other adults, whether this is in the play room or by herself with other adults nearby. The parents say where they are going and are only away for short periods until the child feels secure about this. Then the length of time can gradually be increased. It may be good for young children to have seen the room where parents eat or relax.

When children are crying or showing their anxiety and despair about being separated from their parents, it is tempting to slip away when the child is not looking. This can, however, lead to the child guarding his parents constantly out of fear that they will suddenly disappear again. This is very tiresome for all parties and can be unfortunate for the child in the long term.

The family perspective

As has been emphasised previously, it is important that contact between the sick child and any siblings in the family is maintained. Grandparents, cousins, aunts and uncles can also be important people in the child's life, and they can provide backup help and good support for the parents. Social contact with the world around is easier to re-establish after the child has been discharged if the child has regular contact with the world outside.

When the child is dying

A completely altered perspective

We have mentioned earlier how some chronic illnesses are characterised by uncertainty in relation to several factors - whether the treatment will cure the illness, keep the symptoms under control or whether new methods of treatment will be developed.

Some families experience the very thing all parents and children most fear - that the treatment is not successful and the child's life cannot be saved. Some have been struggling with an illness they were fairly certain would end in this way. Others have gradually come to realise that the child will lose her life because constant relapses have indicated that the treatment no longer has the desired effect; for other children again, the situation deteriorates more suddenly. Whatever the course of the illness, the realisation that the child's life is moving towards an end brings the family into a new and extremely challenging phase.

While treatment is in progress, hope, faith and the fight to help the child survive is a driving force. But there is also a complicated interaction between the hope that the child will survive on the one hand and the fear or certainty that he will not, on the other hand. While the child is under treatment, or the symptoms are being kept under control with the help of medicines, the family has to put to one side the knowledge that the child's life may come to an end. Many people find it impossible to prepare themselves for the loss of their child at the same time as they are thinking all along that the child is going to die.

A change takes place in the final phase which is intensely painful and filled with anxiety, while the situation at the same time feels unreal. This puts great demands on the parents first and foremost, on the child who is sick, but also on siblings, family, friends and health service staff. There may be differences between the staff's interpretation of the situation and what the parents are thinking. The situation can be extremely difficult if the staff think that treatment should be discontinued while the parents are still struggling on with a certain hope. There are parents who refuse to «give up the fight» and refuse to begin with to accept the way things are going. They turn to other forms of treatment or institutions to get help. Some are afraid that unless they have tried everything, they will be reproached or will reproach themselves afterwards. The most usual form of protest we see is families who are reluctant to talk about and make preparations for what is going to happen. They are afraid that this would be a sign of their acceptance of the child dying, and that this could affect the process. Some parents feel that health service personnel and others around them are giving up on their child when they bring up the question of preparing the child's last weeks or days of life, and that it is

their duty as parents to go on hoping and not give up. Many parents have felt alone in this struggle for their child. Sometimes there are differences between the parents in the way they meet this new situation. We have seen examples of couples disagreeing on whether the child and her siblings should be given the same information as them. Or one of them has avoided talking with the doctor, has not wanted to arrange for home nursing and has expressed negative feelings about starting morphine treatment as pain relief. When we have talked with these parents it appears that all this has seemed so final; home nursing and morphine have been such strong signals that there is no longer any way back, that the final phase has begun. Great sensitivity is required on the part of the health service personnel when they meet this kind of resistance, and it is important not to bombastically tear down the defence parents have in keeping the truth at bay, even though they are not «right». Understanding for the way they are thinking, time, support and information can help parents in this painful recognition of the fact that the treatment has not been successful. In this way every possible resource can be directed towards the best arrangements to ensure that the child feels secure and at the same time pain and discomfort can be relieved. After all, no one can take away their hope.

Other families feel that everything possible has been tried and they begin to make the painful preparations themselves for the child's last period of life. We have followed many families through this last phase of the child's life. Our experience is that parents who have gone in actively with preparations for this last phase, have not been left with a feeling of having given up on their child, but have been able to meet the child's need for closeness, openness, consolation and security. Many parents say that they never gave up hope even though they were fully aware that the child was going to die. We have heard parents and children talking about what they would like to do in six months' time, and the next moment be relating in a realistic way to the fact that death can come at any time. Some people say that it brings relief to dream in this way, even though they know.

The way each family arranges the child's last period of life depends on the wishes of the parents and the child, how ill the child is and how close to the hospital the family lives, the extent of the primary health service available to them and the rest of their family and friends. If the child's last period of life can be as secure as possible, it will be easier to think back on it after he has died.

In addition to the inconceivable grief and anxiety connected to what the family is going through, there are several other important things the family has to relate to. Information to the child and the siblings is a difficult process which requires time and sensitivity, and many difficult and ponderous questions from the child or from others can reawaken the parents' own anxiety and pain.

Another factor is the way everyday life is to be coped with - work, school/kindergarten, free time and social life. This is very difficult. All around them, life may perhaps be continuing as before, while the

family feels that the whole world should stop on account of the tragedy they are about to experience. When the child is dying, alleviation of pain is an important part of her care. It is also necessary to prepare and make arrangements for the place the child will be for this last period.

Does being open take all hope away from the child?

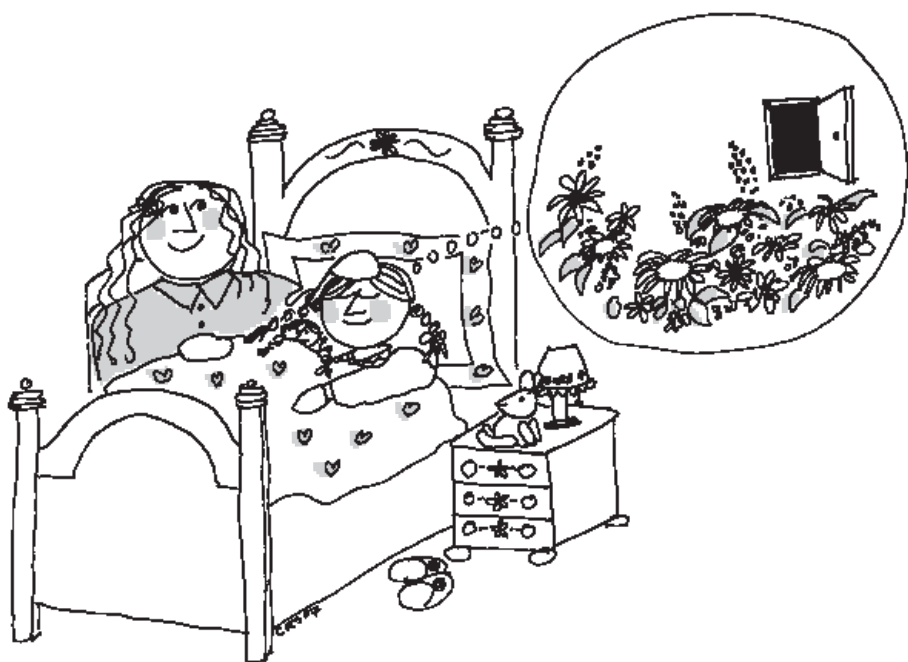
Giving the child information in this new situation is terribly difficult and painful for the parents. They are now faced with the very thing they most want to protect their child from, the certainty that he will die. Our experience shows absolutely clearly that it is important to be open to the child about the serious consequences of the illness. This means that the child should also be told that it now looks as though the illness cannot be cured. He may die. We know that it has been difficult for children to not know and to have to piece things together and interpret all the changes they can of course observe in their own body and in what is happening with the people around them. Many children have understood how serious the situation is without being able to share their thoughts and feelings with anyone. We know that many parents have reproached themselves afterwards because they have not been able to answer their children's questions or meet their need for openness.

Children must be given information that is suited to their age and level of development. Many parents experience that although the message is very painful, the child is already aware of how serious it is and being open is a condition for being able to give security and consolation.

Once the child has this as a starting point, adults must listen out very closely for the questions and reflections the child comes with, build on the images the child has and correct or confirm them. The adult must proceed carefully in this process of communication in close dialogue with the child. A good guideline is that if a child is mature enough to ask questions about something, she is mature enough to deal with the answer. The answer is often already clear for the child, and the adults must be brave enough to confirm it.

Many children have a number of questions about the process they are facing: Who will be with me when I die? How will death come, will I be given a signal that it is approaching? Will I feel anything, will it hurt? Who will take care of my parents, my family, how will they manage? What will happen with all my things?

Answering these kinds of questions from a terminally ill child is painful and difficult. But this is usually most difficult for the adults. The child is partly protected by the fact that he feels ill. All the years of illness and the discomforts he is experiencing at present, may lead to the child expressing a desire to die because life has become so terrible, and he is tired. It gives the child a sense of security to have an overview of what is happening and to have someone they can share their thoughts with.



A seven year old girl knew she was going to die. Her mother asked her whether she was afraid of what was going to happen. «I'm not afraid of dying, but of being away from you and Daddy.» Her mother was able to reassure her daughter that they would be with her all the time.

The child often has questions about what will happen after death, whether there is another «life» or existence. What will happen with me, with my body? Will you bury me? Will I meet Grandma? It is important to maintain the child's religious or existential images. The child may feel comfortable with meeting Jesus, that dead people go to Heaven and are with God. Some parents have given their children other explanations of what death involves, and then it can be confusing to present new, difficult concepts at this stage. It can be difficult for a child to relate to dead people being buried under the ground, while they are supposed to be up in Heaven at the same time. It can also be difficult to accept that Jesus «takes» children to be with him, when they would rather be on earth.

Children do not necessarily have to be given absolute answers, but they should be given the opportunity to talk about difficult things. Children can accept that parents or other adults can say «It's certainly difficult for me to understand as well». Parents often find explanations suited to the family's and the child's culture and beliefs. A six year old boy had a lot of questions about what was waiting for him in Heaven and what it was like to die. His parents told him that they would go with him to a bridge. He would have to go over the bridge by himself. On the other side He would find Jesus and Grandpa waiting for him. This is an example of how openness gives parents the opportunity to console their child and make him feel secure.

Many children find security in reading books like «The brothers Lionheart» or «The Summer Country» which give positive pictures

and associations with death.

Even though the realities of the child's illness are obvious, both children and their parents cling to the hope, like clutching at a straw, that a miracle will take place. At the same time they know that such miracles very seldom happen. Meanwhile, it is important to be able to escape the reality of the situation for short moments. For others hope may have changed from being a hope of recovery to the hope of one more car ride, one more Christmas, or that their mother and father will be with them all the time.

Everyday life and relations

Some families are quite clear about the fact that the child's life is moving towards its end while the child is still - outwardly - in good shape. Others know this because the child is very ill and vital life functions are failing. There are also great variations in how long this last phase goes on for. Some live in this knowledge for months, even years, with only straws to cling on to in the form of hopes of new discoveries in medicine which might save the child. There is a great difference in a child being mortally ill and a child who is dying. A child who is mortally ill can sometimes live an active and almost normal life. When a child is dying, her ability to live a full life is gradually reduced as her life comes to an end and she finally dies.

Care for the child during this phase alters somewhat in perspective, while it is a good thing if as much normality as possible can be maintained. Many resources will now be put towards relieving pain and discomfort, at the same time as the child has the same need for security and content in his life. The child's ability to lead a full life depends on the form he is in. Some are able to continue with school/kindergarten, others are only able to stay at home in bed. Health service personnel and parents have the challenge to give the child a life as long as he lives. Some can be taught at home when they are no longer strong enough to attend school. Friends can come to the child's home when he is no longer able to visit them. The important thing is to adjust this to the child's needs and that it takes place on his own terms.

When the child feels bad, she has a great need for her parents to be there. Children should not be left in other people's care if they do not wish it themselves. Separation from parents can cause tremendous anxiety, while the presence of parents reduces the child's anxiety. But it is important that those closest to the child get the backup help they need. Here it is important to make use of the network the family has of their own, adult friends and the child's friends. It can be a good help if someone comes and helps with the cooking, shopping, washing or sits with the child while the parents read the newspaper or can withdraw to themselves in the house.

Should the child die at home or in hospital?

Most parents and children want hospital stays to be as few and short as possible. In the last phase of the child's life, the parents and the child have to decide whether the child should die at home or in hospital.

Many parents find it impossible to imagine themselves managing to have the child at home. The practical situation may be difficult, or they may think the emotional side of it is frightening and exhausting. Many children would like to be at home as much as possible. But if they notice their parents are anxious, they will probably ask to go to hospital. Sometimes the parents would in retrospect have liked to have had the child at home, but nobody took the question up with them, or they did not feel strong enough to bring it up themselves.

Even children who are very sick still want to be a part of the living environment around them, to feel that they are part of larger context with their family and friends. All experience shows that life at home maintains normality in the child's life in the best way and for the longest time. One condition is that the parents have enough support. Many families are dependent on public services being prepared to step in if the family needs help. Home nursing has a key function here. It is also of great significance that the family is in continual contact with the hospital ward and the personnel who know the child, during the period the child is at home. This kind of open and close contact makes it possible for parents to have the child at home for this last period.

Other solutions can also work well for some families. Some go in to hospital for the last days or hours the child is alive, once the child has become very ill. Most children's wards have an open return arrangement for dying children. This means they can go directly to the ward and to not have to go through the admissions procedure first. Others move into hospital with both parents and all their siblings. Grandparents and other family members have also been there a great deal in some cases. It is important that the ward is flexible. It is also essential that the child has the peace and quiet he needs, at the same time as the family can bring some of the atmosphere at home into the hospital. This can give the feeling that the child's death is a private occurrence for the family, while support is near and easily accessible.

It is important that the family is followed up properly so that they have a real choice about what feels most secure, and that the parents are not put under pressure when they are to decide where the child will be for the last period. The possibilities must be presented for them in a gentle and supportive manner, so that they can find out what feels right for their particular family. The overriding aim is to make the situation as secure as possible and that the family should be together.

Siblings

We have pointed out earlier the importance of siblings being given the same information as the rest of the family and that they can take part and can be included in what is going on. It is very important that siblings are given the same opportunity as the rest of the family to prepare themselves for losing a person they love. This makes it possible for them to say goodbye. Siblings have many of the same reflections and questions about death as the sick child, and need someone to share these with, who can give them answers and reduce their anxiety and insecurity. Some siblings may need to talk about how they can say

goodbye, whether there is something they want to say or do before their brother or sister dies. Others need to express something to their brother or sister after death has taken place. A twelve year old boy lost his sister. He was troubled straight away with feelings of guilt because they had quarrelled. He sat by his sister's bed after she had died, and whispered what he was feeling into her ear. We have many experiences of siblings being present when the child dies. When they are well prepared for what is going to happen, have caring adults to support them, and can come and go as they please themselves, this feels secure and fitting. Many siblings would like to stay close by. They do not want to be there just at the moment their brother or sister dies, but they have said goodbye and feel that they are included in what is happening. They can be brought together with the family gathered around the dead child immediately afterwards.

An important observation!

The experiences and pieces of advice we have passed on may make parents feel guilty for not being able to do so much. We know that many families feel that they are struggling alone and without the support they need when their child is dying. It may be very difficult to put into practice the advice we have given when there is no one to discuss this with. We know that parents do the best for their children according to the knowledge and possibilities they have. Closeness, care and love will always be what is most important.

7 Support for parents

Parents are the most important support for the child. If parents are to be able to bear the strains this involves, they must also have support. Having a good, co-operative relationship with the people treating the child is absolutely decisive. This is not only important for the child to get good medical treatment, it is also important for the parents emotional mastery of the situation.

There are many others in the support services who have a part to play when a child gets a chronic or serious illness, for example the hospital social worker, or the hospital priest, the social work office, the social security office, the educational psychology service (PPT) or the practical aids services.

Parents have different experiences with the people helping them. Some find that in addition to the strains of the actual illness, they have to use a lot of energy acquiring information and getting in touch with the support services, or they find that the contact they have does not help them. There can be long queues and the system is sometimes so rigid that it may be difficult to get the help you are entitled to. In some cases, this struggle is so lengthy and exhausting that parents give up, without getting the help they need.

Families solve their problems in different ways and have varying needs for help and support. The aim is to give them the possibility of living as normally as practicable, even when there is a sick child in the family. A somewhat paraphrased version of the words in Benedicte Ingstad and Hilchen Sommerschild's book on handicapped children can also be used in this connection: «Families with sick children need systematic, fair and differential treatment.»

Patient groups

Support groups and patients' associations have been set up for children with different illnesses. Many people have heard of the largest of these, for example the associations for children with cancer, heart disease, diabetes, asthma/allergies, rheumatism and epilepsy. Most children's hospitals have an overview of how to get in touch with these associations. There are also associations for children with some of the less common illnesses.

Many of these associations are run on a similar experience principle, this means that you can meet people who have experienced the illness themselves or have been close to some one who has. It can be very helpful to speak with someone who has direct experience of the situation, and who has experience and knowledge which can help children and parents.



Conclusion

We feel great respect and humility towards the enormous resources parents show when they are fighting for their sick child at the same time as they keep their family and everyday life going. Families have different experiences. Some feel that life with a chronically ill child costs a great deal. It requires sacrifices from all the members of the family. All the same, many point out that this experience has added something important to life, a new understanding about what really matters, which values really count.

Reading list

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