

Preparing children and parents

On 16 January 1990, the director of Kind en Ziekenhuis, Margreet van Bergen, gave a lecture to a room full of patient communication advisors on preparing children and parents. The essence of her message was that a child must be prepared by an adult whom he or she trusts and who is also able to offer him or her emotional support. The motto is that a child receives the best preparation from a well-prepared adult.

Until recently, the emphasis with regard to the admission of a child to hospital was on medical treatment and nursing care. No account was taken of the emotional needs of a child, as this would stand in the way of efficient treatment. People did not realise that admission to hospital can be a highly traumatic experience for a child. Protest or distress exhibited by the child was regarded by both doctors and parents as an inevitable side effect of hospitalisation. Their consciences were eased by arguments such as 'but children are so tremendously flexible', 'children soon forget' or 'it is for the child's own good'. The parents used to be given a certain amount of information by the doctor at the time of admission. If the parents wanted to know anything else, they would have to try to extract the information from the nurse when they came to visit. As far as informing children was concerned, parents as well as care providers held the view that: 'What they don't know won't hurt them'. A large number of children were simply left with the nurse without knowing what was going to happen to them and without understanding why their mother wasn't there.

Lucy

Until the end of the fifties, practically no-one had any awareness of the way in which children react during and after a stay in hospital. In

1959, however, James Robertson, an English psychologically trained social worker, made a film of a two-year-old girl named Lucy, who had to undergo an operation. He followed Lucy with the camera, hour by hour, and recorded her protests, her distress, her despair, her apathy and the point at which she had to be separated from her mother. This film led to the publication of a government report in England entitled *The welfare of children in hospital* (the *Platt report*). This report established amongst other things that children in hospitals are entitled to be well-prepared for the experience and to have their parents present 24 hours per day.

Psychosocial teams

The events in England did not go unnoticed in the Netherlands. Here too, people gradually began to acknowledge the problems faced by children who are admitted to hospital and are separated from their parents as a result. Instead of involving the parents more in the admission of the child, as was the case in England, the emphasis in the Netherlands was placed on introducing a professional form of assistance for the sick child. Psychosocial teams of psychiatrists, psychologists, educationalists and social workers were formed which offered help to the child and the parents. However, this only happened when the doctor treating the child regarded it as necessary. The

psychosocial teams went in turn to see the parents and encouraged the appointment of play specialists. Professional observation and sufficient distraction in the form of play was regarded as the best way to approach the problems.

Hospital trauma

Despite these efforts, it was found that there were still many children who found it difficult to cope with admission to hospital. The professional experts therefore started to look for additional or better methods to prevent 'hospital trauma'. Informing children about what was going to happen to them in hospital seemed like a good way to help them cope better with their experiences. This task fell to the play specialist. Following Robertson's film and the publication of the Platt report, it would be another twenty years before people in the Netherlands developed any understanding of the fact that the separation of parent and child was the cause of many problems. The fact that people finally began to realise this was primarily as a result of the work of Tera Boelen and Kind en Ziekenhuis, which was formed upon her initiative.

More vocal

Thanks to the work of Kind en Ziekenhuis and its local groups of volunteers, in the seventies parents became increasingly vocal. The hospitals responded to this by ensuring that parents were better informed prior to the admission of the child. This resulted in the publication of a series of information leaflets about hospital admissions. These leaflets had a number of things in common. They generally stated clearly what you could and could not

bring with you to the hospital from home.

Atmosphere

In the early eighties, the tone of the leaflets changed as a result of the activities of Kind en Ziekenhuis. After having argued on a regular basis in favour of providing parents and children with more information, these local groups of volunteers were often involved in the composition of a leaflet. As a member of such a group, I myself have collaborated on an information leaflet for a local hospital. The first time it was no easy task. In time we eventually agreed on a text which addressed the parents in a fully sympathetic tone. However, after having read these sympathetic words, the parents were expecting a completely different approach in the hospital to the one that was taken in reality. The leaflet set a tone which unfortunately was not reflected in the atmosphere in the department.

Veiled texts

Preparing the children for hospitalisation was also discussed in the leaflets. Example sentences incorporated in the texts include: 'You should prepare your child by being honest', 'Explain clearly to your child when you are going to leave and when you are going to come back' and 'Tell your child that you have to go home to take care of the other members of the family'. As we gained a greater understanding of the problems experienced by the children and their parents, the emphasis was increasingly placed on preparation and in many information leaflets the paragraph on preparation became increasingly longer. In spite of all good intentions, this paragraph often insinuated that 'if you prepare a child sufficiently, he or she will not

suffer any trauma'. The information leaflet for parents was also often used to veil the problems and to keep the parents quiet.

It was evident from a survey conducted in 1989 that it was possible in almost all hospitals for parents to stay overnight next to their child's bed (*rooming-in*). But strangely enough, the information leaflets for parents gave only very vague and obscure information about rooming-in and other forms of parental participation.

Publicity

Kind en Ziekenhuis has high expectations of patient communication advisors whose job it is to provide information in hospitals. However, experience tells us that we have to remain on our guard. Information activities for children are subjects which attract a great deal of publicity. Furthermore, launching a spectacular information programme is a good way of drawing attention in the media and enhancing your profile as a hospital in respect of other hospitals. Publicity and competition are however also a sign of the times, which thankfully we can make use of. In our experience, these things are not necessarily incompatible with a high quality of information, as long as this information has children and parents first and foremost in mind.

Psychological damage

How can the hospital best respond to the current insights?

Firstly, we have to ask ourselves what we expect to achieve by preparing young children. In the opinion of Kind en Ziekenhuis, the primary objective of preparation is to reduce anxiety and to prevent children from suffering psychological damage.

In the case of many children, the issue of being separated from the parents lies at the heart of the problems. If the objective of the preparation is to prevent the consequences of this separation, then this preparation will fail. You can tell young children that mummy and daddy will not be there, but that does not ease the distress and does not prevent reactions such as distrust and suspicion. It has become clear that the preparation does not render the presence of the parents during the period of hospitalisation superfluous. In other words: the objective of reducing anxiety and preventing damage cannot be achieved by means of good preparation alone. In addition, it is clearly evident from practice and from literature that preparing a child for a stay in hospital, an examination or treatment can only be expected to have a positive effect if someone who is regarded by the

child as trustworthy can be present during the examination or treatment. In many cases, that someone will be a parent. Only in the case of long-term hospitalisation or repeated hospitalisation of the child can a relationship of trust be built with the play specialist, nurse or doctor. In practice, this means that the patient communication advisor must convince the parents as well as the care providers that the presence of the parents during the period of hospitalisation and during examinations and treatments is beneficial.

Guilt

What is good preparation? Good preparation consists of relevant information which has been specially customised for the child in question. This information includes an explanation of the course of events to come, as well as what the child will see, smell, hear and feel.

We often hear it said that this information must first and foremost be honest. But what exactly is meant by honest? We do not have to take the term too literally. The intention is for children to obtain a tempered and tolerable image of what is waiting for them. One problem is that adults often assume that a child will always understand them if they explain something calmly and clearly. But, children think differently to adults and there is therefore a whole art to being able to immerse yourself in the realm of thought of a child whom you do not know. It is for example a well-known fact that children think they are to blame for their illness or that they are being admitted to hospital as a punishment. Information alone does not help to reduce anxiety. All care providers who treat or care for children should at a minimum know how a period of hospitalisation can be experienced by children. They will



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then be better equipped to communicate with children.

Trusted adult

Who should prepare the child? The information given to the child must be accompanied by a supporting explanation. Ideally, this support should entail a willingness to discuss the ideas, fears and misconceptions of the child. For this reason it is essential that the child is prepared by a trusted adult. Any preparation will fail if the child needs all his or her energy to get used to a strange man or woman. That is why the parents should be the first choice for preparing a child. The parent can tell the child what is going to happen bit by bit and repeat anything that the child has not yet fully understood. Furthermore, the parent will do this in a language that the child understands and he or she will be familiar with the previous experiences of the child. The child will take in the information provided by the parent (information in the form of a story, images or game) piece by piece, like putting together a jigsaw puzzle.

Emotional support

Parents can, however, only prepare their child well if they themselves are not consumed by worries and fear. This fear can be reduced or made manageable by care providers who, in addition to information, provide emotional support. Only then can parents prepare their child and convey their reassurance to the child, verbally or otherwise. Good preparation of the child therefore begins with addressing the fear of the parent. Only then will the provision of concrete information follow (parents must ultimately give their consent). The parents must then be prepared

so that they in turn will be able to perform their task successfully.

Introductory visit

In practice, this means that the information experts should choose an information programme whereby the parents are the target group. This means for example that the parents are invited for an introductory visit without their children. One of the great advantages of this is that the parents can speak freely, without their children listening in with their notoriously perceptive ears. Another advantage is that on the day of admission, the parents will radiate a sense of self-assuredness, which will have a positive knock-on effect on the child. Other elements of an information programme for parents may include:

- showing a video to prepare the parents for anaesthetisation of the child. This will provide the parents with sufficient information in order for them to be able to decide for themselves whether they are able to and want to accompany the child during this procedure;
- compiling a photo book, which the parents can use to tell their child a story at home in their own words, based on what they have been told themselves and what they have seen themselves;
- calling in an interpreting service if the communication between the care providers and the parents is being obstructed by a language barrier;
- preparing the child in the presence of one of the parents, in cases in which the parents are not able to prepare the child themselves.

Speed

When a child can best be prepared depends upon the individual child

and the situation. If the child's admission is scheduled for a particular date, parents have the time to gain an insight into how their child is dealing with the prospect of admission. In general, it can be argued that the younger the child is, the shorter the period of preparation needs to be. Where this becomes more difficult is if the child has gathered from a conversation that something is waiting around the corner for him or her. In this case it is not right to keep quiet about it and to wait until shortly before his or her admission before discussing it with the child. Around seventy percent of children are admitted as an emergency. A large number of these are patients whose condition has gradually deteriorated at home. A proportion of the parents of these children will undoubtedly already be mentally prepared for their child's admission and will have been able to tell their child something about the situation.

For children who are admitted to hospital via the emergency department, the urgency with which action must be taken often plays a role. Despite the urgency, however, it is absolutely essential for the parents to be involved in the treatment, for the precise reason that there has been no time to prepare the child for his or her admission and that this will often be his or her first experience of a hospital. Nevertheless, it is not always easy to convince the employees of the emergency department of the importance of this. Feelings of guilt are often the cause of parents feeling that they have to do everything that the doctor says, without taking any initiative themselves. The provision of personal care and supportive attention to the parents will result in



the parents adopting a more relaxed attitude to the situation, which in turn will certainly be conveyed to their child. Every explanation given immediately before an action takes place or even during the treatment counts as preparation in the case of an emergency.

The preparation must further be supported by ensuring that during the period of hospitalisation, the child is not simply confronted with examinations, x-rays and injections without being prepared for them in advance and without being given the opportunity to deal with the stress that this causes.

Waiting list

A good admissions policy is also important in connection with the preparation of a child. Many hospitals operate a waiting list system. As soon as a space becomes available,

the child is summoned to the hospital (sometimes even days before!). It would be ideal if the hospitals could consult with the parents in regard to the time of admission.

Tailor-made preparation

Good preparation does not, however, render the presence of the parents superfluous. In preparing children for hospitalisation, the emphasis is on advising the parents, so that they are able to offer their child the appropriate guidance before, during and after admission. Because simply providing information in isolation can actually increase anxiety, all information should be accompanied by supporting explanations and personal attention. Although preparing parents and children is an ongoing process, various means and techniques can certainly be used to give this preparation structure and shape.

All preparation is tailor-made. But in the case of children, the tailoring is not carried out by the tailor, but by the parents themselves. They just need to be able to get hold of the pattern from the hospital.

This article is an abridged version of the lecture held on the eighth 'Contactdag Patiëntenvoorlichting' [Patient Information Contact Day] of the Nationaal Ziekenhuisinstituut (NZI) [National Institute of Hospitals] on 16 January 1990. It has previously been published in Kind en Ziekenhuis, June 1990, special issue on 'Voorbereiden van kind en ouders' [Preparation of child and parents], page 46-49. The author, Margreet van Bergen, was until recently the director of the National Office of Kind en Ziekenhuis.