Looking back on thirty years of information provision

A number of the contributions made in relation to the provision of information over the past thirty years will be published once again in this special issue. These contributions together provide an overview of the huge efforts that are required in order to ensure the provision of information to children and parents in an appropriate manner. It is telling that the content of this information is still very much of topical interest. The following article sketches the historical backdrop against which the selected contributions were established.

Marti Troost

Preparing children for a visit to hospital is a tricky task. A classic, but telling example is that of a mother who prepares her young son for treatment in the hospital. In doing so she tells him, amongst other things, that he is going to get a '*slangetje*' in his nose [the word *slangetje* has a double meaning in Dutch: it means a tube, but can also mean a small snake]. When the time comes for this to happen, he resists it with all his might. It later became clear why he had become so hysterical. Because his mother had told him that he was going to get a '*slangetje*' in his nose, the child had thought that she was talking about the live type.

'Be honest'

Up until the seventies, it was fairly widely believed that it was better not to tell toddlers and pre-school children who needed to be admitted to hospital anything in advance. At that time, however, changes in opinion were gradually being introduced. The recently established association Kind

en Ziekenhuis took great pains to draw attention to the consequences of admission to hospital for children and pushed for the presence of parents during the hospitalisation of a child. In response to this, many doctors and nurses held the belief that the emotional reactions of children could be prevented by telling children in advance what was going to happen to them.

Parents were increasingly advised to tell children who were considered to be of an appropriate age what was in store for them. They therefore acted upon this advice as best they could. They were however unable to accurately convey what exactly was going to happen to them. The guidelines that parents were given by the hospital at that time generally consisted of little more than the instruction that they should not deceive the child but 'be honest with them about everything'. The guidelines rarely contained information on the procedure and the treatment. Informing parents so that they could in turn prepare their child for hospitalisation was in itself unusual, so the chances of the parents receiving information that was important in the decision-making process concerning the treatment of their child were even slimmer.

'Hot topic'

In the eighties, informing patients became a 'hot topic'. This was partly due to the *Herziene Erkenningseisen voor ziekenhuizen* [Reviewed Acknowledgement Requirements for Hospitals] (1984), in which 'patient information' was made obligatory. Patient information desks with information leaflets in the house style appeared in hospitals and a new occupational group was formed, known as 'patient communication advisor'. With great enthusiasm these officials launched new activities in the field of information and with equal fervour developed 'products' that were intended for the purpose of informing and preparing children. It has to be said that Kind en Ziekenhuis initially welcomed these activities, that was until the realisation began to hit home that the initiatives served more to benefit the hospital's image than the interests of children and their parents.

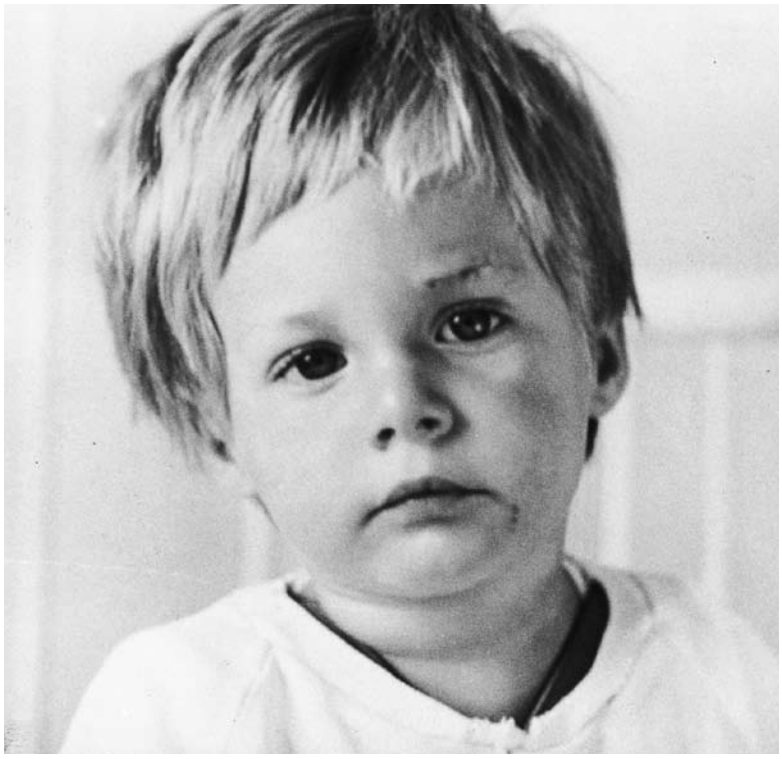
Video camera

In many cases, the activities also had very little to do with the communication between children and parents on the one hand and doctors and nurses on the other hand. This is illustrated by the fact that video films were recorded on a regular basis and shown to children between two and twelve years of age, with a view to collectively preparing them for an anaesthetic or an operation, for example, thereby ignoring the fact that a pre-school child has a very different understanding of illness from a child who has already almost finished primary school. It was also not unheard of for an ENT doctor to film a tonsillectomy and to then show his handiwork to his future patients… Kind en Ziekenhuis therefore lobbied for money (from sponsors) and time to be spent on a film for parents which would clarify what a child will see, hear and feel when being given an anaesthetic and when coming round from an anaesthetic, for example. This way, parents would be better equipped to prepare their child thoroughly for the experience. Unfortunately, however, the plea made by Kind en Ziekenhuis never really found receptive ground. Initiatives of this kind usually got bogged down in a debate about the supposed advantages and disadvantages.

A pre-school child has a very different understanding of illness from a child of twelve

Enthusiasm

Similar debates were often sparked in relation to information leaflets for children. The information was rarely targeted at a specific age group with an appropriate use of language for that group, because this would mean that several versions of the same leaflet would have to be created for the different age groups. It also cost a great deal of effort – and still does to this day – to curb the enthusiasm of teachers who want to prepare healthy young children for a possible admission to hospital in the future in the classroom. Hospitals were, and often still are, very willing to collaborate on teachers' initiatives by giving pre-school classes guided tours of children's wards. Kind en Ziekenhuis should also search its own conscience as far as this is concerned. It was sometimes not easy to curb the enthusiasm of volunteers in our own ranks for these sorts of ex-



Fotografie Leeuwarden

ercises. For these people, organising projects for children was a welcome step towards organising information sessions for parents in the schools concerned.

Environmental studies

All in all, once a certain approach to this issue had been established, it became difficult to change course. Kind en Ziekenhuis did not abandon the 'schools project', but tried to channel the enthusiasm into projects that more closely resembled those undertaken in environmental studies (what is a hospital, who works there and what is the daily schedule), in a similar way to how attention is paid in schools to learning about the post office or the supermarket for example.

Informed consent

The transition to the nineteen nineties was characterised by discussions concerning the legislative proposal in relation to the Wet op de G*eneeskundige Behandelingsovereenkomst* (WGBO) [Medical Treatment Contracts Act]. After the proposal had been adopted by the cabinet, it was passed to the Council of State in mid-1989, but it would take until 1995 for the law to finally come into force. One of the characteristic features of the WGBO was the introduction of informed consent. This means that a patient must be well informed in regard to his or her treatment, the possible risks and any alternatives before he or she can decide whether to consent to the treatment. The law pays attention amongst other things to the position of minors who need to undergo medical treatment. The law was evaluated for the first time in 2000. It was found that the application of the law in practice often proved problematic and many care providers were not aware of the rules in relation to minors.

Site

Since its establishment approximately thirty years ago, Kind en Ziekenhuis has been endlessly reiterating the importance of ensuring that parents and children are well informed. It has always been an essential point for attention and it speaks for itself that even the developments after the WGBO had come into force were followed with Argus' eyes. Time and again, extensive attention has been paid in the special issues of the quarterly publication *Kind en Ziekenhuis* to the introduction of the new law, the interpretation and application of this law in practice and the results of the evaluation. Numerous lectures have also been devoted to this subject and extensive information has been published on the internet for parents as well as for professionals, not forgetting minors. The website '*JA dokter, NEE dokter*' [YES doctor, NO doctor] has been created for the benefit of the latter (www.jadokterneedokter.nl). The information on this website is presented in the form of a comic strip. For the benefit of the three age groups that are also distinguished by the law, a text is available that has been specially adapted for these different age groups. Following the launch of this website, many doctors contacted the association to tell us that the content of the site had also proved highly informative for them. Or as one of them said: 'Only now have I really got my head around it'.

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