

# New policy for *Wilhelmina Kinderziekenhuis*

## [Wilhelmina Children's Hospital]

**At the turn of the millennium, the UMC Utrecht/Wilhelmina Kinderziekenhuis (WKZ) introduced a groundbreaking initiative, which Jeanine van der Giessen wrote an article on in 2004. Since then, in the WKZ parents have been the most important informants of young children, and young people from the age of twelve are now approached directly. This new policy is completely in line with the policy championed by Kind en Ziekenhuis. It was therefore decided that printing this article again would be a good way to round off this special issue.**

In paediatrics, good communication between the care provider, the parent(s) and the sick child is essential. The care provider communicates with the child via the parents and the child alternately, preferably in a 'child-friendly' manner. By child-friendly we refer to the provision of information whereby the child is taken seriously at his or her own level as a partner in the communication. This does not mean that all communication has to go exclusively via the child, but that the child must be given the opportunity during consultations, depending on his or her age, to participate actively in the discussion. The role of the parents in this is of inestimable value. In a process that took a number of years, the UMC Utrecht/Wilhelmina Kinderziekenhuis has developed a formal 'child-friendly information' policy. The introduction of this policy, which is taking place in three phases, is well underway. As part of the first phase, information on the policy and the background to its implementation is being distributed throughout the hospital. This is taking place amongst other things by means of presentations to the department management teams, the child information sector and the management consultations. The second phase involves the development of general

information material. To this end, a leaflet for parents entitled '*Hoe licht ik mijn kind voor*' [How do I inform my child?] is currently under development, along with a leaflet for adolescents in which attention is paid to subjects such as the *Wet op de geneeskundige behandelingsovereenkomst* (WGBO) [Medical Treatment Contracts Act], anaesthesia, pain and asking questions. In the third phase, which runs partly parallel to the second phase, information material relating to specific illnesses and the treatment thereof is to be developed or adapted. This material is aimed at parents and young people aged between twelve and eighteen years. During this phase, the 'child-friendly information' policy will also be discussed in training and continued training courses for care providers.

### **Principles**

The hospital's vision of the way in which policy will be applied in practice can be summarised in six main principles.

- 1. a) Parents are the most important informants for their young children.**
- 1. b) Young people from the age of twelve are approached directly for the provision of information.**



## Parents

In the written information for children from zero to twelve years of age, we have expressly decided to use the parent as the point of contact.

The fact is that parents are the most important and most stable factor when it comes to informing the child. As far as the child is concerned, the parent is the person who is present the most, who the child trusts the most and with whom the most communication takes place. Parents know their own child better than anyone else and are in the best position to assess the level of development of their child.

If a parent is well informed and has confidence in the care provider, this confidence will be passed on to the child. The most important objective of child-friendly information therefore lies in facilitating parents to in-

form their child. Written information material plays an important, supporting role in this. This does not mean that no information resources at all should be developed for children themselves, just that the emphasis should lie on the supporting function of the parents.

In view of this, the written information material actively encourages parents to pass information on to their child themselves. The leaflets that will be compiled based upon the principle formulated will incorporate concrete instructions and tips on how this can best be done. Pictures or other illustrations aimed at children can form part of a leaflet, but only in support of the written information.

## Young people

Young people from twelve years of age form a special group in terms of

information. In accordance with the Medical Treatment Contracts Act, they themselves (also) must give their consent for examination and treatment. This means that young people must always be approached directly when it comes to providing information. Given that at this age they are in a complex phase of development, it is important that the written information is tailored accordingly, not only as far as the form is concerned, but also in terms of content.

## 2. The child is taken seriously.

The term 'serious' can be viewed from two perspectives. On the one hand it means that the child is taken seriously in terms of 'being a child', and on the other hand that the child is taken seriously (at his or her own level) as a partner in the communications. This means that the child has

the opportunity, depending on his or her age, to actively participate in the medical consultations. It is unfeasible to standardise the information requirements of children. Every child is unique and young children will not be capable of specifying themselves what their needs are in terms of information (specific to their illness). They simply do not have the experience or the frame of reference in relation to hospitals, illness and health that adults have in order to do so. The most significant framework that children have is that of 'being a child'. This is a framework which adults can never again fully gain access to. Only children themselves are therefore in a position to indicate where their interests lie. With this in mind, we make a distinction in our information policy between knowledge that is valuable for the child ('need to know') and knowledge that is interesting for the child ('nice to know'). In our eyes, establishing knowledge that is valuable for the child is a task for both parents and care providers, whilst it is the child's prerogative to indicate what (else) he or she would be interested to know.

### **3. Communication based upon trust.**

Two important objectives of the provision of information are to reduce fear and to establish trust in the treatment. In the case of adults, the effectiveness of these objectives has been confirmed by means of research, but it is still unclear as to the extent to which this also applies to children. The fact is, both objectives are based upon rational behaviour, something that children do not yet have, or have to a much lesser extent. The opposite to fear is trust. Building up trust is an equally essential objective of the provision of information

to children. Trust forms the basis for a good relationship between care provider, parent and child. Children lose their trust and therefore become fearful if incorrect or incomplete information is given.

### **4. Dialogue instead of monologue.**

The provision of information must be geared towards an exchange of information instead of a one-sided lecture. Communication in general and with children in particular is an active process. In order for it to be effective, the care provider must gather information (both verbal and non-verbal) as well as give information. This is why it is just as important that the care provider listens carefully to and understands what the child is saying as it is that the child listens to and understands what the care provider is saying. Sensitivity and responsiveness are key words in this regard: the signals sent out by the child must be heard and must be adequately responded to. This always demands an individual approach, i.e. made-to-measure information provision.

### **5. The provision of information in a child-friendly manner is a continuous process and not restricted to a particular place or time.**

There is no one specific moment, as there is for adults, at which it is suitable to inform children. Informing children is a continuous process. Unlike adults, children do not make the distinction between the 'hospital world' and the 'home situation'. Their need for information should therefore not be restricted to one moment, for example during the outpatients' department consultation. Furthermore, they have not yet developed

the same sense of time as adults. If a child is told that an operation will take place in four weeks, this can be difficult for him or her to visualise. A child will ask questions and demand an immediate answer at all manner of unpredictable moments. This is why it is important that those in the child's environment (other family members, friends of the family, the school) are also informed as best as possible.

Communication concerning the child's illness must in so far as possible be integrated into the everyday life of the child. The provision of information should therefore not remain limited to the parents and the child him- or herself, but should extend to a broader circle of people within the child's environment. This is also taken into account in the development of information material.

### **6. Targeted information instead of 'PR oriented' information.**

Child-friendliness entails: creating a secure environment and having concern for the development of the child. For a child, security in the hospital is not a given. It is therefore the task of parents and care providers to help children cope with hospital-related stress. A misconception in this regard is that a secure environment for the child is primarily an environment in which there are lots of fun and nice things to do. This is only true to a limited extent and activities in this field only really serve to 'brighten up' the situation. They can occasionally even have a hampering effect when it comes to trying to allow the daily life of the child to take place as 'normally' as possible, such as by allowing the child the opportunity to play and have contact with friends.

A second factor that contributes to the feeling of security of the child is making the child's environment predictable. This is an important function of the provision of information.

Targeted information to children means that:

- knowledge should in so far as possible be applied to 'the framework' that the child and the parents already have;
- basic knowledge should never be assumed, but should be offered routinely, both to parents and children;
- the essence of simple presentation does not lie so much in the method of presentation, but more in the selection of the information to be presented;
- 'brightening up' must only play a supporting role, and should never be an objective in itself.

Within the framework of the 'child-friendly information' policy, the six principles have now been translated into everyday practice, which means that from now on, all projects or initiatives relating to the provision of information will be assessed against these basic principles. The greatest changes are taking place in the field of written information, because both the existing material and the material to be developed need to be adapted in terms of form and content.

## Responses

Although the new policy is still in the early stages of implementation, we received a considerable number of responses from care providers after its introduction. These were on the whole positive, but there was also some criticism. Opinion was high

in terms of the practical feasibility of the policy. A small sample of the various comments, each of which is accompanied by a brief response from us, highlights a series of aspects which are relevant in the formulation and implementation of a real policy in the field of providing information to sick children.

*'The provision of child-friendly information in a children's hospital is surely something that goes without saying? Who else would the information be targeted at?'*

It is a misconception to think that child-friendly information is targeted solely at children. Parents are also inextricably tied in with this process. It does not make sense to only create leaflets (containing nice pictures) for children. This primarily has the role of 'brightening up' the situation and misses the objective at hand.

*'The new information policy is practical, at least now we do not have to develop material for all age groups.'*

It is not feasible to develop and manage separate leaflets for all categories of children. It is therefore also important to make decisions from a practical perspective.

*'Won't the leaflets be too boring if they do not contain any material for children?'*

On the contrary. The leaflets will become more versatile, because you can also add supporting material to them. You can be very creative with this. The most important thing in this regard is not to lose sight of the objective of the material: can parents use the information to help prepare their child for an examination, treatment or admission to hospital? Imagine that you can add a functional

drawing, a story that the parents can read to their child or photographs for example. Anything is possible, as long as it serves to assist the parents with informing their child.

*'In the development of information material, much more thought now goes into how to formulate the message, so that parents can really work with it.'*

The objective of the leaflet or flyer is clear. The information material becomes more unequivocal and understandable as a result, because it must be of educational value as well as of informative value to the parents. This demands a different approach and a combination of methods and resources is often required.

*'It is good that adolescents receive special attention, as they are an age group which is often forgotten.'*

From a legal perspective, adolescents have the right to make their own decisions in relation to examinations and treatment. Understandable information is therefore a necessity in order to allow them to do so. There is currently almost no information material that corresponds to the perspective of adolescents. For this reason we are making this a priority.

*This article has previously been published in Kind en Ziekenhuis, April 2004, special issue on 'Good practice 2', page 53-57. The author, Jeanine van der Giessen, is patient communication advisor at the UMC Utrecht.*