Rechte der Kinder auch im Krankenhaus
The rights of children in hospital

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A paper based on a talk given in Graz, 22 October 1993,
to the European Association for Children in Hospital

Danke fur ihre Einladund in ihr wunderschonenes Land.

There are three kinds of rights for children. Adults are happy to discuss the first two kinds:

rights to resources and care - good hospital care, food, warmth, safety, parents' loving care;

rights to protection from harm - from neglect and abuse, from fear, pain and loneliness, from too many medical interventions or the neglect of being denied necessary treatment. However, many people are uneasy about children having the third kind of human rights:

rights to dignity, respect, integrity, the right to make personal decisions, to non-interference.

Some adults argue that if you let children decide for themselves, then they will refuse to go to school or to have medical treatment, because they are too ignorant, foolish and inexperienced to know their own best interests. Yet the third kind of rights is the key to all rights. You can talk about resources, care and protection under the heading of children's welfare or interests. You do not need to use rights language to promote these things which are good for children.

When adults talk of their own rights, they start from the basic right, advocated by the German philosopher, Immanuel Kant, of self-determination, the right to make one's own decisions without interference from other people.[1] How can we honestly talk about children's rights yet deny them this basic right? (Kant denied that children could have rights.) For centuries, many adults have believed that the best way to bring up children is to treat them harshly, as the research of the Swiss psychoanalyst, Alice Miller, has shown.[2] Widespread cruelty shows how adults' ideas of `care' and `protection' and what is `right for children' can differ from children's rights to choose how they would like to live. Austria is one of the very few countries to ban all physical punishment of children by law, and to have a children's Ombuds. The right to choose is a crucial part of being a right holder.

The United Nations Convention on the Rights of the Child 1989, which has been ratified by almost every nation, clearly states that some children have rights to influence decisions about their care.

> States shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child will be given due weight in accordance with the age and maturity of the child. (Convention 12.1)
>
> For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial or administrative proceedings affecting the child, either directly, or through a representative or an appropriate body ... (12.2)

> The child shall have the right to freedom of expression: this right shall include freedom to seek, receive and impart information and ideas of all kinds ... (13.1)

Taking the **Convention** seriously means informing children, listening to them, and actively involving children who have views in making decisions about their care. Yet children are very vulnerable. Is it wise to listen to them? Do babies and very young children have anything to tell us? Can older children be trusted to make informed, wise decisions?

This is the first time I have visited Austria and I am very grateful to be invited to the land of Mozart. His aria from the Mass in C minor keeps repeating `et incarnatus est', `he was made flesh by the holy Spirit of the virgin Mary'. Whatever your religion or not-religion, you are perhaps at times amazed by the contrast between the greatness of the human spirit and the child's fragile body, as this music so wonderfully expresses in an international language. (Slides of children in hospital accompanied by the aria.) It illustrates the importance of listening to children, and giving them respect as well as care.

In 1983, with Jean Lovell-Davis, I wrote the first version of the **Charter for Children in Hospital**. Since then, I have been doing research about parents' and children's consent to surgery. I will take three examples from my research interviews which show the value of listening and respecting as well as of giving care.

Jane[3]: learning from babies and mothers

Jane's life was saved by heart surgery when she was a few days old. Her parents were very grateful for this, but were concerned that she had to stay in hospital for months because of a series of infections. Gradually her mother changed from being `a bit cross' to being `angry' about the nursing and medical care. She watched nurses play with one baby and then another without washing in between. Infection spread among the babies. Yet Jane's mother felt that she could not speak because `it would be like giving the nurses a slap in the face' when they were being kind to the babies.

Jane needed antibiotics which were given through an intravenous line, to prevent her from having many injections. However, her veins broke down, and new places had to be found to insert the lines. The staff disagreed over where the lines should be, and in what they told Jane's parents. One day, when Jane was four months old, she was taken into the treatment room, while the doctors tried to insert a line into her neck. Her mother told me, `I'd have probably gone in with her, if I'd been asked, because she calms down much quicker if I pick her up.' Her parents heard the doctors saying that Jane was too distressed for the line to be inserted. At least half an hour later,

> they brought her back in here and put her straight into oxygen, a head box. Jane looked ghastly, grey, breathing very fast. I couldn't pick her up for a while, I felt they'd spent half an hour trying to calm her... When Jane has an infection she can't take much stress, she gets upset very quickly. We felt she should have been sedated for something as dramatic as that. It's quite unpleasant. They turn them upside down so blood rushes to the neck. She would find that particularly uncomfortable because of her breathing difficulties.

Jane's parents explained their views to the doctors, but they found that doctors tried again that day and the next to insert a line without sedating Jane, and she became `really ill'. The doctors wanted to put her back on the ventilator. Her mother, a shy, gentle person, said that then she felt

> very, very angry, because I felt they'd made her like that. She was perfectly happy until they tried to put lines in. They put her life at risk simply to give her antibiotics, on more than one occasion. She has them by injection now and doesn't even wake up, because they couldn't get a line in. I think the consultant told them to try that.

A nurse came to give an injection while we were talking and Jane, asleep on her mother's knee, did not wake when it was given. Jane's case shows how parents can be much closer to their baby, and know her far better, than the large ward team of staff with their changing shifts and rotas. Jane also knows and trusts her mother most, as shown by the way she calms down most quickly when in her mother's arms. For both these reasons, babies can benefit when parents are closely involved in decisions about their treatment. Jane's mother gained her intense knowledge through observing and listening to her baby with empathy, feeling with Jane, almost sharing her fear and pain with her.

Unfortunately, Western society respects `objective', professional expertise, largely based on theories and text-books, but tends to despise parents `subjective' knowledge, gained through experience and loving concern. Yet both kinds of knowledge are very important if we are to understand the needs and rights of each individual child.

Tony[4]: children's minor decisions

We often hear how young children need mothering care, and older ones need respect for privacy. I hope that EACH will help to break through unhelpful age-assumptions. At times, people of every age need respect - even little children are very embarrassed to use a bed-pan in public. At times, people of every age need loving care. During the crisis of major surgery, many older adolescents need and want to be nursed by their mother.

This does not mean that they are `abnormal' or `over-dependent'. As they recover, they move back into their usual independence. It is as unscientific to assess `normal standards' by observing children in hospital, as it would be to assess normal bird life by observing only birds in cages. The example of Tony shows how professionals need to stop judging children and making choices for them. It would be much more helpful to listen, offer choices and respect their wishes.

Tony, aged 15 years, had muscular dystrophy. His mother said, `He needed a lot of reassurance, 24 hours a day. They said, "Maybe because of your weak condition you may not be able to take major surgery". He was desperately nervous. He's lost two of his friends since Christmas'. Tony looked very wasted and spoke in a breathless, low voice. He told me, `I'm so bent over and squashed up, it [the spine] had to be lifted up, but I wanted to put it off to give me more time to get used to the idea. But that may have got my mum anxious'. Tony's mother said, after his two spine operations:

> We've been together in here for 12 weeks. It's a great strain, and you need lots of tolerance and patience! He moaned a lot, he wasn't well between the operations, he needed turning every half hour because he developed sores. In hospital he was a totally different child, I didn't know him. He was so independent before, but in there it was

> `Where are you? Where've you been?'
>
> After the first operation it was very, very upsetting. He woke up in intensive care, no epidural fitted on, no pump. He came round in a terrific state of shock, screaming and shouting, with no pain relief because apparently only an anaesthetist could set it up. He was screaming the place down, `Mum, do something, don't just stand there!' Eventually an anaesthetist came, and it took ten minutes more to set up. She apologised, but I've never spent such a traumatic hour in my life... The second time he woke up peacefully, I made sure the pump was there.

Tony was extremely worried that `my sore could break. They don't come to turn me in the night when I call. I might lie on my back for hours and find it's all broken up. It could so easily break and I'll have to stay in for months'. The hospital was scattered over a large campus, and Tony dreaded the ride on the hard trolley to other departments. His mother said:

> They go bumping over the drains. It made him vomit and he was in a lot of pain with his sore back. He was complaining loudly. The X-ray lady said, `Be quiet!' There were moments when I felt completely helpless. I couldn't believe why it was taking the porters so long to fetch him back to the ward. Two minutes can seem like 30, it was actually 15 minutes we waited. Next time, I insisted he went on a foam mattress on the trolley. I had to reassure him over and over again. Because of his condition he finds himself so vulnerable. I was vulnerable too every first time until I got wise. I learnt I can put my foot down. If you say everything with a smile the staff are willing to listen.

Tony's case shows how older adolescents can feel almost as helpless as babies after major surgery. Many depend on their parents to give the nursing care - turning, comforting, arranging for a foam mattress, giving sips of juice - which nurses are often too busy to give. Children of all ages also depend on their parents to help their protests to be heard when the staff are saying `be quiet'.

Some doctors say that mothers can be with their child in hospital as long as they support everything that the hospital staff do. Of course, helpful cooperation is very important. But sometimes the best way for mothers to help their children is to point out how standards of care can be improved, and to insist that changes are made. The **Charter for Children in Hospital** grew out of the work of parents, doctors and nurses who were saying, `Our hospitals are not yet good enough, we must change and improve them, and think more deeply about children's rights'.

Children's major decisions

Tony showed how children have inside knowledge which is vital in making small decisions: How often need the child be turned over? Is a foam mattress needed? Does the mother need to stay? However, during our study of 120 children aged 8- to 15-years having surgery, and the adults caring for them, we also saw examples of certain children making major decisions.

In 1985, in England and Wales, the Law Lords stated that children need not wait until they are 16- or 18-years before they can consent to medical treatment; they can decide for themselves if they are able to understand the relevant information, and able to make a wise choice in their best interests.[5] (In the UK, a consent form is signed by the patient or parents before major treatment is given.) Our research study set out to ask: When are children old enough to **understand** medical information as well as an average adult can? And when are they old enough to make **wise** decisions about treatment? To respect children's rights, as far as trusting a child to make a major, complex decision, is very difficult.

Many experts assume that children do have the cognitive or moral maturity to make serious decisions until they are at least 14-years. They accept Piaget's work, which was developed in the 1920s and '30s, despite much research which refutes his assumptions.[6] Piaget's continuing influence is shown, for example, in an American ethics book published in 1989.

> Role-taking skills are also thought to be necessary to enable a child to consider as potentially valid both a position presented to him or her by the physician and his or her own, different position, so that the alternatives can be weighed against each other. These skills are undergoing substantial development in the 8 to 11 age period, and are often quite well developed by 12 to 14.[7]

This text continues with an elaborate analysis of competent thinking, as a set of mechanistic skills, isolated from experience, feeling and the social context. The skills include the ability to concentrate,

> to weigh more than one treatment alternative and set of risks simultaneously (i.e. cognitive complexity), ability to abstract or hypothesise as yet non-existent risks and alternatives, and ability to employ inductive and deductive reasoning... and abstract concepts in problem solving.

It is questionable how expert in the listed skills people need be to qualify as competent, but the authors label young children as `incompetents' because they are supposed to be incapable of `cognitive complexity', to have unstable, transient values, no real concept of `the good', of death, of their future, or their likely future values. The children in our study clearly did not realise how incompetent they were supposed to be, because they greatly enjoyed watching television soap operas. To understand soap operas you first have to have `cognitive complexity' and a sophisticated knowledge of many social issues. Otherwise, the films would just be a boring kaleidoscope.

We received many, very different answers from the children and adults we interviewed about an age when understanding and wisdom develop. This final example is taken from an interview with a senior nurse working in a heart-lung transplantation unit.[8] She thought that certain young children, who had already been very ill and had serious treatment, could have profound understanding. Since heart-lung transplantation is so risky, patients are very carefully selected and have four days of intensive information and preparation.

> With more conventional surgery, parents are given enough information to sign the consent form, but I do not believe that they are aware that they have the option to refuse. Transplantation is about choice, therefore you feel able to give families 100 per cent information on which to make their decision. You include all the risks, complications and long-term difficulties, you spare nothing.
>
> Naturally you have to tailor your information to the individual child's age and cognitive development. You'd probably say, `Do you know why you're here? Do you know what's

> wrong with you? ...'
>
> All the children we see have demonstrated an ability to make their own decisions. Whether they do it or not is another matter. Many aren't autonomous enough. One mother said to her son after his brother had died, `We owe it to your brother for you to have a transplant'. He was very distressed. I said to him, `If you didn't want that operation would you tell us?' He said, `No, because my mother would be so sad if I said that.'
>
> I would say that often as young as four or five they can understand a lot about a transplant. Of course, it varies very much, and you can't generalise. I believe the child always has to be involved. We know that they literally have their life in their hands afterwards. If they stop taking their medications, for example, they will die.

The senior nurse discussed whether young children can evaluate risk and benefit.

> Senior nurse: A little girl of about seven with CF ended up by summing up what I had said beautifully. She said, `You're telling me that with CF you can get very ill and die'. I said, `We hope very much that won't happen, but that's why the doctors are thinking about whether, and it is only whether, a transplant might help you.' `And you said that I even if I say I want it, I might not live long enough to get one.' I said, `Well not everyone does. We think you probably will because you're fairly well at the moment but people do die waiting.' `And you're telling me that I could die when I have the operation.' `We haven't had anyone die in the operating theatre, but yes it could happen.' Then she said, `Even if I survive, you're not promising me that everything's going to be good, or that I will be able to do all the things I want to.' So I said, `When we put new lungs inside somebody, you should be able to do a lot more, but it's not a promise that anyone's going to be able to give you.' She said, `But, there is a chance that I could feel really good and I could come first in a race on my pony.' And I said, `Yes'. Then she continued, `All those other things are going to happen to me anyway, so please ask them to give me some new lungs.'
>
> I think for someone of seven or eight to say that illustrates how she had totally taken on board as well as I could, the consequences of transplantation. She had managed to set it all out and look at it very clearly. She had understood the uncertainties. Okay, on a child's level, but who could better it? I couldn't.
>
> I think it's very different when they have CF. Children who have been perfectly healthy don't have that perception of the value of life. Whereas these children were looking at certain death and exchanging that with the uncertainty of transplantation.
>
> Interviewer: So you think their suffering, rather than retarding their understanding, heightens it?
>
> Sen. nurse: They are the most sure, mature children. They're physically immature, but their understanding of life and death knocks spots off us. I think they're immature in some of their attitudes, but their understanding of their own wellbeing and what life is all about is mature. Of course they have temper tantrums. They've got this debilitating illness. They've done nothing to justify being sick day in, day out. It's awful for them. But they tell you it all. Why they have this nebulizer, what this tablet does, et cetera. They're very manipulative children. Knowing that food is a major issue, they'll have steak at 2 o'clock in the morning. But that's very different to their actually understanding.
>
> Int: It seems that suffering and difficulty help some children to grow. The usual convention is that this holds them back.

> Sen nurse: I think it often holds them back in some of the academic things because of missing school. They often have a poor concentration span, and their IQ may be lower.
> Int: Some people have related IQ to wisdom.
> Sen nurse: I think it's totally, totally different. If I'd had this conversation with you three years ago, it would have been very different. Working with these children is a real eye opener. Perviously I'd have said that some level of understanding might be possible, say, for an 8-year old, but I would not have felt comfortable involving a child in actual decision-making unless they were at least 12-years or 13-years old.

If children are not informed, there is the danger that they will be terrified while having painful treatment which they do not expect or understand. If children are excluded from sharing in making decisions, there is a danger that treatment is violently forced onto resisting children. Sincere attempts to listen can sometimes resolve deadlock. A girl aged 10-years whose brother had died of CF refused to consider having a transplant. The senior nurse respected her refusal, but added,

> The next day she asked to go on the waiting list, because, `You listened. I don't like physio but I'm told, "sorry you have to have it". It's the same with medication. I just wanted to see what would happen if I said "no". If you would take any notice.'

The girl's change of decision meant that treatment could be given with her fairly willing cooperation, instead of being withheld or enforced. Occasionally it is necessary to enforce life-saving, emergency treatment. Yet usually there is time to talk, to correct children's misunderstandings, and to give them time to accept that they need the treatment. Some children prefer adults to decide for them, most want a share in making decisions, a few want to be the `main-decider', and are able to make informed decisions. Usually they will agree with the adults, but in some cases the adults are uncertain and disagree with one another about making the best choice.

Conclusion

It can be very hard for adults to respect children's rights, not only to resources and protection, but also to make their own choices. A hospital chaplain and former headmaster said:

> But are you going to lay on children the weight of their future? Perhaps let them make a decision that could lead to their death? These are impossible questions, but hospital staff have to find the answers. Am I big enough to say, `Whatever you choose will be valued, even if you decide against the tide; okay, you've made that decision, I'll do all I can to support you, and we'll go forward together'? It's such a big step for the adult to surrender power to the child.[9]

Respect for children's rights is partly based on adults recognizing the sense and logic of respecting a child. Yet respect is also influenced by adults' feelings: fear, anxiety, distress, anger at the thought of letting a child decide; or hope, trust and a willingness to surrender adult power. In European society, many forces work against respect for children, and for their mothers when they speak for them. These forces include the values summarised in the following table.

Values about people and qualities

Superior

Inferior

professionals	patients, parents
text-book knowledge	knowledge from experience
adult	child
healthy people	sick people
objective detachment	subjective involvement
mind	body
intellect	emotion
intelligence	wisdom

Honest respect for children's rights involves rethinking this table, and realising that sick children and anxious mothers have unique knowledge. We tend to see all knowledge and skill being passed from professionals down to families.

doctors, nurses, therapists

children, mothers, fathers

Taking children's rights seriously involves thinking in more equal, less hierarchical ways:

doctors	**children**
nurses	**mothers**
therapists	**fathers**

Professionals have to learn from children, if they are to make truly informed and humane decisions which respect children's rights.

Acknowledgements

I thank everyone who contributed to the parents' and the children's consent studies; the ESRC, the Leverhulme Trust, the Calouste Gulbenkian Foundation, and Kinderbegleitung for sponsorship.

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The rights of children in hospital

During October, EACH - the European Association for Children in Hospital - met at a beautiful castle in Graz, Austria. Delegates arrived from East and West Europe and from the Nordic States. EACH works to make the **Charter for Children in Hospital** become a reality throughout Europe. Members have used the **Charter** as the base for a range of activities, from a Michelin-type guide to good children's wards in France, to a finely illustrated Polish brochure showing how one hospital implements each section of the **Charter.**

The ten points of the **Charter** offer an ethical foundation for the care of children in hospital, to which readers of the **Bulletin** may wish to draw the attention of their local children's health services.

International rights for children

Aspects of the **Charter** were reinforced by the 1989 **United Nations Convention on the Rights of the Child**, now ratified by almost every nation state. Basically, the Convention advocates three kinds of rights for children. Adults are happy to discuss the first two kinds:

rights to resources and care - good hospital care, food, warmth, safety, parents' loving care;

rights to protection from harm - from neglect and abuse, from fear, pain and loneliness, from too many medical interventions or the neglect of being denied necessary treatment. However, many people are uneasy about children having the third kind of human rights:

rights to self-determination, dignity, respect, integrity, non-interference, the right to make informed personal decisions.

Some adults argue that if you let children decide for themselves, then they will refuse medical treatment, because they are too ignorant, foolish and inexperienced to know their own best interests. Yet the right to self-determination is the key to all rights. You can talk about resources, care and protection under the heading of children's welfare or interests, but do not need to use rights language to promote these benefits.

When adults talk of their own rights, they start from the fundamental Kantian right to self-determination. How can we honestly talk about children's rights but deny them this basic right? (Kant denied that children could have rights.) The right to choose is a crucial part of being a right holder. As the research of the Swiss psychoanalyst, Alice Miller, has shown, centuries of harsh, even cruel, child-rearing illustrate differences between adults' ideas of `care', `protection', what is `right for children', versus children's rights to choose how they would like to live. Austria is one of the very few countries, so far, to ban all physical punishment of children by law, and to have a children's Ombuds. Children form the only group of people in the UK who are not protected by law from assault.

The UN Convention on the Rights of the Child clearly states that some children have rights to influence decisions affecting them.

> States shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child will be given due weight in accordance with the age and maturity of the child. (Convention 12.1)
>
> For this purpose, the child shall in particular be provided the opportunity to be heard in any judicial or administrative proceedings affecting the child, either directly, or through a representative or an appropriate body ... (12.2)
>
> The child shall have the right to freedom of expression: this right shall include freedom to seek, receive and impart information and ideas of all kinds ... (13.1)

Listening to children and mothers

Taking the **Convention** and the **Charter** seriously means informing children, listening to them, and actively involving children who have views in making decisions about their care. This depends on sensitively discussing with young children how much they can, and wish to, be involved in decisions affecting them. It means listening to mothers who pick up cues from their baby about the treatment is benefitting or harming them, and how it might be improved. It also means overcoming age-assumptions, such as that children aged under-3-years cannot understand explanations (they can), or do not mind their privacy and dignity being disregarded (they do), or that children aged 5- or 6-years can never take part in making complex, serious decisions about their treatment (some do), or that older adolescents do not need or want close mothering care (many do during the early days after major surgery).

Patients literally have unique, inside knowledge of their own case, and their parents can help them to be heard when they express their views. Some hospital staff say that mothers can be with their child in hospital as long as they support everything that the hospital staff do. Of course, helpful cooperation is very important. But sometimes the best way for mothers to help their children is to point out how standards of care can be improved, and to insist that changes are made. The **Charter for Children in Hospital** grew out of the work of a few parents, doctors and nurses who were saying in England during the 1950s, `Our hospitals are not yet good enough, we must change and improve them'.

First do not harm

A crucial way to ensure that children's rights are safe-guarded is to avoid admitting them to hospital when possible (**Charter** para.1) and to avoid unnecessary interventions (**Charter** para 5). In reply, some professionals report on how `non-invasive' technology, such as scans, has beneficially replaced invasive surgical investigations. Such advances are to be welcomed. However, some people find scans frightening and psychologically invasive. Discussion of how one kind of technology replaces another raises a risk of diverting attention from the main question: Is the intervention really necessary? Will it do more good than harm?

Sadly, in Europe, there are many children who are denied the treatment and relief they need from illness, pain and disability through poverty, government economies or war. Yet there are other children who are being over-treated, or who have interventions which have not been evaluated through well-designed research. Very little health care is subjected to careful scrutiny. In beautifully designed and equipped wards, with the latest technology and highly skilled staff, it can seem impertinent to question the benefits of the treatment provided. There is a paradox, that the more professionals are convinced that they have provided a child-centred refuge in an unfriendly world, the higher the risk that children and parents who question the care will be seen as negative and ungrateful, so that their right to make informed choices can be threatened. For decades, research and enquiries have shown the great harms perpetuated by the institutional care of children (from Bowlby's work in the s to reports such as the Pindown Enquiry in the 1990s). Yet in many European countries, children are still kept in hospitals or children's homes, for weeks or months, for problems which could more effectively be given at home, including minor eating and sleeping disturbance, or allegations of `bad mothering'. The new children's rights movement sweeping across Europe will help professionals and parents to listen more seriously to children, so that they are all better able to make truly informed and humane decisions which respect children's rights.