

## **A young child's refusal of life saving treatment 1996**

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With some further notes that had to be cut from the published version.

### **When do we stop? Involving children in decisions about withholding or withdrawing treatment intended to extend life**

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#### **Introduction**

Many health professionals listen to children with skill and care, but others find this difficult. This is especially so when the possibility of withholding or withdrawing attempts to sustain life are being considered. In many cases, children are too young or too sick, injured or disabled to share in such decisions. However, some children have important ways of influencing decisions about what their best interests are, and how these can be respected. They may not use words, or share in formal discussions, but they still need to be treated with respect and care. This article begins with a mother's account of a six year old girl's experience of liver transplantation. This is followed by a review of background beliefs about involving children in the most complex and serious decisions. The barriers which adults have to overcome when listening to children, and the benefits of doing so are considered.

#### **One child's experience: a mother's account**

What is right for one family, may not, and should not, be classed as right for another family. Samantha Irwin was born in 1986. She had frequent illnesses and infections, daily medication and several major operations. We explained everything to her, and why it was necessary. She would sit and talk to her dolls, explaining the procedures and playing hospitals. When she was six, she was listed for a liver transplant, and it was decided Samantha should tell the class herself. She took a chair to the front of the class, and sat down. She explained to the class that she needed a transplant, and why, and that she would be away from school.

Five weeks later she was bleeped to the hospital. She was so excited that she was going to have a new liver. She wanted to be able to run around, find clothes to fit, and be pink. A thirteen and a half hour transplant was followed by trips to theatre every week of one and two hours at a time, until another big operation was needed to try to solve her problems. Another eight hour operation was followed by more weekly trips to theatre. During all of this, she would remind me which medicines she needed. She could work an IMED and an IVAC pump. She could explain why she needed most of her treatments and yet she could not write her own name or count past ten. Finally she was sent home for the last stages of recovery.

A week later we were back in hospital needing a second transplant. The doctors were not sure how she would take the news, it was only two months since her first transplant. I asked to be allowed to tell her myself. They agreed. 'Positive thoughts'. I again asked her what she wanted from her new liver. She repeated as before, to run, to wear nice clothes and be pink. I fetched a mirror and asked her if this was what she wanted. Her answer was 'no'. So I told her the doctors thought that this liver was not working properly and they ought to give her another one. She smiled, 'yes please'. I signed the consent form. She needed something to look forward to, and from lots of

travel brochures, she chose Disney world. She was kept very busy planning what she would do there.

Three days after Christmas she went for her second transplant. Things did not go too well and her test results did not improve very much. She was becoming very distressed now at any tests that needed doing. She still had to visit theatre every week, and I would go to the anaesthetic room and the recovery room. We came to know all the staff well, and they would visit her on the ward. Once she came out of intensive care, it was clear to me, here was a different child. Her whole personality had changed. She didn't smile any more. She insisted we cover her scars. If you tried to look at them, she would become hysterical. Every day we would tell her they looked a bit better, but she would not look. To change her clothes, she would make you wrap a towel round her first, so that she couldn't see them. To do an ultrasound scan, which is not painful, it got that she had to be sedated. She stopped talking. Here was a little girl who was terrified. I had to do something. The doctors were discussing the possibility of a third transplant. I said the only possible way was if I could go in her place. As a family we decided that the only hope from another transplant was if her spirits could be raised enough for her to want it to happen.

With help from a charity we went to Disney world for one week. Miracles can happen in these places. We just had to hope for one. We had seven days away with no routine, no tests. Her first day she smiled, and then she saw someone look at her, and she hid under her coat and wouldn't come out. We were treated like VIPs, but in the restaurants she would close her eyes and pretend to be asleep. In the whole week she only had one hot dog and a glass of coke on the first day, and then nothing. This did not strike me as a child who was glad to be alive. She got weaker. On the way home she asked to go back to hospital so that they could stop the pain in her back. At the hospital, after a couple of hours the pain killers began to take effect. 'I'm so fed-up, I just want to go home. Can I go home? Please?' The doctors returned with the test results, and said they were much worse. If she was to have a third transplant, it needed doing. This was our last chance. I wanted to say 'yes', I didn't want her to die. But there was only such a slim chance of a third transplant working, maybe two per cent. She didn't want anything else. She wanted to go home. What should I do? 'Positive action'.

I am trying to convey my thought processes here, which are obviously very complex. To make it simple makes it appear somewhat naive, maybe. This, however, is the only way I can describe what was going on in my mind. We really had two choices of action. A) stop treatment or B) accept a third transplant.

Course A. If we stop treatment, we could:

- 1) take Sam home as she requested;
- 2) give her special attention for the time she had left;
- 3) let her have her family back;
- 4) let her have choice of routine;
- 5) allow her dignity with quality of life.

All this would make Sam happy. The end result being that she will die, which the family left behind will have to deal with.

Course B. If we accept the third transplant:

- 1) Sam will have to face more time in hospital;
- 2) she would have to face worse scarring;

- 3) she would continue with hospital routine;
- 4) she may well live a little longer.

However, we were talking quantity of time, not quality of time.

End result. I am sure she would pick quality over quantity of life. She will almost certainly still die. I could not have taken away her choice, self-worth, quality of life and her dignity. After her death I am sure we, as a family, would have found her death much more difficult to come to terms with. A doctor told me he felt the medical profession had failed her, if they just allowed her to die. My response was they had only failed if they did not listen to her, and continued when she was no longer capable of responding.

We also felt that Samantha's two year old sister Kirsty would benefit if we chose course 1. They were very close. I explained all of this to the doctors, and they agreed. They were so helpful, organising hospital at home services. And they said if I couldn't manage we would be welcome back. I asked how long they thought we had. They didn't know. We went home and she died three days later. These were very important days to us. We felt we had listened to Samantha. She seemed relieved to get home. The three days were the most strenuous and stressful days of my life, but I do not regret my (our) decision.

In my view, the ethics is not a clear-cut case in any direction. If we can teach parents to step back, put themselves in their children's shoes, and decide with informed choices what is in the child's best interests. I am trying to say that we must learn to listen to our children in whatever way they are capable of telling us their views. We must learn to reason at a child's level with adult knowledge.

### **Commentary: Taking bodies seriously**

The sight of very premature babies and deformed children raises crucial questions about human nature. Why is the human spirit trapped in such a puny, frail body? If anyone had to send such a great marvel of the universe in a parcel, who would choose such packaging as these fragile bodies? Is the stark contrast between spirit and body a tragic paradox or a cruel joke?

One age-old response to these questions has been to separate mind from body, and to see the body as little more than an unfortunate package for the mind. Traditionally, it was widely believed that the more we exist in our heads, as purely rational intellectuals, and the less we are affected by our bodies, the more fully human we are. Western philosophy and religion are deeply riven by the mind-body split. Scientific understanding of humanity is similarly divided, between medicine and psychology.

However, the essence of humanity is the spirit which fuses mind and body, which can relate and celebrate, laugh and grieve, aspire and imagine, question and create. This elusive spirit slips through the grid of scientific analysis, its essential nature is lost between dichotomies. Although poetry and music reflect deeply on human nature, science scarcely has words or methods to address this 'soft' subject.

Care of the body and attention to patients' knowledge gained through their bodies are crucial to informed nursing practice. Yet knowledge gained and communicated through the body tends to be denigrated and mistrusted in science and philosophy and, paradoxically, even in medicine and medical ethics. Since young children are especially liable to learn and speak through their feelings and body language, their knowledge tends to be devalued. We all exist in and through our bodies, and indeed

we are our bodies, though adults often try to deny or disguise this. Another effect of the mind-body split has been to lose sight of the whole thinking, feeling person in the child, to see infants primarily as bodies, and childhood as a prelude to the full personhood of the mind.

The split creates great problems when listening to sick children if they are seen in terms of physical malfunction and rudimentary cognition. When words are the only valid currency for communication, body language is seen as counterfeit, to be mistrusted as valueless and misleading. Yet words too can be misleading, confusing and misunderstood. The first barrier to overcome, when taking children seriously, is to rethink the mind-body split, and to see the body as much more than a mere container. Bodies can be the source of profound knowledge, when children learn through their illness and disability, and express themselves physically. Samantha's body was a main point of reference for her through the account, interwoven with her feelings, hopes and fears, and her parents' belief that unless 'her spirits could be raised enough for her to want it to happen' the treatment could not benefit her.

### **Listening to children**

During a study of children's consent to surgery,(1) 120 people aged 8 to 15-years and having elective orthopaedic surgery were interviewed. Half of them had two or more chronic diseases or disabilities. In that group were many remarkable and exceptionally mature young people. As one mother remarked, 'He may have a small body, but he has a great personality'. They had courage, compassion and good sense. The study found that of the 120 young people, 13 of them believed that they were 'the main decider' about whether to accept treatment proposed by the surgeon; 13 parents thought that their child was 'the main decider'. 'Main deciders' were aged from eight years upwards.

The children were asked who should be 'the main decider'. It is one thing to feel able to do something, and another to be willing to do it. After surgery, 21 children said that they wanted to be the 'main decider', 47 wanted to share in making decisions with adults, and 45 wanted adults to decide for them. Before surgery, only two children wanted their parents alone to decide, though this rose to seven when they were asked again after surgery. They seemed to have more confidence in their doctor's judgement than their parents'. This raises questions as to whether children see their parents less as decision makers, and more as mediators, interpreters, support-givers or advocates. The research was not about the final stages of life-saving treatment, though three children knew that without spinal surgery they would not have long to live.

Another study, of children with cancer in Bristol, found that even 2-year-olds understood the names of drugs and their purpose, and cooperated with their treatment. Some made a fuss over washing and feeding, perhaps to compensate, but to judge them as immature because of this would be mistaken.(2)

Most of the young people in the surgery study, though they complained at times, showed dignity and stoic courage when they faced repeated surgery. Nurses and parents commented on children who, in order to protect their parents, would not talk of their own distress. The sister in a heart-lung transplant unit asked one boy with cystic fibrosis, whose elder brother had died of the disease, 'Do you really want to have the transplant?' He did not reply, except to say, 'I've got to have it, or my mother would be so sad'. This courage is a great strength, but it is also a barrier which can

make it harder to listen perceptively to children.

### **Overcoming barriers to listening to children**

In the past few decades, health professionals have become far more interested in listening to adult, and more recently child, patients and sharing information and decisions with them. There are many barriers to overcome - lack of time, skill and confidence, problems with finding the right words, with communicating with people who speak other languages, and adults' anxiety that they may look foolish or lose control if they risk allowing children to influence decisions.(3) When children are extremely ill, and possibly very distressed, all the pressures are increased.

Many health professionals demonstrate how successfully these barriers can be overcome, but others find them very daunting. A useful first step, before trying to overcome the practical barriers, is to recognise some of the psychological ones, such as anxieties and prejudices. Is it worth listening to children? What should be done if their views might seem to involve self-harm? What if the parents object? Can young children have any idea about enormities such as death?

Reports from nurses who do listen to children show how very worthwhile and important their work is when they take children's minds and bodies seriously.

### **References**

1. Alderson P 1993 Children's consent to surgery. Open University Press
2. Kendrick C 1988 Young children with cancer: understanding and communication. Paper given at the RSM, London
3. Alderson P, Montgomery J 1996 Health care choices: making decisions with children. Institute for Public Policy Research

Some extra notes that had to be cut from the Nursing Times article.

There are several factors which often underlie reluctance to approach children directly, and to consider ways of coping with these.

The greatest problem is lack of time. It can be so much quicker to speak to parents. Children tend to balk at abrupt questioning, and a few moments spent discussing their hobbies or pets first can help them to open up and be far more responsive. Yet busy professionals question whether this is the best way to use their own time. Subtle ways of silencing children learnt by junior staff who worry that they will be criticised for delays if they talk to children can develop into habit and example among senior staff.

Another strong deterrent is lack of confidence, with anxiety about making mistakes and looking foolish. Anything worth doing can be risky and involves making mistakes while gaining new skills. Research interviews with children and parents in hospital suggest that they are more interested in the goodwill of health staff, their sincere manner and intentions, than in slick communication skills. Lack of skill in talking with children can be a severe restriction, though many people feel more inadequate than they are. We have all been children and talked to our peers, so this is partly a matter of remembering former skills. Some adults find that the best teachers are children themselves. The idea that talking to children is such an esoteric art it requires special courses is unhelpful, since it requires the same skills as talking to anyone else. For

example, as with adults, staff who listen sit at about the same eye level (get rid of baby chairs in clinics), adapt their volume, tone and pace of talking to suit the other person, use a simple or more complex vocabulary as appropriate, word and rephrase questions clearly, wait attentively for answers, respect what is said, try not to interrupt or dismiss what is said, and so on. Children with chronic conditions often use sophisticated terms and do not like to be talked down to, or discussed above their head.

Language can be a barrier when the children or the staff use pet words, colloquialisms, jargon and any terms which the other either does not understand or misunderstands. This is true at all ages, though small children use many personal words. Parents can be helpful two-way interpreters. If talking through an interpreter is hard with adults, it can be harder with small children whose first language is not English. Additionally, the interpreter may plainly consider the encounter a waste of time and the parents may feel offended or excluded. Extra time, patience and perseverance may be required. Language can also be a barrier when communication is confined to words. Other languages need to be noted, such as body language, sighs, cries, and laughter. Drawings, toys and visual aids can enrich mutual understanding.

Addressing children directly can challenge family dynamics. Many parents gently encourage their child to take a growing share in the conversation, or are pleased about their child's independence, but some parents wish to dominate the interaction. The mid-years alliance, the assumption that adults speak to adults and that children listen is still very powerful. It works when people are believed to have entered second childhood, and their middle-aged children speak for them, as well as with very ill or disabled people. It can require tact and confidence to resist deferring to the parents without offending them, especially during the crisis of their child's severe illness.

Fear of losing control drives some staff to avoid speaking to children. A simple command, 'put her on the couch mother', can, they feel, avoid minefields. If requested to get on the couch, might the child refuse, dawdle, start an argument or resort to other time-wasting tactics? If staff are too friendly, will children try to play power games - and win? To cope with this, many professionals skilfully combine friendly respect with firm confidence. A major restraint on efforts to talk seriously with patients is anxiety about which topics might be raised: unanswerable questions, pleas for treatment and healing which cannot be promised, long personal accounts which hardly seem relevant, and cries of anguish and despair. Such responses span the age groups, and there are helpful books and teaching videos on how to respond.

Prejudice is another vital issue. It is so common to mistrust and disrespect children, based on decades of misleading psychological research. Work that challenges these old ideas includes:

Alderson P 2000 *Young children's rights*. London: Jessica Kingsley/Save the Children

Bradley, B. (1989) *Visions of Infancy*. Cambridge; Polity Press.

Donaldson, M. (1978) *Children's Minds*. Glasgow: Fontana .

Franklin B 2001 *The new handbook of children's rights*. London: RoutledgeFalmer

James, A. and Prout, A. (eds) (1990/97) *Constructing and Reconstructing Childhood: Contemporary Issues of the Sociology of Childhood*. London: Falmer Press.

Mayall B 1994 *Children's childhoods observed and experienced*: London: Falmer

Mayall B 2002 *Towards a sociology for childhood*. London: RoutledgeFalmer  
 Siegal, M. (1997) *Knowing children: Experiments in Conversation and Cognition*. Hove: Lawrence Erlbaum Associates.

Stainton, Rogers, R. Stainton, and Rogers, W. (1992) *Stories of Childhood: Shifting Agendas in Child Concern*. Hemmel Hempstead: Harvester.

So far, views on children's ability to give or withhold consent have been reported. A separate question is whether children want to take on the burden of choosing. Parents and young patients were asked who they thought made the decision whether to accept proposed surgery (table 16) and who should be the 'main decider' (table 17).

Table 16 Views about who was the 'main decider'.

<u>Main decider</u>	<u>Views of what did happen</u>	
	<u>Parent's view</u> n=120	<u>Child's view</u> n=120
Child	13	13
Child + adults	62	44
Adults	32	60
Child accepted after persuasion	9	-
don't know	4	3

Ages of the 13 'main deciders' ranged from 8- to 15-years. The figures represent widely-ranging comments, such as Julie aged 11, who said, 'I think everyone should give an opinion, and maybe the doctor put them together.'

Table 17 Views about who should be the 'main decider'.

<u>Main decider</u>	<u>Views of what should happen</u>	
	<u>120 children's views</u>	
	<u>before op.</u>	<u>after op.</u>
Child	18	21
Child + parents	3	5
child + doctors	3	1
all together	49	41
parents + doctors	19	13
doctors	25	25
parents	2	7
don't know	1	7

The children showed more confidence in their doctors' than in their parents' judgement. The figures suggest that parents are seen as mediators rather than 'main deciders', and that joint decision-making is a major preference.

Our study of 120 young people having elective orthopaedic surgery found that 13 of them believed that they were 'the main decider' about whether to accept treatment proposed by the surgeon; 13 parents thought that their child was 'the main decider'. 'Main deciders' were aged from eight years upwards. We asked for the children's views on who should be 'the main decider'. It is one thing to feel able to do something, and another to be willing to do it. After surgery 21 children said that they wanted to be the 'main decider', 47 wanted to share in making decisions with adults, and 45 wanted adults to decide for them. Only two children wanted their parents alone to decide, this rose to seven after surgery. They seemed to have more confidence in their doctor's judgement than their parents'. This raises questions as to whether children see their children less as decision makers, and more as mediators, interpreters, support-givers or advocates. Our research was not about the final stages of life-saving treatment, though three children knew that without spinal surgery they would not have long to live. In our research about breast cancer surgery, there was a similar curve; a minority of women wanted to be the 'main decider', a minority wanted doctors to decide, the largest group wanted to share in making decisions with doctors. The replies among different patient groups with different conditions are likely to vary but would possibly follow the same breadth of responses.

### **Why listen to children?**

For the same reasons that it is worth listening to adults.

**respect**

**avoid coercion fear  
ignorance resentment**

**encourage informed willing commitment**

**learn from the child**

**clarify misunderstanding and disagreement**

**listen as part of therapy**

**work together towards the  
least harmful decision**

Respect is a reason sufficient in itself. If the patient has a question or comment about the treatment, then it should have a response; anyone who disagrees should have to justify silence. Yet there are also benefits which accrue from listening. Health staff can discover children's fear, misunderstandings and reluctance and help to reduce fear, ignorance and coercion except when they believe that it is unavoidable. Listening to children can be part of their therapy. By respecting and taking time the staff can work together with the child and/or the parents towards the least harmful decision for each



person. However, this does raise the dilemma in rare cases: what should adults do when the child wishes to end rescue treatment?

A hospital chaplain and former headmaster (ref interview)

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.

In view of the growing respect for young children's ability to develop informed views about their treatment the main issue in some cases is not so much children's ignorance and immaturity but adults' power, and desire to protect and control children. This can be the greatest barrier to perceptive listening which depends on mutual trust and respect.

Quotes and examples from Alderson OP 1993 Children's consent to surgery. Buckingham/New York: Open University Press.