

Channel 4 *Inside Out*: "A heart for Jo"  
22 August

## A view from the back of the queue

Jo Harris is a sparky teenager with Down's syndrome and a hole in her heart. The combination seems certain to kill her. As a baby she could have had cardiac surgery but attitudes to Down's children were even more discriminatory then. Now her lungs are damaged. Whereas "normal" people have the chance, however slight, of a heart-lung transplant, Down's patients are simply not eligible. Jo is "a right little ... in the bum," according to her mum, but the real pain is that because of a label she will not even be considered on equal terms with other transplant candidates.

At first glance then, this programme seems another heart-tugging scenario of sick child and desperate parents pitted against the implacable medical community. Her mother bluntly sums up the medical argument "there are so few organs and they are so very precious, they're not going to waste one on my child." But beneath this superficial view another sad reality is captured. It is the struggle of conscientious doctors searching for criteria with which to address the obscene dilemma of selecting who will live. For many, time will run out before they get to the operating table. Not all can be treated, so desperate efforts are made to match the big waiting list with the small organ supply. Cold logic dictates that some simply will not make it on to the list, even though, like Jo, their apparent potential to function as independent human beings is probably no less.

"It's not just Down's we are discriminating against. It is anybody with any disability. We take, when faced with a choice, the person who is the most whole," says the medical director of Harefield Hospital, Dr Rosemary Radley-Smith. Unlike the viewer she has the



"There are so few organs they're not going to waste one on my child," says Jo's mother

disadvantage of not witnessing Jo's "wholeness." But agree or not, her bravely honest attempt to cut through the euphemisms and explain the reality demands respect. Her tensely hunched body language echoes the misery of facing such dilemmas.

Jo herself is the unquestioned star of the programme. Even when she is not centre stage, the descriptions of her achievements continually emphasise that she is an interesting person with a fulfilling life. She undermines the stereotypical view of Down's syndrome and shows the risks of labelling. Jo is special by any standard and, perhaps unfairly, will change forever many people's view of those with Down's syndrome. The doctors' apparent indifference to her seems all the more inexcusable for this and is reinforced by an example. One American doctor who was forced by antidiscrimination legislation to assess a patient with Down's syndrome, said that her explanation that she "wanted to live" was not good enough. Even with such legislation, some are obviously more equal than others.

Predictably, doctors do not come out of this

programme well. Apparently it was not until Jo reached 12 that the family were told the implications of her condition, and then quite brusquely. I suspect that, were there not a camera at her elbow, Jo's mother would have been unlikely to receive either an interview with specialists or a full explanation. The viewer is drawn to share her conclusions, on hearing a variety of medical explanations, that most are "a load of bull." But the programme also leaves hanging in the air the impossible question of how rationing decisions *should* be made, and it leaves the feeling that it is too easy to blame doctors.

At the centre of everything is Jo herself—a lively, funny kid full of joie de vivre. Small touches convey her special courage. As the programme begins, her terror of horses is shown; as it ends she feeds a horse without finching. Likewise the programme does not flinch from unpalatable reality. Instead it portrays individuals in a desperate situation all trying to do the right thing and all suffering in some way for it.—ANN SOMMERVILLE, *head of medical ethics, BMA*

BBC1 *Rantzen Report*: "Speaking up for Geoffrey" 19 August

## Advocates for those who suffer in silence

Left unattended in a hot bath, Geoffrey McConnell inhaled some bubble bath and slowly slipped into a coma. He never recovered, dying some hours later in hospital. His mother describes this event as the final act of neglect in a lifelong history of abuse. Geoffrey was born with cerebral palsy and had

been "cared" for in eight different homes and institutions during his 29 years. According to his family, he had been treated very much as a person without desire or opinion. Despite his age and obvious intelligence he was treated as a young child for much of his adult life.

But this story is not simply about abuse of people in care. Geoffrey's tale, and the others which were succinctly—if simperingly—unfolded by Esther Rantzen in her latest report, is about the pressing need for independent advocacy in Britain. It is about the right of all individuals to have a say in the running of their own lives.

The success of Rantzen's own "Childline," a confidential telephone help line developed for children in need of advice and support, is

legendary. Yet this programme makes it clear that there are others in our society whom we are still failing.

There are those, both young and old, who suffer in silence simply because they cannot speak up for themselves. Many, like Geoffrey, do not have sufficient control of their bodies to pick up a telephone in private; others cannot speak. For those whose minds are intact but whose bodies let them down, the situation is frequently frustrating and insulting. But those with mental impairment have needs and desires too, and this is too often overlooked. All these people need help to make their voices heard.

It is a credit to the programme makers and participants that the message is so striking.

The message is also an uncomfortable one. Strange that, in our supposedly civilised society, social workers seem to take more notice of the state of the kitchens in care institutions than of the people who live inside. Strange too, perhaps, that relatives are deemed too emotionally involved to know what's really best for their loved ones.

Independent advocacy is a good idea, but one that has apparently failed to be implemented in Britain. According to one speaker on the programme, there is a need for people

who are neither related to inhabitants nor providing any services to these homes to carry out spot checks on what is actually happening inside. Where necessary, such advocates would be in a strong position to blow the whistle. Yet even where the provision of advocacy has been proposed there seems to be no way of ensuring that it actually takes place. Neither resources nor an inspection framework have been created to turn theory into reality.

What Rantzen does well in this programme

is to identify the problem clearly and to propose a potential solution. But one of the aggrieved mothers is surely right to proclaim "we need a radical change of attitude, rather than a quick shot of emergency child protection training." I suspect that the only way to make sure independent advocacy actually comes to fruition is to make it a legal obligation. Without legal intervention, a good intention may remain just that—a good intention.—ABI BERGER, *general practitioner, London*

## PERSONAL VIEW

### We all need an Annie's Place

Chris Brittain

Yesterday I sat within earshot of Heathrow Airport in a cold impersonal hotel ready to start one of our many medical meetings. By common consent we all stood in silence as a homage to those who had been touched by the horror at Dunblane three days before. Many of us around the table knew the area well. We had worked, trained, and socialised with many of the professionals who were now trying to bring love and care out of chaos and horror.

---

***"Annie's Place offered us a chance of self help and a few minutes of support without judgment."***

---

During the silence my mind went back to the warmth and comfort of Annie's Place. For nearly 17 years it had been my privilege to serve as medical adviser and crew member to our local lifeboat. It was luckily not a busy station, but we did have our share of excitement and disasters. These affected each of the crew in different ways. Like many of our friends in the lifeboat service, however, we also had our secret resource, Annie and Bill. They ran a small pub that sat beside the lifeboat shed and was always known as Annie's Place.

It was a typical harbour pub used by travellers and fishermen over the years. The white weather beaten building was full of character and as you opened the door you were surrounded by warmth and the smell of good hospitality. It was Annie's Place that we visited after our regular practices, and an enormous amount of fund raising was focused there which helped our cause. When you became involved with the lifeboat you were given an invisible membership card to the club. Its unspoken rules entitled you to express your

thoughts, successes, and anger, easily and in safe surroundings; in return you had only to agree to listen to the others.

What made Annie's Place special was that whenever we returned from a "shout," no matter what the time of day or night, there was always an open door, comfort, and reassurance. The same ritual was followed wherever possible. The boat was rehoused, re-fuelled, and washed down ready for service. Equipment was checked and the families told that we were back safely. After that we went to Annie's. Some people stayed and talked, others sat quietly in the corner. If someone had been less than perfect in their actions it was discussed, but never in a destructive or aggressive way. Sometimes we drank tea and ate toasted sandwiches. Occasionally a bottle of spirit was ceremoniously downed.

If Annie's had not been there each one of us would have returned home with our thoughts still occupying us. When we answered the call we had often left unsettled the usual minor domestic crises. I often had to abandon family or patients without much warning. Those left behind had to keep the home or the practice ticking over, and yet they also realised that sometimes lifeboat crews do not return. In these circumstances the normal expressions of relief could have caused additional unwanted stress. Annie's provided the buffer for us and our families.

When Bill died at a tragically young age Annie and her daughter were devastated. I hope that they received the quiet, confidential help that they needed from many members of the crew. I am pleased that Annie was soon able to return to the rigours of running a public house. She returned to providing that calm haven for each of us. We did not require any formal counselling, the informal support was enough. If we had detected any problems they would be addressed rather than denied and if necessary outside help obtained. It provided the best of all worlds.

Most emergency care personnel or health care staff used to have their own Annie's Place of some sort. Perhaps a medical mess rest room or coffee room, perhaps one senior member of the team and his family who held open house. In becoming part of the team they were also given the ticket to this most valuable commodity. In recent years, however, there has been a loss of these facilities. Shift

working has become the norm and no sooner has the team dealt with each incident than it is called to the next. I have seen team members grieving over a child's lifeless body, trying to speak to the parents and share their distress, and yet there is another call waiting and they must respond.

When there are attempts to provide support these are at set times and often include strangers who did not feel the emotions themselves. The result is that our staff, instead of talking freely, feel embarrassed and inhibited in what they say. The emotions are not "left on the bar" but taken away where they may resurface some time later.

---

***"If someone had been less than perfect ... it was discussed, but never in a destructive or aggressive way."***

---

Now the minute was up and as I looked around the table I saw people who had been at Hungerford, King's Cross, Clapham, Kegworth, Lockerbie, and the many other disasters that hit the headlines. In an average year many of them see more shootings than Dunblane. Trauma, suicide, and medical emergencies pass before them. They often work in small communities and know the victim and the family. They are dedicated to the relief of suffering, and yet this motivation adds a sense of failure to their human emotions when the outcome is unfavourable.

We will quite rightly be supporting the people of Dunblane over the weeks and years to come. How many of those who work with this stress from day to day will receive the same support when they need it? Annie's Place offered us a chance of self help and a few minutes of support without judgment.

If we really value the skills and the love of those who provide first line care we should actively encourage them to find their own Annie's Place in their community.—CHRIS BRITTAİN is a general practitioner in Anstruther, Fife, and Chairman of the British Association for Immediate Care