A trip to Jersey with a ventilator

R D Croft

All children love a seaside holiday and I recently learnt that it is possible to provide a worthwhile seaside holiday for even the most severely disabled and dependent youngsters.

Every summer Chailey Heritage arranges holidays for parties of disabled children. Last year a group of four severely disabled youngsters spent a week in Jersey accompanied by nine nursing staff and me. All four were confined to wheelchairs, although Corrine, aged 15, with severe cerebral palsy, can take a few steps assisted by one or two helpers. Christopher, aged 8, is paralysed from the neck down and has to be mechanically ventilated via a tracheostomy. Victoria, 13, and Vicki, 19, both have spastic quadriplegia. Vicki in addition has a tracheostomy and gastrostomy. Our minibus went ahead by boat with an advance party of nurses and the equipment. The main party went by air; we needed an extra seat in the aeroplane for Chris's battery driven ventilator.

It had not been easy to find a suitable hotel. The rooms had to be at ground level with easy access for wheelchairs. We also needed a room with an electric power point for Chris's ventilator. This facility is not provided in holiday camp chalets, which meant that we were limited to a hotel holiday. Some hotels had politely declined; perhaps they thought that people on holiday don't wish to see handicapped people in wheelchairs. The hotel that accepted us made us welcome in every way, and we did not seem to bother the other guests at all. I had initially suspected that our expedition was slightly overstuffed. Two nurses took turns at night duty, mainly to watch over Christopher, leaving two staff members for each disabled youngster by day. It took two people up to an hour each morning to bathe, toilet, and dress each disabled young person. Feeding, entertaining, handling wheelchairs across beaches and theme parks, giving gastrostomy feeds, and other nursing procedures easily occupied eight staff members by day. We made daily trips in our minibus to places of interest—the zoo, shops, theme parks, a model farm. Shopping for pearls was popular with the girls, while at the model farm Victoria and Christopher had a ride in a hay cart pulled by a shire horse. The other passengers were friendly and not at all alarmed at sharing a ride with a child who was being hand ventilated. Christopher also had a donkey ride, with a nurse on one side to support him and another on the other side to ventilate him. We feel this may be a record of some kind.

This was my first experience pushing wheelchairs in public. I was surprised to find how self conscious I felt. I can only guess at how a disabled person feels. The public mostly ignored us politely, but a few people stared, sometimes in a rather hostile way. One woman barged us in a shop queue but was soon disposed of with a jab from a wheelchair. I learnt that it is
No bar to disco dancing

The grand finale was the Saturday night cabaret at our hotel. The show was garish, deafening, and brightly lit. Our four young charges were agog. Vicki, who often has her head on her chest, partly through depression and partly because of the effort required to hold it up, sat for three hours with her head bolt upright, eyes shining with fascination. The disc jockey was quite drunk and frequently muddled up his patter and equipment. He took it in good part when Victoria fended him off with a gentle kick of her one good leg to his groin when he became a little familiar with one of our nurses. Two children, with a little help, picked a raffle ticket; the hotel manager won both prizes and donated them to Victoria and Chris. The evening ended with wheelchair disco dancing. The other hotel guests were a rather listless bunch and there had been no dancing until Bill, our leader, organised the waitresses to link hands with our children and ourselves. The floor shook to the stomping of feet and the rumbling of wheelchairs. This rather shamed the other guests into taking to the floor. Wheelchairs glided, couples mooched, the disc jockey was drowned by the pounding beat, and soon it was 1 am and time for bed. We had taken a few risks; few ventilated patients get held aloft in a nurse’s arms to join in a circle of dancers. Also Vicki had a fit from excitement later that night. But there had been no mistaking the excitement and smiles on all their faces. We had also livened up the hotel for an evening. The manager kindly said he would have us back another year. Next morning we left early and the staff got up an hour earlier to give us breakfast and see us off.

It had been an exhausting week. It had also been expensive. Are such trips worth while? The local estate agents, who footed the £2500 bill for the accommodation, seemed to think so. Indeed Chailey benefactors often prefer their money to go on specific projects like this rather than to be sunk into some general fund. The nurses tell me that the long term performance and mood of disabled children often improve after such trips. I am in no doubt as to the short term benefits; it was clear from the children’s faces that they were having a good time.

Disability arouses powerful feelings, not always positive. We had received a few hostile glares, but also much kindness and support from the public. My own feelings towards the disabled have changed. I lived for a week with four severely disabled young people and got to know and like them. I now find it easier to deal with disabled people as individuals with human worth rather than as objects of pity, or worse. I recommend such a trip to any doctor working with the disabled.

Dry haricot bean: A new continence aid for elderly men?

Anup Patel

An 82 year old man had been registered blind owing to bilateral myopic macular degeneration. Since starting treatment with oral diuretics from his family practitioner he had been troubled by urinary incontinence. He had previously had no lower urinary tract symptoms. In August 1989 he was visited by a childhood friend who had lived and worked as an itinerant labourer on sheep farms in the Australian outback. His friend had experienced similar urinary problems during the latter part of his career as a shepherder and seemed able to maintain urinary continence by inserting a dry haricot bean into the external urethral meatus. He removed and replaced the bean with specially adapted blunt ended tweezers every 24-48 hours.

The patient, impressed by his friend’s tale, decided to try the technique. Before his friend returned to Australia the patient took a dry haricot bean from his ample supply. Two days later he tried to retrieve the bean from the external urethral meatus with a pair of angled hair plucking tweezers. Because of his poor sight the retrieval process proved to be too difficult. After several minutes it was apparent that rather than removing the bean he had pushed it further into the urethra. Embarrassed at his predicament, he did not seek help until three days later, when his penis had become swollen and painful and micturition was “difficult.” He was immediately referred to hospital as an “unusal case of urinary retention.”

The patient was in severe discomfort from an oedematous penis, which was maximally indurated in the region of the midpenile urethra. The bladder was impalpable. An ascending urethrogram (fig 1) confirmed the presence of a filling defect in the penile