

CARING FOR 'SPITTING SID'

Eric Hargreaves

Abstract: the author writes matter-of-factly but movingly about life with Paul, his adopted son, who was vaccine damaged at an early age. He describes the devastating consequences of this damage, not only for Paul, who was left very severely epileptic, but also for the whole family. There is much in this article which hints at the anger, the frustration, the isolation and the hurt occasioned by those, healthcare professionals included, who seem to lack the time or the will to understand and to empathise; this is balanced by a down to earth practicality, a dogged persistence in the task of caring, and a sense that in many a situation there can be a redeeming element of humour. The article gives an insight into the cost, for a particular family, of caring for one of its members, and of retaining that responsibility and privilege, with professional support, for as long as possible. The Editors

The story I have to tell begins two years before we adopted Paul. It begins with the birth, and, seven months later, the death of our first, precious daughter. She died of a rare genetic condition, called Ver-nich Hoffman's Disease.

Young as we were, new parents, we felt guilty, as if we were somehow partly to blame. Nor was that feeling alleviated by the vicar who voiced some thoughts about the sins of the fathers being visited upon the children. Impeccably biblical. Totally unhelpful. Devastatingly inappropriate.

We decided to become adoptive parents, and we were happy in 1967 when Paul came to us. But events in his life, and in ours, took a cruel and unexpected twist when, at the age of three months, Paul began to suffer epileptic attacks. It emerged that he had been damaged by a routine smallpox vaccination. Could we cope with him? Did we understand the implications? Would we consider 'putting him away', as it seemed to us - giving him over into the care of the professionals, and getting on with life?

We crossed our fingers, and took our son home.

The first years

We coped. We hoped. One fit per month until Paul was just over two years old, followed by a series of severe fits, and a slow but inexorable deterioration. Paul was a strong willed child, whose frustrations were apt to boil over into tantrums, but only when nursery school days were almost over did we receive

our first intimation of how difficult things were going to be in future. A psychologist's report seemed to justify the reluctance of the local junior school to take Paul on. He was deemed in need of special schooling, and so, for the next two years, Paul attended the David Lewis Centre for Epilepsy. We travelled to see him at weekends. They discharged him at seven years old. He had not responded to treatment.

Growing up

Paul came home again, and attended a local special school until he was nineteen. It was rarely plain sailing; Paul's response, then and now, to pressure and frustration, was to scream and spit. It put people off at times. But the years passed. We meanwhile welcomed a daughter, and a second son, into our growing family, and we wondered what would become of Paul when his schooldays were over.

When that time came, and in the absence of any local authority provision for day care for him, we found Paul a place at a local Training Centre, where, although unable to contribute much of a practical nature, he could at least find something to occupy his attention. Inevitably we encountered at times the familiar difficulties and negative reactions of people exposed to Paul's characteristic expressions of temper. In addition, his epilepsy worsened, and on a monthly basis we endured the tedium and repetitive history taking of a hospital admission through A&E. New doctors, misplaced notes, unfamiliar ward staff, lack of communication - these were the dreary reali-

ties of getting Paul admitted to hospital. But at times, we had no option.

Improvements

In 1986, we moved to Aberdeen, and at last we found a GP who understood. Paul was reviewed at Aberdeen Royal Infirmary, by the neuromedical department. Goodwill, good planning, good communication ensured that the depressingly familiar problems around hospital admissions disappeared. We found support too, through our membership of St Ternan's Episcopal Church, and through the swift exchange of information between the hospital chaplain and our own priest.

Life with Paul.

Let me give you a flavour of everyday life with Paul.

- **A Good Day.**

7am Paul wakes, has his bath, and eats breakfast in bed.

9am Day Carers arrive and remain for an hour or so
10.30am We take Paul to his day centre

3.30pm Paul returns home by taxi. He watches TV or videos, or does jigsaws.

10.30pm Bedtime.

- **A Bad Day.**

7am Paul wakes, and has his first fit. We give him his medication, his bath, and change his bed.

9am Day carers arrive. Paul reacts best if he knows them

Mid morning. Paul has a second fit. We give him medication, and he sleeps for 4-5 hours.

Afternoon. If the usual pattern is to unfold, then Paul will have a series of fits, each one coming closer after the last. We know that he will need to go into hospital, otherwise the risk is that eventually his heart would give out.

10pm Paul is admitted to hospital.

For many years now, the bad days have come about once every three weeks. Even the good days can be tiring, and experience has taught us to acknowledge that we need the occasional break, even holiday, away from practical caring. A local organisation called Archway provides respite care, and lets us get away sometimes. Crossroads provides home carers,

so that we can have some time to ourselves during the day or of an evening.

The 'extended family'

Paul's many problems mean involvement with a vast array of different agencies, which in itself can be a source of stress as well as of support. I could include on such a list the Benefits Agency, day carers and supervisors, GP, hospital staff, community nurses and CPN's, physiotherapists, psychologists, occupational therapists.....and so on and on. When someone in the household is handicapped, things are never the same again.

The future

Paul is now thirty two years old, a young man with his own space, his own room, and as much privacy and autonomy as it is possible for him to have. Although we have never exactly had a 'normal' family life, Paul has been very much a part of that life, which has adapted in response to his needs. Muriel and I have maintained outside interests and involvements, some of which, such as our involvement with Crossroads, arise directly out of our experience of caring for Paul. If Paul is in hospital, we can attend church together, but if he is at home this isn't always possible. I have sometimes reflected about how helpful it would have been if someone from the congregation had volunteered to keep an eye on Paul occasionally on a Sunday morning, so that Muriel and I could worship together. But then, its hard for people to understand how things are.

As I said, we have adapted. But as the years pass, and Paul deteriorates, we wonder what the future will hold. I feel that in future the balance of our caring might change, and that Paul might be away from home more often, with us providing the respite care. Sometimes, though, it is hard and painful to think too far ahead.

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Editorial Comment: Georgina Nelson

This article started life as an oral contribution to the study conference for healthcare chaplains held at Crieff in May 1999. Eric Hargreaves' remit was to give an insight into the experience of a patient's relative, as someone who had had extensive contact with healthcare professionals in that capacity over a number of years.

He kindly agreed to write up his original talk for inclusion in the journal, and to allow it to be extensively edited. I hope that the resulting article retains the essential elements of its original.

The author writes of life with his eldest son Paul, vaccine damaged at an early age, and the 'spitting sid' referred to in the title. Why 'spitting sid'? He explains that Paul has a habit of venting some of his frustrations by spitting at those who threaten to encroach upon his personal space or otherwise place him under stress. One way of coping with this difficult behaviour is through humour:- 'spitting sid' is a variant of the nickname 'hissing sid' which was used in the 1970's by the comedy duo Little and Large. Paul became 'spitting sid'. Anger was tempered by humour.

In the first edition of this journal, John Murning quoted Emily Pearl Kingsley to the effect that bringing up a child with a disability is a bit like getting on a plane to Italy, only to find that you have landed in Holland. Everything is different, and has to be encountered and learnt anew. And forever afterwards, despite the discovery of unexpected pleasures which Holland has to offer, there is still the pain of a plan, a dream which never became reality.

I'm not sure how Eric Hargreaves would regard this analogy. He writes, quite simply 'we were so happy in 1967 when Paul came to us', and it seems to me that his account of the sadnesses and challenges, the frustrations and hard won successes which followed lends that comment all the poignancy of dreams, plans and hopes which had to be laid aside, unrealised. Having set out for Italy, as it were, the whole family resolutely learn to live in Holland.

The author's story of life with Paul pulls no punches. But it is loving, precisely because it is un-

flinching and unsentimental. Having chosen at the outset the road of retaining and caring for Paul as part of the family, rather than taking up the offer to have him 'put away' as he puts it, into the care of the professionals, the author makes no bones about how hard that road has proved to be hard. Often, not so much because of who Paul is or how he is in himself, but because of the attitudes which his condition evokes in others - others too judgmental, too distanced, or simply too busy to understand. In a recent monograph, John Swinton writes of his young friend Stephen that 'the real problem is that people very often cannot see Stephen as a *person*, because Stephen as a *disability* clouds their vision', and that Stephen's primary identity is as a person to be loved, not a problem to be solved. I have the impression, especially from Eric Hargreaves' account of the family's experience before moving to Aberdeen, that extensive contact with a whole variety of professionals did not always, or even often, promote real empathy or depth of understanding towards Paul. He seems at times to have been more of a problem to be solved than a person to be loved.

Against this background, one could say that spitting and screaming can be understood as a plea for communication, a demand to be attended to, taken seriously, accorded worth as an individual.

'When someone in the household is handicapped, things are never the same again' writes the author. His story gives an insight into the cost to an entire family of the decision to care, and to go on caring. Perhaps there have been times when, despite their otherwise varied and well rounded lives, every family member has participated to some extent in the sense of frustration, even isolation, which Paul himself has experienced, when faced with well meaning but uncomprehending institutions and individuals. This is a story from which all those involved in the caring professions can learn, not just as individuals, but as part of a society which aspires to care for all of its members.

Reference

SWINTON J (1999) *Building a church for strangers*. Contact Pastoral Monograph no.9