

## A handicapped child means a handicapped family

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**SUMMARY.** The medical history of a 16-year-old severely handicapped girl and the social history of her family are traced, with particular emphasis on the extent to which the handicap affected each member of the family. The role of the general practitioner is also highlighted.

### The family

The members of the family are:

Mr X	(40 years)	Brewery loader/drayman
Mrs X	(40 years)	Part-time shop assistant
Sophie	(17 years)	Medical records clerk
Mary	(16 years)	Handicapped
Tom	(9 years)	

### The child

The handicapped child, Mary, is now just 16. She is microcephalic, grossly mentally subnormal, spastic, blind, doubly incontinent, and epileptic. She is unable to speak, walk or crawl, sit up, or feed or dress herself. Over the years Mrs X has cared for Mary with remarkably little help from outside the family. This care, in addition to the obvious needs of washing, changing, clothing, and feeding her, includes winding her like a baby after every feed and keeping a constant eye open to stop her harming herself during a fit. Mary has slept in her parents' bedroom since birth.

### Medical history

Mary was born on 12 October 1962 and weighed 2.9 kg (6lbs 10 oz). Pregnancy and delivery were normal and the baby cried at birth (no Apgar score was recorded). The head circumference was "noted to be small at birth" and she was seen by the paediatrician. No cause was suggested; there was no family history of note except that Mr X's mother was at that time an inpatient in a mental hospital.

Hospital records show that a detailed assessment and diagnosis was not made until Mary was two years old. At 24 months her head circumference was 40 cm (16") (normal range 45-50 cm (18"-20")); she was just crawling

and able to stand with support (she has regressed in these skills since); she was having fits three to four times a week but was not losing consciousness, and her EEG trace was abnormal.

Mrs X said that this was the first time that anyone had told her that Mary was severely handicapped (though she obviously knew that all was not well) and that the phrases used, including "half a brain" and "epileptic" seemed very brutal. In her own words: "I cried continuously for two and a half days and then determined to do all I could for Mary."

Shortly after this the Eye Hospital confirmed that Mary was blind and paid "no attention to light or moving objects". Mrs X has always hotly disputed this, saying Mary has some response to light, and this is now agreed by others.

There are only 24 entries on the general practice records for the years 1964 to 1977 and no hospital support, which is remarkable evidence of Mrs X's ability to cope with her severely handicapped daughter.

In 1977 Mrs X was trying to stop Mary from choking during a fit, and in doing so unfortunately fractured her right femur. This was plated in the local hospital but the plate worked loose and the final result was not good, although in view of her spasticity was acceptable. Mrs X has nothing but praise for the staff on the children's ward, showing that she is by no means prejudiced against hospitals in general.

Since then Mary has been in generally good health and her fits, which have been getting less frequent as she gets older, are now occurring only one or twice a month. She has had no regular medication since 1967.

### Social history

Until 1972 when the children were aged 11, nine and three, the family lived in a two-bedroomed council flat. Their general practitioner strongly supported an application for a larger house but it was two years before they moved to their present three-bedroomed council house.

Mary has been cared for in two local authority day centres, the first from the age of four and a half until it closed in 1978, and the second since then. I visited the latter which cares for 30 'children' ranging from five to 23 years, and which Mrs X describes as better equipped

and more caring than the first centre. Certainly, I was very impressed with the standard of care and the attention to detail the staff pay in stimulating each individual. In Mary's case they use a full length mirror to reflect light and movement onto her face, and find that she responds specifically to different pieces of music. Mrs X understands that Mary can continue at this centre indefinitely, and finds this by far the most important support she has in caring for Mary.

In 1977 Mary spent a week at a residential hospital while the family went on holiday, and this was the first break they had had from caring for her continuously for 15 years. Mrs X found it hard to leave her and telephoned daily to ensure that she was well, but the break was clearly a success.

### **Support and assistance**

Financial support specifically related to caring for Mary at home has come from three sources:

1. Attendance allowance: the family qualify for the higher rate of £14 per week.
2. Non-contributory pension for Mary on reaching the age of 16 of £10.50 per week (this has yet to be confirmed). Before this Mrs X received only the normal family allowance of £3 per week due for any child.
3. Specific items paid for by the Rowntree Family Fund. Each application requires the support of a professional worker, usually the general practitioner, and the fund exists only to help families of children under 16. In the period 1974 to 1977 the fund paid for a radio and cassette player, the installation of a telephone and one year's rental washing machine and tumble dryer, and driving lessons for Mrs X.

Practical support on a regular basis includes provision of disposable napkins and the day centre care. The latter is five days a week with only short holiday breaks.

Apart from this the health visitor and social worker involved have been providing occasional support, but this has become less frequent over the years as Mrs X has coped so well.

### **Effect on the family**

Mrs X is without question the driving force of the family and has carried almost the full burden of caring for Mary. Talking to her, one gets the clear impression that her priorities have been Mary, the other children, and her husband, in that order, and this is reflected in comments from the social services files.

Mr X is a pleasant though rather taciturn man who seemed not to welcome too much intrusion into his family's affairs; impressions of how he feels about the situation are therefore difficult to gain. He has had a drinking problem in the past: in 1970 he was investigated for gastro-intestinal and neurological symptoms

and these were put down primarily to a daily consumption in excess of 10 pints of beer. His employment no doubt encouraged this. Mrs X said to me in front of both Sophie and Tom that the children had hardly had a father as he used to spend so much time in the pub, but that recently he had taken more interest, especially in Tom, and that he would be more upset than any of them if Mary did die.

Sophie has been seen as a potential problem by social workers in the past. As recently as 1976 she was reported to be spending hours playing with Mary as though she were a doll and having few interests one would expect of a 15-year-old. She seems to have come out of this phase well and presents now as a bright though quiet girl. She is enjoying her job as a medical records clerk (which I would judge to carry quite high status amongst her peers) and has a steady boyfriend.

Tom appears to be virtually untouched by any family stresses resulting from Mary's problems, and is a cheerful, football-crazy, nine-year-old schoolboy. Mr X's comparatively recent interest in Tom has no doubt been a considerable help to both of them and also to Mrs X. The social worker's notes state that Mrs X's third pregnancy was unplanned: presumably the arrival of a healthy boy offset any feelings of the child being unwanted, and his relationship with all members of the family, including Mary, appears to be positive and mature for his age.

It may be helpful to summarize the history above in terms of the effect on the family, as certain crisis points have emerged. The first was the realization of the severity of Mary's handicap and the resultant concentration of Mrs X on Mary with relative neglect of both Mr X and Sophie (the presence of Mary in the parents' bedroom ever since can hardly have helped the sexual side of their marriage). Mr X's referral to hospital in 1970 when Sophie was nine, Mary eight and Tom one, possibly reflects Mr X's further feelings of rejection at this time. Housing pressures must also have been acute, as there were three children and the parents in two bedrooms for a period of four years until a larger house was made available. Sophie's rather unnatural attitude to Mary when the former was 15 suggests a long period of relative neglect and stress felt by Sophie. She may possibly have gone through adolescence aware of coming from a family who were 'different' and a home into which it was difficult to introduce her friends.

The present atmosphere in the family is one of optimism. The potentially difficult landmark of Mary's 16th birthday has not resulted in any change in her care and Sophie and Tom both seem happy and stable. As a result, Mr and Mrs X are probably enjoying a happier phase in their marriage than for some years.

The key factor in the general practitioner's role throughout this case has been to make the family feel that he was ready to help and advise in a practical way when needed. It seems probable that the paediatrician (whom I was not able to meet) was guiding Mrs X

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towards accepting full-time residential care for Mary. When she rejected this the general practitioner needed to help her cope with tremendous practical and emotional problems. This help has been just as important in non-medical matters such as housing and application to the Rowntree Fund. The case also highlights how important it is for a general practitioner to be able to advise on prognosis and aspects of genetic counselling, especially when the parents' confidence in the hospital has been lost.

## Future prospects

Mary's life expectancy is unpredictable, but it is reasonable to suppose that her present pattern of day centre care will continue until either she dies or becomes ill enough to need long-term hospital care. Sophie is now well set to leave the parental home in the next few years but Tom has still to pass through adolescence with some of the problems that also affected Sophie. In terms of practical help, more frequent residential care for Mary which would allow Mr and Mrs X to get regular breaks is indicated. In the longer term, their greatest problems may be those of psychological readjustment if they no longer have to care constantly for Mary.

## Conclusions

Mrs X has coped extremely well with the very real problems of bringing up a grossly handicapped child. The help the family have received has on the whole been appropriate, particularly in the day centre care of Mary where a good relationship exists. There is also a sense of mutual confidence between the family and the primary care team, the latter seeing no need to visit unnecessarily, and the former feeling that help is available when necessary, as for instance when Mary's leg was broken in 1977.

Three points arise from the history where the family might have been better helped:

1. The original diagnosis and explanation of Mary's handicap might have been more successfully handled both at the Children's Hospital and the Eye Hospital. No doubt the intentions of all involved were excellent, but the fact is that the family's confidence in the hospital was not maintained.
2. Rehousing the family appears to have taken longer than might have been necessary.
3. Earlier and more frequent short-term residential care for Mary to allow more frequent family holidays would have been appropriate, although this might have been refused had it been offered.

The question, "Has this handicapped child meant a handicapped family?" (Pereira Gray, 1970) remains. There have obviously been problems during the 16 years since Mary was born, but thanks mainly to Mrs X's perseverance, the family has survived them well. If we speculate what might have been, had the challenge of

caring for Mary been replaced by the guilt of rejecting her, we could easily see a worse situation developing with no housing transfer possible and Mr X's tendency to drink increasing. My own conclusion is that this child has been cared for lovingly under difficult conditions to the overall benefit of the whole family.

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### Acknowledgement

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### Addendum

Sources of information were: general practitioner records, hospital records, social services records, and the local authority day centre.

## Centres of excellence

A centre of excellence cannot be planned; it grows. It grows in medicine when, under inspired leadership, a group of enthusiastic, intelligent, and compassionate people work together in circumstances which they enjoy, or at least accept, with the necessary tools provided. We do have some centres of excellence but none can deny that we still have many centres where the service is poor, the staff limited and so overworked that standards fall, the buildings only good for pulling down, and that in some of these institutions the patients' safety can hardly be guaranteed. Chasing the will o' the wisp of centres of excellence is exciting but it is escapism. The urgent need is to rid the service of centres of incompetence. The present redistribution of wealth of the NHS aims in this direction but if it confines itself to buildings it will bring little benefit. Dedicated men can work wonders in dilapidated buildings. And if this redistribution is at the expense of the leaders and the teachers it will do harm.

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