

During the preschool years assessment is an on-going process, ideally in a nursery school with specially trained staff. In doubtful cases the child may start in a special school and be promoted to an ordinary school. The responsibility for placing a child in an ordinary school is a serious one because failure can be a searing experience for the child. A child who has to be transferred from a normal to a special school should be moved, if possible, at a time when a transfer would normally be expected—for example, from infant to junior or junior to secondary school.

Many children have to transfer to special schools for secondary education because of lack of special facilities in comprehensive schools. This problem needs urgent review. Some comprehensive schools should be provided with the buildings, remedial teaching, and counselling facilities that handicapped pupils need. Special schools should have links with comprehensive schools and technical colleges so that no physically handicapped child is unnecessarily limited in his or her curriculum or social contacts.

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Some Observations on the Management of the Child with a Spina Bifida

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British Medical Journal, 1975, 1, 145-146

Opinion is changing over the management of the child with a spina bifida from a climate of optimism and enthusiasm to caution, even depression, as the results of the more enthusiastic approaches are evaluated. It's the "quality of life," as it is called, which is causing concern. I have experienced life as one having a moderate degree of residual handicap from a spina bifida. But despite this or perhaps because of this I would hesitate to judge the quality of life being enjoyed by someone else with a similar defect, as it is influenced by such a variety of factors. Surgical management is no doubt an important factor in determining the child's future, but there are other ways in which I feel we could all contribute much more to the successful integration of the spina bifida child into the community. This process plays a large part in determining the so-called quality of life.

Breaking the News

A study of the problems of children with spina bifida and their families in Glasgow showed that many parents felt the way in which news was broken to them left a lot to be desired. From this study and from other parents I have spoken to I found that this rather unpleasant duty is too often left to a junior member of the medical staff or to a nurse. Surely this information, which may influence the whole attitude of the parents towards their child and its handicap for the rest of his life, ought to be handled by the person whom the mother has known and trusted during her pregnancy, backed up by a paediatrician. Certainly the delivery may often be conducted by someone other than the obstetrician or general practitioner who has provided antenatal

care, but then if the patient's own doctor is not available the duty of breaking the sad news to the parents should surely fall to the most senior person available.

The questions generally asked are, "Will he live?" And "Will he need an operation?" The person breaking the news should be competent to answer the first question at least for the immediate future, but in respect of the second it is better to wait until a paediatric surgeon has seen the infant. This should be done within a matter of hours, and the whole problem can then be discussed in more detail with the parents.

Introducing the problems of a spina bifida to parents who are already under emotional stress requires skill, imagination, and experience. How can parents who have no previous medical knowledge be expected to grasp the complexities of the anatomy, physiology, and pathology of the central nervous system all in one day? I think simple diagrams might prove helpful. Having explained the lesion, one has to say something about its implications. Once again I would advocate a cautious approach, with more emphasis on the immediate future than on possible attainments in later life. I say this for two reasons: firstly, the future is always uncertain; secondly, descriptions of crutches, calipers, and other aids can wait until they can be seen as a means of gaining extra independence.

Advice to Parents

What then does one say? When the infant leaves hospital he is essentially normal in appearance and development unless there is a significant degree of hydrocephalus. While it is important never to give the parents the false impression that the child is going to be normal, this phase can be used to let the mother learn about the normal aspects of her child's development. Thus, having accepted that her baby will have the same feeding and sleeping problems as other infants, the mother should be encouraged to attend the local child welfare clinic, where she will meet other mothers and gain the support and help of the clinic, help which she will require as the handicap becomes more obvious.

Predictions beyond infancy are more difficult because of the

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possibility of mental handicap, though the handicapped children with normal intelligence are in the majority. These and indeed some with mild mental handicap need to be directed more towards taking part in normal life than they are at present. This should not prove so difficult when one considers that infants and toddlers spend a considerable amount of time on the floor. Considerable paralysis will impair mobility at an early stage, but parents should be encouraged to let their toddler enjoy these years as much as possible, when the lack of mobility counts for so little.

Parents should be advised, in suitable cases, that their child can compete on equal or nearly equal terms with his normal peers. What is wrong with brick-building, snakes and ladders, jig-saw puzzles, etc., to be followed later by card games, chess, drawing and painting, reading, and a host of other occupations—not to mention television? I emphasize the need to point out these occupations to parents because there is an odd tendency to feel that handicapped children require "way out" occupations. Publicity is given to archery, horse riding, and swimming, for instance, but it would take a lot to convince me that most children would not prefer to play modified football with neighbouring children, using their calipers and crutches. Horse riding might be acceptable to some children, but it will be out of context for the majority. Even swimming has its disadvantages, because, while swimming itself is fairly easy, walking in water certainly is not, and without calipers and other walking aids getting in and out of the water creates problems. A physiotherapy department can give advice on such occupations.

Gaining Independence

As I remarked above, calipers and crutches are easier to accept when they become a means of gaining independence. I would stress, however, that when the time comes to need appliances, parents require extra support and explanation if they are not to end up with the impression that calipers are something imposed on their child by the doctor. I personally have met on a social level only two children with a spina bifida, and in both cases

calipers and crutches were something to be dispensed with on Sundays and special occasions—just the very times when the child most values his independence.

Parents are generally reluctant for their children to attend a special school. On this issue I am entirely with the parents, as approximately half the children with spina bifida will go to schools for the physically handicapped. If education is designed to fit a child for later life, how can one expect an employer to accept a teenager who, by implication, could not cope with normal life and competition up to that point? Similarly, workmates are unlikely to be able to accept as an equal someone who has been different during school life. As for the child himself, is it fair to expect an overprotected teenager suddenly to find his feet in a society that is hesitant to accept him because it does not know or understand his problems? In the argument for special schools the problems brought up are transport, coping with stairs, being easily knocked over, being in competition with peers with superior motor ability, and extra demands on teachers' time. But it is difficult to accept that transport is really such a problem, since so many people have a car, and anyway schools are generally within walking distance, so that parents or friends ought to be able to wheel even the older child to school. As to coping with stairs and being easily knocked over, I know personally several paraplegics who were educated in normal schools with different levels and had no special nurse or teacher's assistant. Finally, what about the impaired motor ability of the child in competition with normal peers and the consequent demands on teachers' time? Is it not likely that, if the child cannot keep up with the others, special schooling may postpone problems until later life? I cannot see that it will solve them. I propose, then, that much of what is gained by the extra help from the staff at special schools will be offset by losing the willing help of friends and companions.

Why not give the community the opportunity to prove their willingness and ability to help their less able members? Success in the face of a handicap is not an achievement of the individual alone but comes also from the help and support of his family, teachers, and schoolmates in early life, and later of colleagues, workmates, friends, and neighbours.

Any Questions?

We publish below a selection of questions and answers of general interest

Spontaneous Deep Vein Thrombosis

A man in his fifties with a spontaneous deep femoral vein thrombosis complicated by a pulmonary embolism has been advised to take a small daily dose (10-25 mg) of phenindone. Is such an apparently subtherapeutic dose of any value?

The effective prophylaxis of venous thromboembolism depends on balancing the anticoagulant effect against the often multifactorial and ill-defined stimuli for thrombosis. Thus small doses of heparin, undoubtedly effective in prophylaxis against many types of postoperative thrombosis, fail more often when delayed until after an episode of trauma—for example, fractured neck of femur—or when certain major operations are considered. If the patient is fully active then the stimulus to thrombosis, even with an already damaged venous system, is unlikely to be excessive (and yet in this instance the patient's first episode was apparently spontaneous). Those studies which have investigated the prophylaxis of venous thrombosis by oral anticoagulants have shown clearly the need to produce a defined level of anticoagulation but all have been

associated with a recognizable stimulus to thrombosis: operation, trauma, or myocardial infarction. Minor changes in the synthesis of the vitamin K-dependent factors might conceivably be of minor benefit; the concept is unproved and it is difficult to see how it could be disproved. Nevertheless, the administration of even small doses of phenindione may be hazardous. Hypersensitivity reactions occur, though they are uncommon in patients who have been taking the drug for six weeks or more. Many factors might potentiate the action of a dose of 10-25 mg daily, which is not inconsiderable, into the range where bleeding is possible. Indeed, some patients on such a dose may show defective synthesis of coagulation factors sufficient to place them in the therapeutic range of anticoagulation (British Comparative Ratio 2.0-3.0). Reduced vitamin K intake, increased catabolism of coagulation factors due to fever, reduced synthesis due to hepatic disorders, or interaction with other drugs might easily combine to produce a severe defect of haemostasis even in one who normally showed little change in factor synthesis. In these circumstances the use of uncontrolled low doses of oral anticoagulants must be contraindicated.