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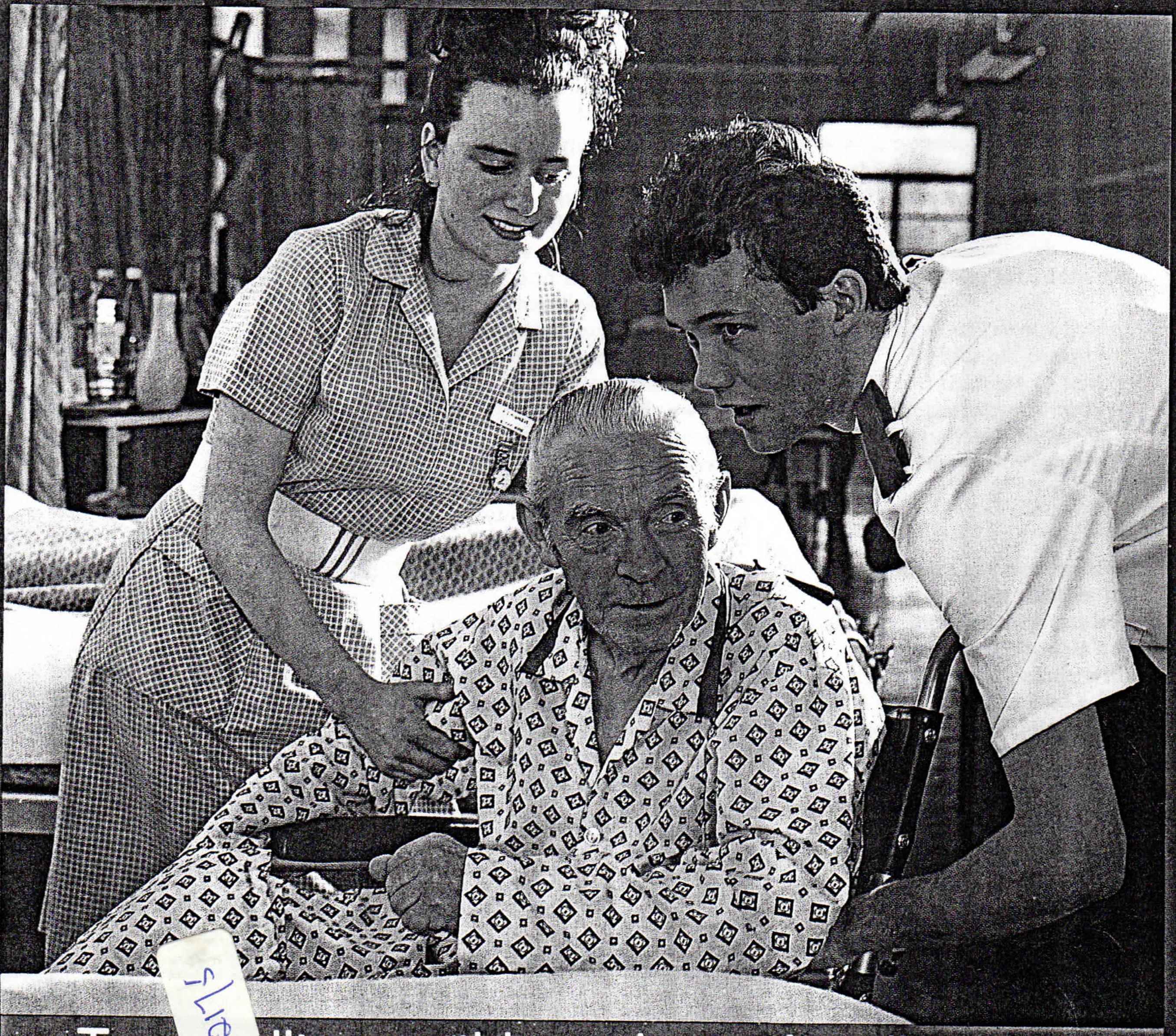

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A good start to a full life

Managing continence in children with spina bifida and hydrocephalus

Maintaining full continence control is an essential first-step for children living with spina bifida and hydrocephalus. This will result in increased self-esteem and pave the way for independent living. A multidisciplinary approach is required to ensure continence training takes account of all aspects of the child's lifestyle.

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There was a time when people born with spina bifida and/or hydrocephalus did not die of old age. They died while still young, of renal failure, and the quality of their short lives was questionable. When it became possible to preserve renal function, children were educated in special establishments which were frequently residential (Anderson, 1973). The children were well cared for in these establishements, changed every few hours and entertained, but their academic education was limited, and they had no responsibilities – everything was done *for* them and *to* them by care staff.

It was not envisaged that people with spina bifida would earn a living, and on leaving school they usually moved into a residential centre for adults. These people were denied the pleasures and traumas of family life, the right to make their own mistakes and the opportunity to receive an education which would prepare them for independent living in a caring community. Their quality of life was poor, although their longevity considerable.

Integration

Children born with spina bifida and/or hydrocephalus are now treated as 'normal' and educated with their able-bodied peers. Care centres on helping them to overcome the effects of their condition, so they can live as independently as possible. Healthcare and other professionals are endeavouring to foster a positive attitude in society towards people with disabilities, so that they are not discriminated against and can lead a full life. There is, consequently, much genuine concern in society about 'meeting special needs' and 'integration' (Abeson, 1975), but the political issues raised frequently eclipse and overshadow the difficulties faced by children or their families, teachers and peers. In some cases, individual needs are not being met due to fear of 'labelling' and thus 'prejudging those concerned', and this means that some children are not being properly identified or assessed.

Education

Success in mainstream school for any child is dependent upon the child's resilience, and this is doubly the case for a child with disabilities. Continence and independence training are invariably non-existent in schools (White, 1990) and teachers are frequently unaware that a child with spina bifida is struggling with double incontinence and its social consequences. The added problem of hydrocephalus, with its effect on the learning process and the possibility of associated behavioural problems (White, 1990), is neither anticipated nor properly understood in the school system.

The amount of school time lost due to hospital appointments and time 'off sick' make it almost impossible for any but the brightest children with spina bifida to do much more than struggle through their school life. On leaving school they have not generally received sufficient relevant personal and social education to enable them to either earn a living or live independently in a society which is increasingly geared towards self-sufficiency.

Many of these young people consequently suffer from low self-esteem and their sexual awareness is damaged by the intrusion of personal care (Hunt, 1981). Young people with spina bifida are likely to know little about their condition and understand even less. They have probably never had any counselling, so will have many unanswered questions. There is still much to be done to improve the quality of life of people living with spina bifida and hydrocephalus so that the prospect of long life becomes truly desirable.

Continence management

The physical and intellectual impairment associated with spina bifida and hydrocephalus is considerable (White, 1990), and affected children are likely to have mobility, educational, emotional and continence problems. The management of incontinence is a priority, and training should be undertaken at the usual age. Neural deficit is a barrier to full continence, but one that can be overcome, and a habit training approach should be adopted 'creating' the desire for bladder and bowel evacuation rather than 'responding' to it. Incontinence is unhealthy, socially unacceptable and expensive, and is a problem that can usually be successfully dealt with.

Babies born with spina bifida and/or hydrocephalus are likely to have a neuropathic bladder and bowel (Hunt, 1981). This may become apparent within a few days, but equally may not become obvious for some months or even years. Parents will require careful counselling when their child's condition is diagnosed, and this should concentrate on the possibilities that exist for the child, rather than the negative aspects of living with the condition. They should not, for example, be told 'your child will be doubly incontinent' but rather that the presence of a neuropathic bladder and bowel means that full continence control will have to be achieved by early habit training.

Children with spina bifida should be able to enjoy their education and pasttimes without social stigma.

Urodynamic studies and scans carried out early in the child's life and assessment of family dynamics and the social and domestic situation will give urologists, paediatricians and continence advisors all the information they require to decide upon the best method of continence management and training for the child concerned. The chosen method should ensure the future preservation of the child's renal tract, sparing the parents/carers from the emotional and physical trap set by more intrusive daily procedures such as manual evacuations and catheterisation (carried out by carers).

Incontinence in babies and toddlers is considered acceptable, some may even say endearing, but is totally unacceptable in young children, adolescents and adults, both to the individual concerned and to his or her family, peers and teachers. The long-term damage to self-esteem, sexuality and the ability to form relationships is inestimable, and must be avoided at all costs.

The damage to health can be measured in terms of the cost of hospital admissions, of treatment for urinary tract infections and of ordering, supplying and disposing of aids and appliances for years on end. The cost of treating the resulting behavioural, educational and psychological effect is measurable, but the fact that it is distributed between the different disciplines makes it difficult to appreciate both the size and complexity of the problem.

Establishing a daily routine

As soon as investigations are completed, the continence advisor or a nurse with suitable experience should be introduced to the child. She or he can advise upon the importance of diet, and can devise a daily care plan that will fit in with the family's lifestyle; an awareness of the possible presence of emotional, financial or marital problems is also required, and this requires tact and sensitivity in eliciting. As the usual age for continence training approaches, the nurse or continence advisor can set the stage for habit training if appropriate.

Bowel A simple daily routine should be established to encourage self-evacuation, and exercises such as blowing up a balloon or coughing can be taught to facilitate this (Claydon and Agnarson, 1991). Giving the child a high-fibre diet and allowing him or her to spend 10 minutes every morning and evening on a potty with supported sides, back and safety bar may be enough to enable daily self-evacuation and to avoid the occurrence of the 'mega bowel' which is so much a feature of neuropathic bladder and bowel. Self-evacuation is that which is achieved by the child without resort to intrusive intervention by carers, such as manual evacuation.

Bladder Urinary tract infections are symptomatic of inadequate bladder emptying. Carers need to be aware that dryness does not necessarily indicate that the bladder is empty. Children with neuropathic bladders with or without reflux generally respond well to catheterisation, and this can be introduced soon after birth if indicated. The size of bladder and competence of sphincter will dictate whether or not drugs are required. If there are concerns about the use of oral oxybutynin, it can be used intravascularly (Jamieson, 1989). A simple clean procedure is sufficient and the catheter should be rinsed well before and after use and not sterilised.

Children with hydrocephalus can be taught a simple step-by-step route to self-catheterisation. The great variety of catheters available on the market enables the continence advisor to experiment and find the one which best suits the child. Results should be charted carefully to establish the maximum dry period, and this can be used to establish the child's 'safe dry period'. If, for example, the child is usually dry for three hours, the 'safe dry period' would last for 2¾ hours to avoid 'accidents'.

The use of nappies should be actively discouraged – they do little for the child's self-esteem, particularly at school, and are not helpful in encouraging the child to become continent. Reusable pants with a reinforced crotch should be sufficient when the child's routine is well-established. These can be easily purchased, and can be machine washed with the rest of the laundry. A daily intake of cranberry juice is known to have an antibiotic effect and would also be beneficial for bowel management. The commercially prepared juice has a lower concentration of cranberries, but is still beneficial (Sobota, 1984; Blatherwick, 1923).

Charting results to assess the pattern of micturition is useful, and adjustments to the child's routine can then be made if necessary. The physiotherapists, occupational therapist and preschool advisory teacher should now be involved to ensure interprofessional cooperation and a daily care plan are formulated that will allow for other demands on the child's time.

The child should be given a multiprofessional assessment to ensure that his or her physical, educational and emotional needs will be met at school. The assessment should result in a statement of special need and the local education authority's recommendation for school placement, advisory and support requirements. If appropriate assessment is given during the preschool years, the team should be already working well together and need only transfer their attention from home to school.

Reaching full potential

Children born with spina bifida and/or hydrocephalus can now benefit from medical and social urological management that will enable them to be educated alongside their able-bodied peers. They should be able to enjoy their education without carrying the social stigma and health threat of double incontinence. Relevant personal and social education and access to counselling when it is needed, will enable them to reach their full potential.

If healthcare professionals pool their expertise and resources and work together, the time will come when children born with spina bifida, hydrocephalus and other disabilities will be able to enjoy both good quality of life and a long lifespan. Their social, medical and educational management will then equip them for independent living.

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