Care of the child with spina bifida / prepared by the Standing Medical Advisory Committee for the Central Health Services Council, the Secretary of State for Social Services, and the Secretary of State for Wales.

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Prepared by
The Standing Medical Advisory Committee
for the Central Health Services Council
the Secretary of State for Social Services
and the Secretary of State for Wales

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CARE OF THE CHILD WITH SPINA BIFIDA

Introduction

1.1 Spina bifida is one of the major handicapping conditions of childhood. Approximately 1,500 live born babies are affected each year in England and Wales. Prior to the introduction of early surgical treatment in the 1950s most babies with spina bifida died in early life, but today some 600 are each year reaching the age of five. Modern surgical treatment has improved the quality of life for many, but a number of children are now reaching adolescence who have severe intellectual, physical and emotional handicaps which impose a considerable strain on them and their parents. These factors led to an appraisal (Lorber 1971) of the results of early surgical treatment in the light of experience in a long-standing special neonatal surgical centre.

1.2 In July 1971 the Standing Medical Advisory Committee of the Central Health Services Council considered a paper which set out (in terms of mortality and morbidity) the results of modern treatment of spina bifida. They requested the Chief Medical Officer to convene a multi-disciplinary conference (which was held in September 1971) of those engaged in the work, with a view to formulating advice on the management of spina bifida.

1.3 The conference examined the subject under 3 main headings: (a) the result of early surgical treatment, (b) the reaction of nursing staff to newborn babies with spina bifida, (c) the child with spina bifida and the family. It was acknowledged that while doctors will have to continue to work out their own ethical and clinical solutions to the problems of the individual patient with spina bifida, guidance on management would be welcome in general terms. This memorandum prepared by a small drafting group from the conference briefly refers to the incidence and aetiology of the condition, summarises the present position concerning early surgical treatment, and sets out the main points in subsequent management, counselling of parents, and stresses the importance of medical, social, educational supporting services and their co-ordination. It is also intended to be of help to family doctors and others who are particularly concerned with the child suffering from spina bifida in the family setting.

1.4 Sections 10 and 11 (on educational placement, and school leavers) were prepared after consultation with the Department of Education and Science.

Incidence

2.1 In this memorandum only spina bifida cystica will be considered and the definitions used will be found in Appendix 1. The incidence of spina

bifida cystica varies geographically and from year to year in an individual country. In England and Wales the incidence varies from 1 in 250 total births in South Wales to less than 1 in 500 total births in East Anglia (Laurence, Carter, David 1968). In contrast in Japan the incidence is less than 1 per 1,000 total births. The incidence is greatest in the first born children, among offspring of the youngest and oldest groups of mothers, and in the lowest social classes. Seasonal variations with an excess from conceptions in the winter months, have also been noted.

Aetiology

3.1 The malformation which will result in spina bifida cystica is determined by the fourth week from conception. The aetiology is multifactorial, having genetic and environmental components. A polygenic mode of inheritance is probable. Females are more often affected than males. The incidence among siblings is far higher than in the general population, but is less than could be expected even in simple recessive inheritance. A couple who have one baby affected with spina bifida, may have a 1 in 20 chance that any subsequent offspring will have a major malformation of the central nervous system. If a couple have two or more affected infants the risk of further affected offspring is about 1 in 4 to 1 in 8. (Carter, Fraser Roberts 1967). Environmental factors which may be of significance include social class, birth order, maternal age and nutritional state, and infections in early pregnancy.

Results of Modern Surgical Treatment

4.1 The increased survival of children with spina bifida in the past ten to fifteen years is due to advances in paediatric surgical management (Report on Surgery of Newborn 1968), in neonatal anaesthesia, early surgical closure of the spinal defect within 24 hours of birth, antibiotics and the introduction and development of ventriculo-atrial drainage of hydrocephalus.

4.2 Laurence & Tew (1971) in 1968 reviewed a series of cases, few of which had received modern treatment, and showed a mortality in the perinatal period and in infancy of 85%. The survival at 11 years was 12·8%. The authors suggested that this series provided a "base line" for evaluation of modern treatment.

4.3 In contrast Lorber (1971) showed a survival rate of 64% at age 2 years in all patients with modern management. Of the children born between 1959–63 41% survived to the age of 7 to 11 years. The extent of their handicap was assessed as follows:

	Percentage of survivors	*Percentage of all affected children*
No handicap	3%	1%
Moderate physical handicap (all with IQ of 75 or above)	15%	6%
Severe physical handicap (IQ 80 or above)	49%	20%
Severe physical handicap (IQ 61–79)	21%	9%
Extreme physical handicap (IQ 60 or below)	12%	5%
	100%	41%

4.4 24% walked without aid, 9% with sticks, and the remaining 67% required calipers, crutches or a wheelchair. The results of treatment are naturally affected by many factors but the one which primarily determines the ability to walk is the severity of the original paralysis. Apart from defects of locomotion the physical handicaps included hydrocephalus, defects of sensation, scoliosis, pathological fractures, disorders of the urinary tract and faecal incontinence.

4.5 In Lorber's series intellectual handicap was related to the presence of hydrocephalus and to whether or not it required surgery. Where hydrocephalus had required surgery only 50% had an IQ of 80 or above.

4.6 In a survey carried out by the GLC (Bernadette Spain 1969) it was shown that the survival rate at five years of those born in the London area between 1962–64 was about 35%. The estimated long term survival of those born during 1967–68 was approximately 45% and the estimate in long term survival of those born in the future is unlikely to exceed 50–55%.

4.7 Of those surviving to school age in London about 60% require special education, 50% within schools for the physically handicapped. Spain estimated that in future about 60% would require placement in schools for the physically handicapped and a further 10% in schools for the severely subnormal.

The Child in the Family

5.1 Active surgical treatment of children born with spina bifida cystica has increased the number of survivors, but has also posed problems of clinical management and caused considerable social and emotional problems for the child and his family. Special studies have been done in this field (Hare *et al*, Freeston 1971, Walker *et al* 1971).

5.2 Up to 50% of parents of these children had never previously heard of spina bifida and the majority were ignorant of the way in which it would

affect their child. The initial emotional reaction of parents to the birth consisted of shock, grief and confusion. Mothers separated from infants in intensive care felt a sense of isolation and deprivation. All these studies of parent reaction emphasise the need for repeated opportunities for counselling and explanation. Too often the birth of a child with spina bifida led to physical and emotional isolation. Long periods of separation in hospital cause emotional and personality difficulties which add to the child's existing handicaps. Repeated admission of the child to hospital, and frequent visits to a variety of out-patient departments disrupted the life of the entire family.

5.3 The studies showed that although parents were helped to some extent by both health visitors and family doctors they were often dissatisfied and frequently felt better informed about spina bifida than either. The majority did not appear to receive the continuing comprehensive care they so clearly needed.

The Needs of Children with Spina Bifida Cystica

6.1 These needs may be broadly summarised as medical, nursing, social, educational, parent guidance, coordination and integration of services as well as comprehensive assessment, some aspects of which are discussed in the following paragraphs.

Medical Management

6.2 With increasing attention to the ante-natal diagnosis of foetal abnormalities the condition may be detected to a greater extent antenatally. Decisions about the management of the delivery, the early surgical treatment, and subsequent medical management are the responsibility of the individual doctor concerned who takes account of all the relevant factors including the wishes of the parents.

6.3 It is essential to have the child examined by a paediatrician or a paediatric surgeon preferably within the first six hours. He may find that the baby is unlikely to survive longer than a few days or has either obvious active movement or complete paralysis of the lower limbs. Assessment of the degree of activity and muscle power in the lower limbs in the first few hours of life is of particular importance. Preservation of this activity may be jeopardised by any delay in closure of the sac. Following the initial assessment it is essential that there is full discussion with one or preferably both parents.

6.4 In the light of the foregoing, some workers are now trying to apply a policy of selection. Some of the criteria they are using include complete paraplegia, gross hydrocephalus, severe kyphosis, meningitis or ventriculitis, other severe congenital malformation.

6.5 Whether early closure of the sac is undertaken or not further surgical treatment may be necessary. 80% to 90% of the children with meningomyelocele develop progressive hydrocephalus which requires insertion of a ventriculo-atrial shunt. 50% of these children will require further surgery for their shunt. (Eckstein 1972). Those responsible for the care of these infants must be aware that these shunts may block at any time. Where there is any doubt consultation with the unit responsible for the child's care is essential since blockage of the valve may lead to sudden coning and death or to blindness due to optic nerve damage.

6.6 At the time of birth over 90% of the children with meningomyelocele have some degree of paralysis of one or both lower limbs, 70% are severely affected and in 20% the paralysis is complete (Sharrard 1964). As a result of early closure some apparent improvement may occur, but this is transient so that at the end of the first year the position is never better than at the time of birth. (Brocklehurst *et al* 1967, Duckworth & Brown 1970). In some children there may also be some progressive loss of muscle function. Because of muscle imbalance skeletal deformities occur, and one third of these children develop a dislocation of one or both hips (Sharrard 1964). This may be present at birth or develop gradually during the first years of life. Deformities of the foot are present in 80% of cases (Sharrard & Grossfield 1968). Spontaneous fractures are common in the paralysed limbs, particularly after a period of plaster immobilisation. Kyphosis is present at birth in one child in eight (Hoppenfield 1967) and may interfere with surgical closure. Severe scoliosis is also a common problem.

6.7 No matter how severely the paralysis all children have a strong desire to walk, and even though a variety of supporting appliances are required this should be encouraged, even though it is recognised that they may ultimately be chair-bound. An extensive programme of orthopaedic operative procedures may be necessary but justified provided nothing is done which might interfere with sitting posture. Surgery represents only part of the treatment. Provision of splints and calipers and the services of a physiotherapy department with special experience in the management of these children are equally important. As the physiotherapist teaches the child to use his limbs more effectively with or without appliances physiotherapy should be started at the earliest possible opportunity. It is important that physiotherapists are included in the team so that they are in full possession of any future plans for the child's management. (See paragraph 12.1).

6.8 Insensitivity of the skin carries the risk of ulceration. This can be kept under control in young children by common sense precautions, although recurrent troubles may arise over bony prominences. In older children with increased body weight the risk of skin ulceration becomes much greater, and those who survive to teenage require formal training in paraplegic skin care.

6.9 The majority of children with meningomyelocele will suffer from

incontinence of urine. It is unlikely that more than 10% will develop normal urinary control (Eckstein 1972). The neurogenic bladder fails to empty properly and there is urinary stasis with resultant infection. Structural abnormalities of the renal tract, ureteric reflux and upper renal tract dilation, are also common. By 5 years of age about 60% suffer from recurrent urinary tract infections (Cooper 1967). Bacteriological and radiological examination of the renal tract are important aspects of management in these children from infancy onwards. Some children can be kept socially dry by regular expression of the bladder but this form of management is only applicable to a minority as they get older. Urinary incontinence in girls necessitates a urinary diversion using one of the standard surgical procedures.

6.10 Despite absent sphincter control socially unacceptable faecal incontinence can be avoided in the majority of cases by encouraging a regular bowel routine.

Nursing Staff

7.1 The nursing staff caring for the mother and baby have a particularly difficult task. The nurse's initial response may profoundly affect the mother's attitude to her infant. Some of the staff may be in training either as midwives or as paediatric nurses, and find these situations distressing. If it is the policy of the unit to employ a form of selection, it is imperative that the nursing staff caring for those cases where surgical procedures and medical treatment to prolong life are not indicated are brought into the discussion at the earliest possible moment.

Counselling of Parents

8.1 If the diagnosis is made in the antenatal period it may be necessary to begin counselling of the parents during this period. The birth of a child with spina bifida must be regarded as acute an emotional and social crisis as it is a clinical challenge. As much skill is required in the care of the parents as in the care of the infant. If at all possible the mother should be allowed to see and handle the child shortly after birth particularly if surgery is indicated and a temporary separation unavoidable. The father should be involved in the early discussions and the malformation explained to both parents in the simplest terms consistent with accuracy. Since both parents are emotionally disturbed during this period, their involvement in the decision to operate requires skill and patience. Repeated opportunities for both to discuss their grief and anxiety must be provided and ideally one member of the staff should assume a particular responsibility for this relationship. Often the parents are completely unable to grasp the initial information provided and the importance of repeated opportunities for discussion both in hospital and at home cannot be over-emphasised. If a process of selection is used, the parents of babies who are not offered

active treatment require as much or more support as those whose infants have undergone surgery.

Genetic Counselling

8.2 As the risk of spina bifida in subsequent children rises substantially after one affected child, genetic counselling and family planning advice are urgent and important aspects of the care of the family. A list of Advisory Centres is in Appendix 2; the memorandum on Human Genetics may also be found useful. Many couples are reluctant to seek family planning advice even following the birth of a handicapped child, and may need substantial encouragement to do this. If sterilisation is recommended; this too may produce emotional problems which require special help.

Social Needs

9.1 Irrespective of the quality of care the handicapped child inevitably suffers some degree of deprivation because of his inability to explore his environment spontaneously. Socialisation problems and emotional difficulties may be minimised if placement in a nursery school or a day nursery for handicapped children can be arranged. The majority of these children would benefit from some form of nursery education from the age of 2 years.

9.2 The life of the parents becomes increasingly complex as the child grows and a wider range of professions become involved in assessment and education. Parents require a continuing advocate such as a social worker or health visitor working closely with the clinical team including the family doctor and providing advice, guidance and support, in the management of their child. The child or young adult with spina bifida has a variety of problems, many of which can be diminished by careful planning.

Educational Placement*

10.1 While the educational placement of physically handicapped children is the responsibility of the Local Education Authority, the choice of the most appropriate placement should be made on the advice of both doctors and educational staff in cooperation with the parents and following full assessment of the child's physical, intellectual, and psychological make-up.

10.2 Children deprived by their physical limitations of the exploratory experiences of normal childhood and of the company and stimulus of other children—experiences on which much of their later intellectual and social development depend—should where possible have the advantage of a period of nursery education. An increasing number of day schools for

* Sections 10 and 11 were prepared after consultation with the Department of Education and Science.

the physically handicapped have a nursery class where the full medical, nursing and therapy services of the school are available as well as the skills of teachers experienced in this work. Support and advice offered to parents is a further advantage of early education. Places may be available for handicapped children at ordinary nursery schools with consequent intellectual and social gains; care must be taken, however, to ensure that the staff are fully informed about the child's needs and the possible dangers to his physical well-being. If the school is near the child's home, his mother may be able to come into school to deal with changing and toilet training. Early education will also offer valuable guidance to those responsible for placement at school age.

10.3 There is general agreement that handicapped children should be educated as near home as possible. The main alternatives available after the age of 5 are education in an ordinary school, in a day special school or class, or in a boarding special school. The suitability of an ordinary school may depend on adaptations to the building, especially the lavatories, to ensure privacy and the hygienic conditions in which to help a child to establish a bowel and bladder control. Training towards personal independence is an essential part of the education of these children, and the suitability of an ordinary school can also depend on the presence of staff able to undertake this training and aware of the hazards to which children with spina bifida are exposed. The availability of physiotherapy can also be an important consideration. Each child must be reviewed regularly to ensure that he is able to benefit fully from education in an ordinary school.

10.4 The advantages of education in a special school for a severely handicapped child are clear: supporting, nursing and therapy services are provided in the school; there is regular medical supervision; buildings are planned or adapted to meet needs; classes are small; and teachers are knowledgeable about the living and learning problems of children with handicaps. Special classes and units can generally offer the same advantages, but placement can only be for a limited period as children quickly outgrow what a small unit can offer educationally and socially.

10.5 A boarding special school may be appropriate for children whose home conditions are poor or for those whose family is under stress through having to care for a seriously disabled child. For some boarding education may be necessary because they live too far from a day special school or may offer a richer, social and educational life. It may also be appropriate for children who need a great deal of skilled nursing, when it would serve as an alternative to a long stay in hospital; if the latter is however unavoidable, education will nonetheless be arranged by the Local Education Authority.

10.6 It is important to appreciate that the initial decision regarding school will not necessarily hold good for the whole of a child's education and that there must be regular review, not only of his physical, but also of his educational and psychological development. One child who thrives in a

primary school may find life too great a strain in a large secondary school with its less intimate and protective atmosphere, its more frequent changes of teacher and its wider range of physical and practical activities: another child, however, having benefited from the services and support of a special school in his early years, may be ready for the demands of a well-chosen secondary school.

School Leavers and Employment

11.1 Employment will be a difficult problem for the majority of these children. Well before the time comes for them to leave school, their employment will need to be the subject of continuing discussion between the Careers Advisory Officer or Disablement Resettlement Officer and the staff of the school. In this way careful consideration can be given to each child's particular aptitudes and abilities, and to the question of whether further assessment and training are required.

Coordination of Effort

12.1 These children require continuous follow-up and reassessment. Although the paediatrician may act as coordinator, the child's needs change and emphasis of care passes from one member of the team to another, the neurosurgeon or paediatric surgeon, the urologist, the orthopaedic surgeon, the school medical officer, the educational psychologist, the physiotherapist, and the nurse. The family doctor is concerned in management and it is especially important to consult, inform and involve him throughout. Good communication based on adequate records is essential, and the continuing role of the social worker or health visitor must be maintained.

Comprehensive Assessment

13.1 Comprehensive assessment, treatment and training must be closely coordinated to be effective. Regular review involving all those concerned with the child's care is of vital importance.

13.2 The development of Regional and District assessment centres will provide an ideal focus for such work.

13.3 Close collaboration between regional assessment centres and special surgical units should provide effective continuing evaluation of current methods of management.

Supporting Services

14.1 Although large gaps still exist many of the problems facing families of children with spina bifida can be dealt with by existing voluntary or

statutory services. A booklet "Help for Handicapped People" which is obtainable from local authority offices contains advice and information regarding services and assistance available.

14.2 A number of Associations have a particular interest in children with spina bifida and their families. Parents should be encouraged to contact these associations for they may be able to offer considerable support. Addresses of some associations and other sources of advice are shown in Appendix 3.

Conclusions

15.1 Current methods of management of spina bifida cystica have led to an increase in the proportion of survivors, the majority of whom have multiple handicaps.

15.2 Studies have shown that survival is associated with substantial and emotional family disturbance.

15.3 As physical and intellectual outcome are related to the severity of the initial malformation certain contra-indications to active treatment have been suggested.

15.4 The early management of each individual child remains the responsibility of the doctor concerned.

15.5 Selection for active treatment should be only the first step in a planned programme of care in which the clinical, social and educational components are considered.

15.6 A decision not to operate implies the existence of a coordinated medical and nursing policy which recognises the emotional and ethical problems involved.

15.7 Communication within the team is critical and links between hospital, community and family doctors should be strengthened by the appointment of special social workers or health visitors.

15.8 The functional outcome in individual children depends upon the adequate provision of practical help, in particular splints, calipers, surgical appliances and the availability of experienced physiotherapists.

15.9 The establishment of comprehensive assessment services will assist in total assessment and suitable education placement.

15.10 Genetic counselling and family planning advice are important.

APPENDIX I

Definition

Spina bifida cystica is of 2 main types:—

(1) MENINGOCELE: The cystic swelling or sac consists only of the meninges and cerebro-spinal fluid. These patients comprise only 5% of the spina bifida cystica population, and have no motor or sensory defects. Hydrocephalus is less common in this type.

(2) MENINGOMYELOCELE: The spinal cord and its nerve roots are involved in the cystic swelling as well as the meninges. These patients have varying degrees of motor and sensory paralysis depending upon the site and extent of the neurological malformation. They are liable to meningitis and to hydrocephalus. Urinary and faecal incontinence are common.

The commonest sites of spina bifida with meningomyelocele are the thoraco-lumbar and lumbo-sacral regions with consequential paralysis of the spinal muscles lower limbs and sphincters. Hydrocephalus occurs in about 85% of these patients. By contrast, when spina bifida occurs in the cervical, high thoracic and sacral areas the paralysis is often less severe.

APPENDIX II

Genetic Advisory Centres

Hospital Areas

NEWCASTLE

Regional Genetics Advisory Service
Laboratory of Human Genetics
University Department of Child Health
19 Claremont Place
Newcastle-upon-Tyne NE2 4AA

Genetic Clinic
The Children's Hospital
Durham Road
Stockton-on-Tees
Co Durham TS19 0EA

LEEDS	Genetic Clinic The General Infirmary of Leeds Great George Street Leeds LS1 3EX
SHEFFIELD	Centre for Human Genetics (Sub-Department of Medical Genetics) Langhill 117 Manchester Road Sheffield S10 5DN
METROPOLITAN	
North West	Galton Laboratory Department of Human Genetics University College, London Wolfson House 4 Stephenson Way London NW1 2HE
	Genetic Clinic Paediatric Department University College Hospital Huntley Street London WC1E 6AU
	Genetic Clinic for Skin Disorders The Institute of Dermatology St John's Hospital for Diseases of the Skin Lisle Street Leicester Squrae London WC2H 7BJ
	Institute of Child Health The Hospital for Sick Children Great Ormond Street London WC1N 3JH
	Kennedy Galton Unit (Research Centre) Harperbury Hospital Harper Lane Shenley Radlett Herts WD7 9HQ
North East	Examination Centre Royal Eastern Counties Hospital Turner Road Mile End Colchester CO3 38T

	Genetic Clinic Moorfields Eye Hospital City Road London EC1V 2PD
South East	Paediatric Research Unit Guy's Hospital London SE1 9RT
	The Maudsley Hospital Denmark Hill London SE5 8AZ
South West	Queen Mary's Hospital for Children Queen's Drive Beeches Carshalton Surrey
WESSEX	Genetic Counselling Centre Children's Hospital 154 Winchester Road Shirley Southampton SO9 4WR
OXFORD	Population Genetics Research Unit Old Road Headington Oxford OX3 7LF
SOUTH WESTERN	Department of Child Health Bristol Royal Hospital for Sick Children St Michael's Hill Bristol BS2 8BJ
	Paediatric Research Unit Royal Devon and Exeter Hospital Gladstone Road Exeter EX1 2ED
BIRMINGHAM	Infant Development Unit Birmingham Maternity Hospital Edgbaston Birmingham B15 2TG

The Gulson Hospital
Gulson Road
Coventry CV1 2HR

Quarterly clinics at:—
Central Out-patients Department
North Staffordshire Hospital Centre
Hartshill Road
Stoke-on-Trent
Staffs ST4 7PA

Royal Salop Infirmary
Shrewsbury
Salop SY1 1DY

Warwick Hospital
Lakin Road
Warwick

Worcester Royal Infirmary
(Castle Street Branch)
Castle Street
Worcester WR1 3AS

Referral through Paediatric Department of these hospitals

MANCHESTER

Department of Medical Genetics
Manchester Royal Infirmary
Oxford Road
Manchester M13 9WL

Medical Genetics Clinic
County Medical Officer
Health Department
Pepper House
Pepper Row
Chester WD1 8SB

Royal Manchester Children's Hospital
Pendlebury
Manchester M27 1HA

LIVERPOOL

Genetic Counselling Clinic
Department of Child Health
Alder Hey Children's Hospital
Liverpool L12 2AP

The Endocrine Clinic
David Lewis Northern Hospital
Leeds Street
Liverpool L3 6AU

WALES

The Department of Child Health
University Hospital of Wales
Heath Park
Cardiff CF4 4XN

APPENDIX III

Sources of Information:

A. LOCAL AUTHORITY SERVICES:

The Local Health, Social Services and Education Departments. (The Citizens' Advice Bureau or Civic Information Department in the area will help with addresses of the Departments referred to in this paper.)

B. VOLUNTARY ORGANISATIONS:

The Central Council for the Disabled.
34 Eccleston Square, London SW1.

Disabled Living Foundation.

Information Service for the Disabled
346 Kensington High Street, London W14.
Tel: 01–602–2491

Joint Committee on Mobility for the Disabled,
c/o Spastics Society, 12 Park Crescent, London W1N 3EQ

The Association for Spina Bifida and Hydrocephalus
National Office: 112 City Road, London EC1V 2ND
Tel: 01–253–2735.

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