Link

Association for Spina Bifida and Hydrocephalus/ASBAH 15p May/June 80

A Question of Ethics: About ASBAH: Campaign to Defend 1970 Act: True Prevention of Spina Bifida?: Attitudes and Responsibilities: The Effects of Hospitalisation: Living with Spina Bifida: Across the Channel by Parachute.

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CONTENTS

A Question of Ethics

by Professor John Lorber

Dr. Stig Melander's articles (LINK 66 and 67) are provocative and represent his own views, without any important personal experience with individuals with spina bifida and their families. He works in a small town in Sweden as an obstetrician, where the incidence of spina bifida is very low, much less than one baby a year. He has no further contact with these babies after delivery. I know this because I had the privilege of being Chairman of the meeting of the International Spina Bifida Conference in Stockholm, where he delivered this now published talk and had opportunity to discuss this with him.

In my experience throughout the world, and in contact with tens of thousands of spina bifida individuals and their families, I have never come across a feeling in these people that antenatal diagnosis, followed by termination of pregnancy is considered "insulting, injurious, humiliating and a violation of the human dignity of those already born and living with the handicap". The two things are simply not comparable.

I do not know of any parent of a spina bifida child who considers that terminating a pregnancy, where the foetus is abnormal, is in any way humiliating, etc. to their living spina bifida child. I do not know of any spina bifida person who feels this way and nor is there any need for it.

Our spina bifida population is as well looked after and loved as much as any other members of the family, even if the parents decide to terminate a pregnancy if the foetus is abnormal. I know that spina bifida subjects, who hope to have the opportunity to have children, welcome my reassurance that they will have a good chance of having a normal child as a result of antenatal diagnosis.

It is totally false to stress that antenatal diagnosis leads to the killing of many foetuses. On the contrary, it creates many more lives than it destroys. The matter must be put in perspective. Out of every 100 pregnancies in high risk families, only five will be affected by neural tube defects: two of these will have anencephaly and would not result in a viable child; one will have mild spina bifida, not diagnosable by alpha-foetoprotein test, and only two will have large open spina bifida which can be diagnosed, and followed by termination, if the mother attends early enough for this to be carried out and if she agrees. The decision is invariably the mother's free choice after expert information has been given.

So, out of 100 only two potentially viable babies would be aborted and one of those is likely to die early in life, even if fully treated.

In contrast, most mothers at high risk would not dare another pregnancy, for the real fear of having another affected baby, if there were no antenatal test. Is it humiliating to a spina bifida child if his parents do not have other children for fear of having spina bifida again? The failure to carry out antenatal test loses many lives of normal children who would not be conceived if there were no assurance of antenatal diagnosis. "High risk" families may not have a normal child and the family may grow up without any child at all, if they lose their handicapped child. Is it ethical to deprive such families of having normal children?

Continued on Page 7

COVER STORY: Summer is coming—a picture that captures the exhilaration and freedom of playing in water. Our thanks—once again—to Camilla Jessel for this evocative photograph.

While every care is taken to ensure the accuracy of information published in LINK the publishers can accept no liability. Opinions expressed in articles are not necessarily those of ASBAH.

Carol goes disco dancing

CAROL Smith, (right) of Marlow, Bucks gets a lot of fun out of life from disco dancing. After only a few weeks' tuition at Slough Community Centre she has passed a disco dancing exam and won a bronze medal.

She said "I feel really great. I've always liked doing disco dancing and I'm hoping to take further exams . . ."

Carol, 20, works in a baby clinic in Marlow. She is also keen on formation wheelchair dancing, playing table tennis and taking part in various wheelchair sports.

Carol Smith

Photo: Slough Observer

Girls Brigade honours Sandra

ANOTHER girl who deserves much praise is 14-year-old Sandra Jobson of Grimsby. In recognition of her long fight against spina bifida she was awarded the Girls' Brigade Endurance Award. She attempts as many activities as she can with the Brigade and has been a member for more than three years.

Tina wins bronze award

CONGRATULATIONS also to 15-year-old Tina Billett of the Southampton and District Association. Tina, who has spina bifida, has won the Bronze Award under the Duke of Edinburgh scheme.

She is a ranger and had to pass a number of tests. They included a six-month cookery course, giving service to the community (which involved 16 hours clearing undergrowth), and a course in hair care and make-up. An arduous part of the test was a seven-mile expedition which she had to map out and plan. She also had to walk part of the route. Tina has recently joined the local Sports for the Disabled group and in September this year will start at college.

On the road to recovery

LINK is always pleased to receive letters from readers . . . letters with ideas for articles, letters of encouragement, letters about problems, letters with personal accounts. One recent note came from Miss Margaret Fewell of Alderbourne House, Hillingdon Hospital . . .

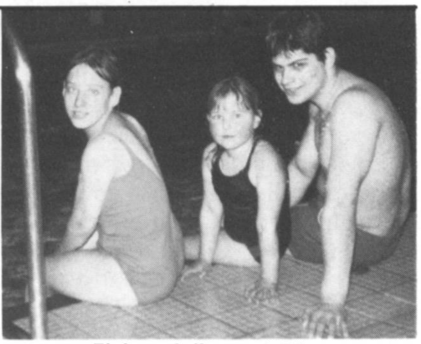
She was born with meningocele and without leg movement but after an operation she was able to lead a fairly normal life. But then complications set in and her legs and arms became weak and there were other problems. After many tests and a CT scan she had an operation to remove a blockage in the spine.

She is now making a good recovery. Miss Fewell reports that she has regained the use of her legs and also has more use in her right hand than before. We hope her recovery continues.

ASBAH swimmers aid local pool

THREE young members of Grantham local association—and also members of the Handicapped Swimming Group of Grantham—took part recently in a David Wilkie Swimalong. The three decided that the money they raised should go towards the Appeal for a swimming pool for the use of handicapped children at Queen's Park.

Between them, Elaine Blatherwick, 15, Clive Wright, also 15, and Juliet Asken, who is only 4, raised £55.



Elaine, Juliet and Clive

The three of them were later presented with certificates and photographs of themselves with Geoff Capes (shotput champion) and David Wilkie—fitting reminders of their splendid swimalong.

THIRTEEN-year-old Nina Bugden of Southampton and District Association with (left) the Vice Chairman, Mr Stan Fitzgerald, and the then Captain of the Southampton football team, Alan Ball, who presented the Association in Southampton with the magnificent sum of £1,600. It was raised from a sponsored walk by members of the Green Jackets Army Pay Corps and customers of the Running Horse public house at Littleton.

ABOUT ASBAH

SIXTY members attended the last Council Meeting and contributed to a lively and detailed discussion of Asbah's affairs.

The day started with reports from each Department. As well as the increased activity by the Appeals staff, which is reported elsewhere, Council Members were pleased to hear that two projects, supported by ASBAH, to look at the effects of vocational and non-vocational training on young people with hydrocephalus are in progress—one at Banstead Place and one at Derwen College.

A busy programme of independence training weeks has been planned for the current year, and two-day conferences for young people, combined with workshops for parents, have been so successful that they will become a regular feature in the diary.

Readers will be sorry to learn that Jan Tomlinson has left us to become a Community Centre Organiser. She takes with her our very best wishes for the future and we hope that she will keep in touch with us.

Meetings

A large part of the day was spent discussing the regional meetings which had been held (some are still being arranged). It was emphasized that we all hope that the financial difficulties will be short-lived. Every Department is constantly looking at its work very closely to see if there are any ways in which savings can be made. The support which is being given now by Local Associations in the form of donations, loans and accepting responsibility for field work costs is very much appreciated.

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Campaign defends the Act

THE CHRONICALLY Sick and Disabled Persons Act Conference which was held on 17 January adopted the following Declaration:

"We believe that the 1970 Act though in need of strengthening, has played an essential part in the improvement of services and conditions for all disabled people in the last decade.

"We are gravely concerned that the Act is being undermined both directly and indirectly as national and local government plan and implement financial cut-backs.

ACTION

"We call upon our elected representatives at every level of Government to maintain the present provisions of the Act; press for its full implementation; and remedy its defects, so that all disabled people receive as of right the services they require."

A Committee elected from the Conference is now organizing a campaign in defence of the Act, leading up to a mass lobby of Government departments and Parliament on 10 June.

The campaign to defend the Act is called "Act Now" and ASBAH is represented on the steering group.

The names are not the same . . .

THE NATIONAL Council for Social Service has changed its name to the National Council for Voluntary Organisations. The new name more accurately describes the Council's purpose and function and should end the confusion which sometimes exists with the work done by local government social services departments.

THERE IS a new name, too, for the National Society for Mentally Handicapped Children. It is now known as the National Society for Mentally Handicapped Children **and Adults**, but its short title will still be MENCAP.

Read all about it

'Making Life Easier for Disabled People' is the name of a new leaflet from the Electricity Council, with advice on appliances and details of some of the special controls which can be fitted.

Free copies from your local Electricity Board Shop, or post free from the Electricity Council, 30 Millbank, London SW1P 4RD.

'Hand Controls for Motor Vehicles' is a useful leaflet produced by the Mobility Information Service. It lists manufacturers with the kinds of controls and conversions they can supply.

Free from MIS, Copthorne Community Hall, Shelton Road, Shrewsbury, Shropshire.

AN UPDATED version of *'Directory of Clubs in Greater London* is now available. It contains information about clubs operating throughout London, catering for the needs of disabled people.

Copies from: The Information Department, GLAD (The Greater London Association for the Disabled), 1 Thorpe Close, London W10 5XL. Price: £1.20 including p and p.

PHAB week is for families

PHAB FAMILY Course 1980 is being held at the Old Manor House, Avon Tyrrell in the New Forest, August 9–16. There is a flexible programme of outings, social occasions and surprises for all groups. Families are welcome and small groups from clubs. Cost: £46 (under 12) rising to £60 (over 18 years) approximately.

Details: PHAB Family Week, 42 Devonshire Street, London W1N 1LN.

NAIDEX has bigger plans

NAIDEX has now reached such a size that it has been decided that the Exhibition will take place at the Cunard International Hotel in London, and the Conference at Kensington Town Hall. Dates: 28–30 October.

Three hostels in London

BEACON HOSTELS provide three hostels in London for single working people. Priority for ground floor accommodation is given to people who are disabled. There are one or two rooms in one hostel, Castle Lane, for people confined to wheelchairs.

Most of the rooms are available for either a short visit or long stay. A short visit might help someone of working age who is temporarily disabled or needs hospital investigation. Long stay accommodation would be for those in employment. The accommodation is 'housing' not 'care' and nobody can be accepted unless they are able to look after their own basic needs.

DETAILS

Further information can be obtained from the Managers at the hostels: Beacon House, 7 Dock Street, London E1 8JN (01-481 1326); Beacon House, Castle Lane, London SW1E 6DW (01-828 9137); Beacon House, 30–31 Leicester Square, London W2 4NQ (01-229 2220).

The head office of the Look Ahead (Beacon Hostels) Housing Association is at the Dock Street address.

Summer course for the over 21's

A HOLIDAY and Summer course for physically handicapped and able-bodied people over 21 is being organised by the Harford Group at Prospect Hall, Selly Oak, Birmingham. August 9–16. Cost £60 including outings and visits. The courses include painting, the spoken and written word, and the theatre. Nursing help is provided. The Harford Group, affiliated to National PHAB caters for the older age groups.

Details : Mrs P. Gregory, New Place, Finchingfield, Braintree, Essex CM7 4LS.

Grapevine looks at community action

GRAPEVINE is a BBC2 magazine programme featuring community action and self-help projects on Saturdays and Wednesdays, from 12 April. A new series is currently being prepared and the programme would like to hear from anyone trying to do things to make a better life for themselves and their neighbours, and helping to solve personal problems like drug dependency, physical handicap, ill-health, family difficulties etc.

The address is: Grapevine, BBC TV London, W12 8QT. Tel: 01-743 8000, ext 5180.

New service for travellers

TRAVEL WELL is a new specialist holidays and travel service for the disabled and their families and friends. It has organised holidays in various parts of the UK and overseas. It is also offering facilities for supporters wishing to go to the Paraplegic Olympic Games in Arnhem in June and July. The address is Carlisle House, 8 Southampton Row, London WC1B 4AE. Tel: 01-405 9481.

Jan makes a move

JAN Tomlinson, who for two years has ably carried out the task of Young ASBAH officer, has now left the Association. LINK wishes her well in her new role as Organiser of the Hampden Community Centre in the London Borough of Camden.

It was through Jan's work that Young ASBAH (LIFT) got off the ground, and she was also active in helping to organise and run the very successful Independence Training Weeks. Both LIFT and the Independence Training programme are now firmly established and we hope they will continue to flourish.

Continued from Page 3

In Britain, as in Sweden, termination of pregnancy is legal on very many grounds and well over 100,000 pregnancies are terminated every year in Britain alone, of which the overwhelming majority of foetuses are normal. How does this compare with a few hundred terminations in which the foetus is abnormal?

We are pleased in ASBAH to have provided a modest sum for the research by Dr. Brock and Dr. Sutcliffe in Edinburgh, which led to the development of antenatal testing. Much has developed since. I consider that it is not only permissible but essential to have a screening programme for antenatal diagnosis. Every pregnant women should have the right to full information about antenatal diagnosis of any congenital disorder; the right to decide whether she wants to have the test done and the right to decide whether the pregnancy should be terminated if the test is positive.

No one in any civilised society should attempt to make such tests or the termination to follow, compulsory. Nowhere has this been tried to my knowledge. Antenatal diagnosis does not mean humiliation to anyone: knowingly encouraging the birth of severely handicapped infants is humiliating and I consider it irresponsible and inhuman to do so.

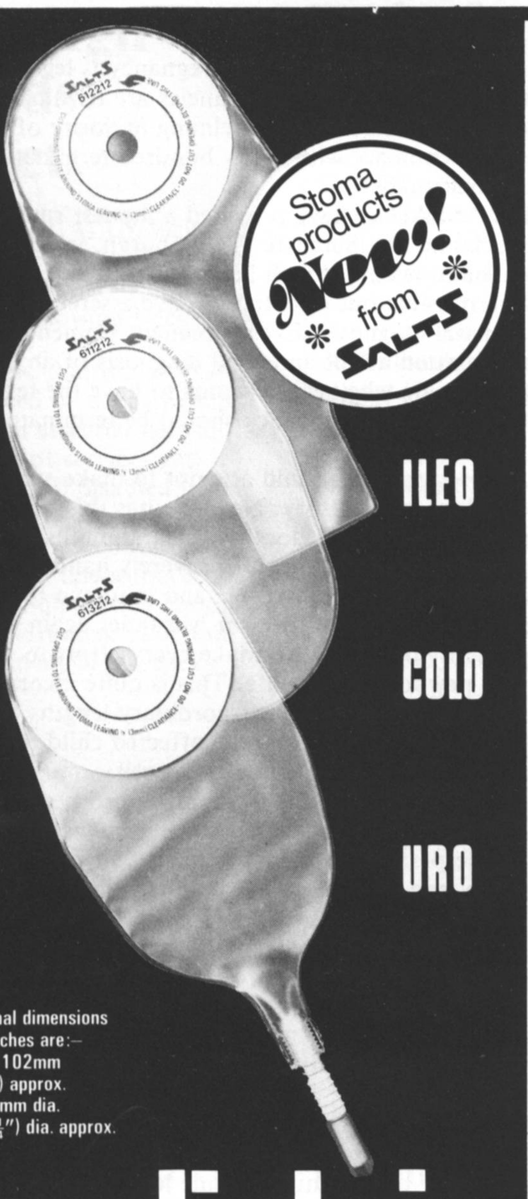
In the second part of his article Professor Melander again asserts that it undermines the sanctity of life not to make every effort to "save" a severely handicapped newborn baby's life. This is quite incorrect. It does undermine the sanctity of life to go to extraordinary lengths to perpetuate a life which not only subjects the affected child to prolonged suffering and disability, but his whole family as well.

It is true that very occasionally severely handicapped persons make a success in life, like Karen whom he quoted. But I know several such individuals, who are desperately unhappy inspite of success and openly say that they wish they had been allowed to die in infancy.

I agree with the quoted principles of the Swedish Medical Association, that "the development of modern medicine has now reached such a level that uncritical use of all possibilities of treatment can lead to untenable consequences . . ." "It cannot be regarded as conflicting with either profane or Christian ethics and now medical tradition to withhold treatment in certain cases". The British Medical Association came to similar conclusions in 1979:

> ‘Though many doctors may be involved in the care of severely malformed infants, one doctor must assume leadership. The doctor's leadership does not detract from the necessity for a clear understanding as to who is finally responsible for decisions about whether the child should be treated or not. Adult patients can make their own decisions, but for an infant the parents must ultimately decide. The responsible physician must help the parents to understand the choices. They may wish to consult other doctors they know and trust, such as their general practitioner, who will assist the family in their decision.
>
> The parents must never be left with the feeling that they are having to make these decisions without help. The doctor must attend primarily to the needs and rights of the individual infant, but in this situation he must have concern for the family as a whole.
>
> The doctor must find a just and humane solution for the infant and the family, to which consultation with hospital colleagues, the general practitioner, nurses and social workers may contribute.’

From my very long experience with parents of spina bifida babies I find overwhelming support for selective treatment for the newborn baby and the joint decision making between parents and doctor is fully satisfactory. I have had discussions with many young adults with spina bifida, who uniformly expressed their desire not to have their own baby treated, if he should be severely handicapped. Fortunately, with new advances in prevention and ante-natal diagnosis, they will very rarely have to face such a problem.



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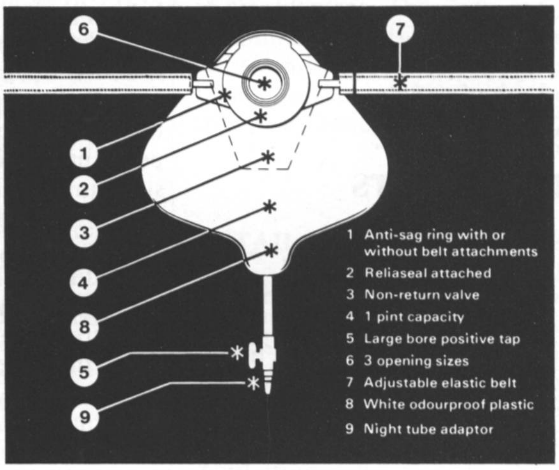

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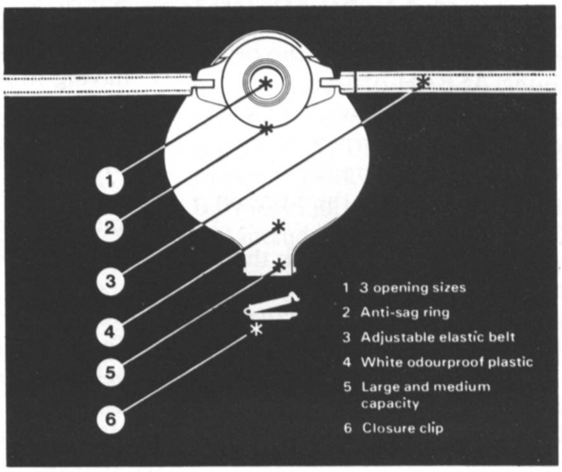

Aspiring writers take note

SAMUEL M. Miller, physically handicapped English graduate of McGill University, Montreal and A writer of short stories himself, is launching *'Disabled Writers Quarterly'*, a literary magazine. His intention is to encourage the physically disabled, throughout the English-speaking world, to write for publication. The magazine will be circulated in Canada, USA, and the UK.

'Disabled Writers Quarterly' will include prose fiction of all types: short stories, poems, novellas and plays are especially needed for its first issue. Autobiographical or 'personal' fiction, in particular, will be highlighted and a pen pal service, will also be instituted. Fiction written by prominent handicapped writers will be incorporated and their works analysed. Books written by and/or for the handicapped will also be reviewed.

The Associate Editor for Great Britain cannot accept responsibility for unsolicited contributions, but will do his best to ensure that they will be returned to the sender if not accepted, provided that they are accompanied by a self-addressed and stamped envelope. The only stipulations are that all articles submitted should be original and written by a physically disabled person.

Persons interested in submitting should write to: Mr Tom Gair, Associate Editor for Great Britain, Northumberland Cheshire Home, Maften Hall, Maften, Newcastle upon Tyne, NE20 0RH, or Samuel Miller, Editor, 2495 Major Street, St. Laurent, Montreal, Quebec, Canada. H4M 1E5.

Drivers meet in Scotland

GLASGOW IS the venue of the 1980 National Annual Meeting of the Disabled Drivers' Association. It is being held at the EuroCrest Hotel on Saturday 27 September.

Details: Glasgow group DDA, 8 Aboukir St, Glasgow G51 4QX.

Spina Bifida: True Prevention?

Prof JOHN LORBER, MD, FRCP

IT HAS long been known that there is a higher incidence of spina bifida in families in poorer social circumstances. This led to speculation and search for some cause or causes, such as deficiency of nutrition, as at least one contributory factor responsible for the birth of babies with spina bifida and anencephaly. Many avenues have been explored, but with negative results.

Mothers of spina bifida children are not evidently malnourished and do not have any of the recognised vitamin deficiencies. Nevertheless, laboratory investigations carried out by Professor Smithells, of the University of Leeds, and his colleagues since 1965, have shown that certain essential substances of the vitamin range, have lower levels in the food intake and the blood levels of mothers in the lower social class. These observations suggested that sub-clinical (that is, not detectable by ordinary examinations) deficiencies of one or more vitamins may contribute to the causation of neural tube defects, including spina bifida.

Trial

Following from this, Professor Smithells and seven colleagues from England and Northern Ireland carried out a trial in which a group of women who already had at least one infant with neural tube defects, were given a supplementary vitamin complex with iron (''Pregnavite Forte F''), starting at least one month before they decided to have another baby. The supplementary vitamin intake continued at least until the second missed period. A similar group of mothers who also had previously affected infants were not given vitamin supplements. They were either already pregnant or did not wish to take the extra vitamins. The two groups were therefore not strictly comparable. This study therefore was not a ''controlled clinical trial'' in the true sense.

Nevertheless, the results are most interesting and promising. The mothers who did not receive supplementary vitamins had 260 babies or foetuses and 13 of these, or 5%, again had neural tube defects. This is exactly the same proportion as would be expected, based on past experience of recurrence risks. All but one of these were aborted. 11 of the 12 after amniocentesis showed that the foetus was abnormal. Only one baby with a skin covered lesion was delivered normally—and such a baby of course has a good future.

Striking

In contrast, there was only a single affected infant out of 178 pregnancies: 0.6%, in which the mothers had supplementary vitamin treatment. The difference between the two groups is striking and statistically highly significant in favour of the vitamin supplemented group.

Professor Smithells and his colleagues published these as preliminary results in the Lancet on the 16 February 1980. Fuller results will be available later, but it is already very apparent that a major new line of probable true prevention has been opened up. Antenatal diagnosis and subsequent termination of pregnancy is a very good, but not perfect method of preventing the birth of babies with spina bifida, and is not true prevention.

Scheme

In view of these findings we must draw up a scheme on a national scale, involving all women who wish to have babies, whether they have had a spina bifida baby or not. The days when we had such a lot of spina bifida babies are already receding: this new knowledge should hasten the true prevention of spina bifida on a much larger scale and cause no inconvenience or ethical problems to anyone.

Avril at ASBAH's Independence Training Week at Newcastle. (Second row, 3rd from right.)

Attitudes and

by AVRIL MACDONALD

THIS IS an edited version of a paper gi
a conference in April. The conference w
Council for the Disabled on the Needs o
Adults with Spina Bifida and Hydroceph
Avril, who is completing her training
therapist, said she was no expert, unlike
she did have "37 years' experience of be
credit.
Other speakers at the conference inclu
ASBAH—Barbara Newman, Jill Vernon
the conference they and Avril went on t
Week for young people with spi[illegible]ifid
ASBAH at Newcastle University Medica
Avril was one of the helpers. Because
she was able to be of special value and h

AS A physically handicapped child, the attitudes of the people caring for you are crucial to your successful integration into normal society. If you are to learn to take responsibility for yourself you need to absorb realistic attitudes from your parents or professional helpers very early in life.

You also need to recognise and accept yourself as a disabled person with attributes and limitations. For me this came gradually, from the time I went to my local primary school. I walked in two long-legged calipers at that time and quickly came to realise that I could not keep up with the others in chasing or ball games, and that they were not prepared to wait for me. However, I did discover, with my already strong arms, I could turn a large skipping rope for much longer than they could. So I became a popular rope turner. This was one of my first steps in accepting and adapting to the limitations of having spina bifida.

Later, as a teenager, other limitations were more difficult to accept. I was still mainly on my feet at this time without calipers but with both knees and ankles arthrodic. At 16-plus dancing and boyfriends were very important.

With some timely advice from my father I was able to reach a compromise. I began to learn to sit, looking decorative and pretending to enjoy watching others dance at school and youth club parties. Surprisingly and imperceivably—to me at least—I began to enjoy watching and later became relieved I was not expected to support some rather drunk young man round a dance floor. However I have been known, in recent years after a few drinks, to get on the floor in my wheelchair and try a little disco-type dancing.

REALISM

I feel you also need to be realistic about your limitations. When I was a Civil Servant and I wanted to use a typewriter I could, with a struggle, get it off a desk, onto my lap, and with even greater heaving and shoving lever it on to my own desk. But what was the point when someone else could do it much more easily and quickly? It didn't prove I was independent. It only proved I was rather unrealistic and pig-headed.

Similarly when it comes to contacts with the general public, I feel that sometimes parents and professional staff encourage an attitude of independence *at all costs*. But you do need to know how and when to accept or refuse help graciously. As a teenager I went through a phase when I really snapped people's noses off if they dared to offer me help.

My mother pointed out, in very strong terms, that one day I would do this once too often, and when I really needed assistance no-one would offer as I would have driven them away. So I had to learn to refuse help graciously and sometimes accept help when I didn't really need it, so that I didn't hurt the person's feelings, or put them off offering help to someone else who might really need it.

In the same vein, I don't think it is a good idea to be very demanding and rude about lack of access to public buildings etc. It is much more productive to ask politely if they had ever considered putting in a ramp, or an alternative entrance, or a wider door etc. Repeated polite requests, by several people, could well produce the desired result as the management become aware of the problem.

In the choosing of a job, the

Responsibilities

**ven by Avril MacDonald to
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Centre.
she herself has spina bifida
elp to the young people.**

Avril—back in the days of her childhood

final decision rests with the individual. In the past too frequently the choice was between office work and routine factory work or sewing. Unfortunately this is still true to a certain extent today. Throughout my schooling I was firmly directed towards a commercial office career. I bitterly [illegible]sented this fact but could only compromise by doing clerical work in the Civil Service. But at least it was more varied and demanded more initiative and responsibility than many commercial offices in my home town.

DIFFICULTIES

In fact, it has taken me 15 years to realise I was a round peg in a square hole and do something about it. Even then I came across the usual difficulties of a disabled person trying to enter a profession . . . one accessible occupational therapy school I applied to would not even consider me as a student because I was in a wheelchair.

So, please, if a teenager wants to do a job that few, if any, walking or wheelchair disabled have done before don't dismiss it as impossible. Help them to consider what is physically and mentally essential for the job. Is there any way they can get round, overcome or compensate for the physical problems? Have they the will to succeed and pave the way for others?

With maturity came greater awareness that I needed to be responsible for my own body with its various defects. I had to remember to check for tell-tale red marks after wearing my new pair of shoes, and remember to take the medicine which was prescribed.

When it came to the problem of incontinence, I had to learn to accept this as an integral part of myself and find ways to cope with it—not an easy problem when you know no-one else with the problem. Though not something you shout from the roof tops, I had to come to terms with the fact that it was something I could mention when staying with friends. The need for a plastic sheet on my bed and some means of disposing of wet pads had to be explained.

Over the years I have had to fight the Battle of the Flab—a losing battle I fear. Perhaps if my parents had received some advice on diets when I was a child I could have been encouraged then to enjoy a low calory diet. As it was, I had to learn the lesson later in life.

In secondary school I was given little encouragement to participate in PE classes and usually attended extra classes in an academic subject at this time. It wasn't until I was about 30 years old that I first discovered the enjoyment and physical benefits of paraplegic sport. Later, by training and competing in games (field events and archery mainly) I benefited by being physically much fitter and also *knowing,* for the first time in my life, that anything I won was gained by my own efforts in fair competition and not because someone felt a little sorry for me.

Not every one is a competitive animal, but teenagers with spina bifida could get great benefit and enjoyment from participating in the many activities available to them now.

Maturity also brought with it an awareness of the things others of my age had done or could do. Or perhaps I had a premonition that I would not have my parents for much longer. Anyway I started to set myself challenges:

- to go to the cinema on my own in a nearby town.
- to get my own meal in a self-service restaurant
- to stay for a weekend in a hotel on my own.

Each entailed advance planning to ascertain access etc., and this soon became an accepted part of any outing. I now do it without thinking. In fact, several of my able-bodied friends are getting into the habit as well.

If the spina bifida teenager is to gain the maturity to reach this stage, we come back to the attitudes of the parents. You need the opportunity from your earliest years to be realistically as independent as possible in order to lead an independent life as an adult.

To misquote the words of Sir Ludwig Guttman, talking about the rehabilitation of spinal injury patients:

'Habilitation of the spina bifida person is reached when he or she becomes a tax-payer'—something I hope to be doing again in the very near future.

How they do things in Queensland

ASBAH's patron, HRH The Duchess of Gloucester, visited Australia last year, and Mrs Betty Russell of the Spina Bifida Association of Queensland has sent LINK this photograph of her daughter, Jillian,. who presented the Duchess with a bouquet of Cooktown orchids. Her Royal Highness visited Brisbane to open the new Parliament House.

MRS BETTY Russell, Office Manager of the Spina Bifida Association of Queensland, Australia writes here especially for LINK readers about the association in her part of the world:

"There are great variations in facilities and services from state to state. Some associations function under the umbrella of the State Crippled Children's Society which provides live-in facilities and quite often education facilities for their children.

In Queensland we function as an independent charitable organisation employing two part-time pre-school teachers who run an early intervention programme on a one to one basis for 30 children. We employ two occupational therapists, one full time and the other part time, who works with all age groups and liaise very closely with schools, kindergartens, hospitals and families. Our two social workers are part time and have a fairly heavy work load.

All these salaries are subsidised by the State Department of Education. Other finance comes in the form of donations, bequests and fund raising.

All over Australia the problems of country families are magnified, distances from the main cities are tremendous. Medical care, therapies, and schooling are the initial problems followed closely by travel costs to the cities for treatment, accommodation and of course, employment.

We have a small hostel for country families at our Centre which has been most useful and recently our two main hospitals, Royal Brisbane Hospital and the Mater Hospital have opened units where parents of seriously ill children can stay and, as you can

Continued on Page 14

Growing Concern?

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Will I have to stay in?

The effect hospitals can have on our children

by STEVEN DORNER
Principal Psychologist
at the Wessex Unit for
Children and Parents
in Portsmouth

IT IS only stating the obvious to begin by saying that children with spina bifida and hydrocephalus, particularly when they are young, have to spend considerable periods of time in hospital. Reports from major treatment centres indicate that over half of them will have had five or more admissions to hospital before the age of four.

It is not unknown for a child to need up to 20 admissions, though this is admittedly an extreme case. Often the period spent in hospital may be a matter of weeks rather than days.

As long ago as the 1940's, research began to explore the effects of hospitalisation on children, and important changes aimed at reducing stress as much as possible have occurred since then. Perhaps the most important change was the decision, over 20 years ago, that there should be unrestricted visiting of children in hospital. Nowadays, too, many hospitals do their best to offer mothers of younger children the chance to stay in with their child, a notion that would have been almost inconceivable not all that long ago.

Nevertheless, hospitalisation still causes distress to many children, and many parents reading this article will have no difficulty in recalling the apprehensive question of their child, as yet another hospital visit looms . . . "Will I have to stay in?" Many parents, too, will know how difficult it is to be reassuring, particularly if their child has symptoms that might, or might not, mean immediate admission.

The fact, too, that children with spina bifida and hydrocephalus are often generally fearful and anxious makes the prospect of hospital admission especially worrying for them. Although the reasons for their tendency to be very anxious are not fully understood, early and repeated hospitalisation is probably an important factor as we shall see.

General Psychological Effects of Hospitalisation

Research has shown a typical reaction to hospitalisation with young children. Many (though not all) young children initially show acute distress (the period of protest). Following this comes what is described as the phase of despair (when the child becomes miserable and apathetic). Sometimes one sees an apparent loss of interest in parents, or apparent contentment (detachment).

On return home, the hospitalised child may seem to reject his parents, be difficult, irritable, angry; at the same time he may show clinging, anxious behaviour and be reluctant to let his mother out of sight. It has been shown that emotional distress is most marked in children admitted to hospital between six months and four years of age, and there is some suggestion that repeated admissions increased the likelihood of disturbance, though psychologists are less agreed about this.

Vulnerable

Since it is often in the early years that children with spina bifida and hydrocephalus need hospital admission, it is very likely that they are particularly vulnerable to the distress that hospitalisation creates.

Although school age children are described as adjusting better to hospitalisation, to some extent this has been shown to be affected by the kind of medical and surgical procedures they have to undergo, and there is little doubt that children with spina bifida and hydrocephalus have to undergo a variety of worrying , uncomfortable, complex procedures. One need not be surprised therefore, that hospitalisation is so often associated with distress.

Hospitalisation is not stressful just for the child. A number of studies have described the difficulties for families where the child has to be admitted. There is understandable family anxiety about shunt revisions for example, when a child may have been admitted as an emergency.

Regular visiting may involve worrying expense. Arrangements may have to be made for the care of other children in the family. There has actually been very little research carried out into the effects of hospitalisation on *other* children in the family, though many parents I have seen are aware that their other children often feel left out and have their own private, or expressed worries about what is happening to their brother or sister in hospital.

Ways of Reducing Anxiety

Research has confirmed what seems pretty self-evident on the basis of experience and common sense. Distress *is* much less for younger children who can be admitted with a parent. Distress *can* be reduced by daily visiting, even though one has to acknowledge just how hard this is for some families who may live long distances from the hospital. Where daily visiting is not possible, it is clearly helpful for parents to try to be present immediately before and after a worrying procedure such as an operation.

One point that should be made here is that visiting children in hospital also means leaving them when it is time to go. This can often be distressing since children may begin to cry. However upsetting this may be, in my view it is important to tell the children the truth, rather than pretend as some parents do, that one is just

Continued on Page 14

Hospitals—*Continued from Page 13*

going to get a cup of tea, say in the canteen.

It may be more immediately painful to leave a child in tears, but in the long term, the child learns that their parents can be trusted. In general, goodbye tears do not last all that long. Even where parents sit with their child until they fall asleep, it is important for them to know that their parents will be leaving after a while (but of course coming back on the next or another day).

Sometimes children with spina bifida and hydrocephalus have to be admitted as an emergency, e.g. for a blocked valve. At other times, the date of admission is known some time in advance. Again, in my experience, it is better to give one's child a good deal of advance notice wherever possible, so that anxieties can be expressed in the familiar and reassuring situation of the family and home.

I find it understandable that parents should choose to leave it to the last moment before telling the child about admission, but I am not at all convinced that it really protects the child from their anxiety about hospitalisation. Many sensitive parents I have spoken to later acknowledge that it is probably to protect themselves more than their child.

Explanations

Research suggests that it helps children to have some explanation of what it is that will happen to them once they are in hospital. Older children will, of course, understand verbal explanations though very often they will need the complex medical terminology which they overhear to be translated into simpler language.

Younger children, however, can also be helped by the use of doll or puppet play to explain the process of treatment. It is encouraging to note that doctors and others are becoming increasingly aware of the helpfulness of such preparations.

One of the great advantages of sensible explanation to children is that it helps them to be realistic about the outcome of treatment. Many handicapped children have an entirely understandable "magic" wish, that one day they will be "normal". At the same time, there is a risk that they build up unrealistic hopes. How many children have I seen who have not had adequate explanation of say, an orthopaedic operation and misinterpret what is to happen, as meaning that they will be able to walk normally?

Schemes

Explanation need not shatter hope of which all of us are in need, but it may prevent the disappointment and disillusion that often follows unrealistic expectations, particularly in my experience during adolescence.

Finally hospitals themselves are doing something to alleviate the effects of hospitalisation. There are many schemes involving play leaders, nursery nurses etc., on wards, which do their best to ensure that children have things to play with and things to do when they are in hospital.

Research has shown that hospitalised children are more likely to fret if there is nothing to play with or even, more importantly, *nobody* to play with. One of the most encouraging changes in hospital policy is that this is increasingly recognised.

Film Society for disabled

THE FIRST film society in Britain for disabled people has opened in York. It's called the Grange Film Society and its aim is to ensure disabled people have access to good films at low cost and to encourage those who run film shows and cinemas to consider the number of disabled people who would like to go to their local cinema or theatre, if only it was more easily accessible.

For further information on how to join and of films being shown, contact: Mr Frank Emmett, Flag Office, York Community Council, 10 Priory Street, York. Telephone: York (0904) 38467 or 21133 (9 a.m. to 4 p.m. Mondays to Thursdays).

LINK, in the last issue, carried an article on 'Tests on Valves in Hydrocephalus' by R. J. Brereton. Dr Brereton is, in fact, Senior Surgical Registrar at Alder Hey Children's Hospital, Liverpool, and attached to the Department of Paediatric Surgery at the University of Liverpool. In error, LINK stated that he was with the University of Sheffield. Apologies for any confusion caused.

Queensland—*Continued from Page 12*

imagine, these are in constant use.

Recently, we completed an adventure playground. This was achieved with funds donated by a women's group and a service club and the design and labour came from a team of students from the Mt. Gravatt College of Advanced Education, as an assignment for their course. There is a very large sandpit with a pergola covered with shade cloth—our summers are extremely hot—in the shade of a Tepuana tree, tunnels, mounds, a slippery slide and a log cubby house. This all had a tremendous amount of use when we held Holiday Programme activities for the children.

We are fortunate that we receive funding from the Department of Welfare for these programmes and we are able to employ extra casual staff, recreation officers, and nurses. Our Grammar Schools conduct Community Services, and for two hours each week girls in the senior school are allocated to various charities where they come to assist in any way they can. We are doubly fortunate in that many of these young people return during school holidays to assist in a voluntary capacity.

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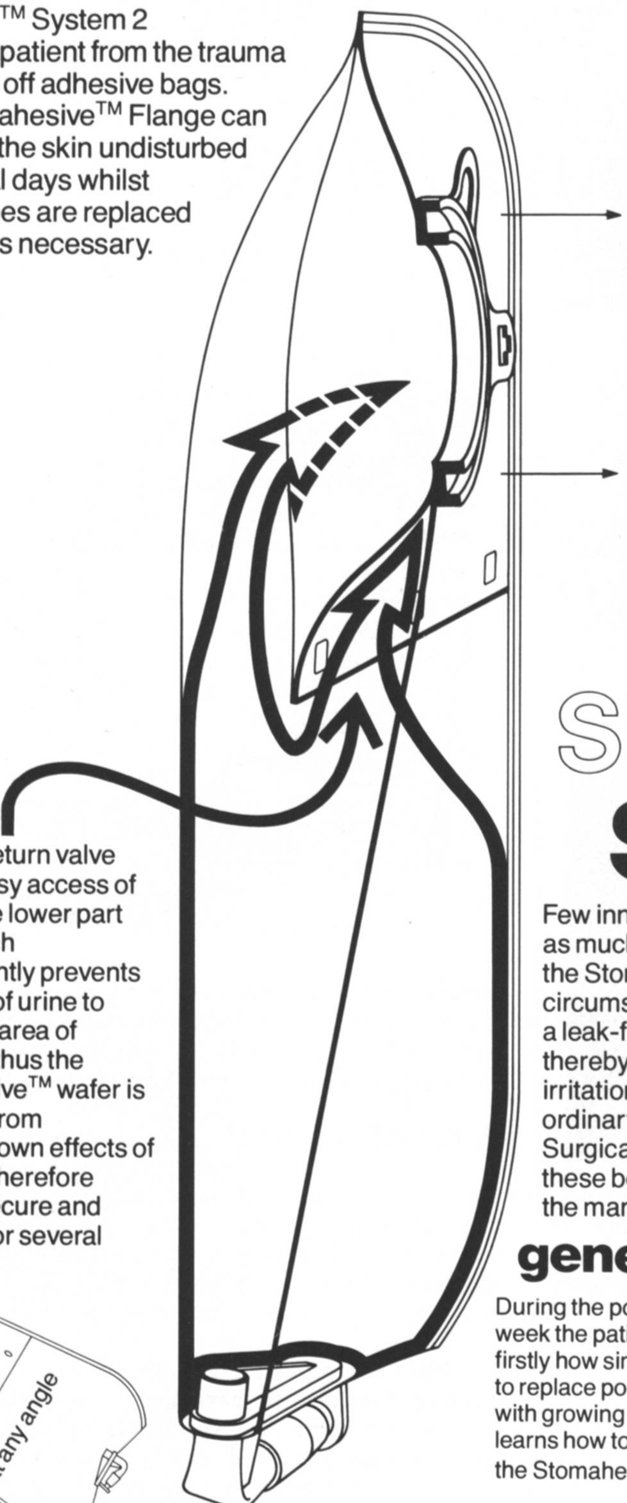

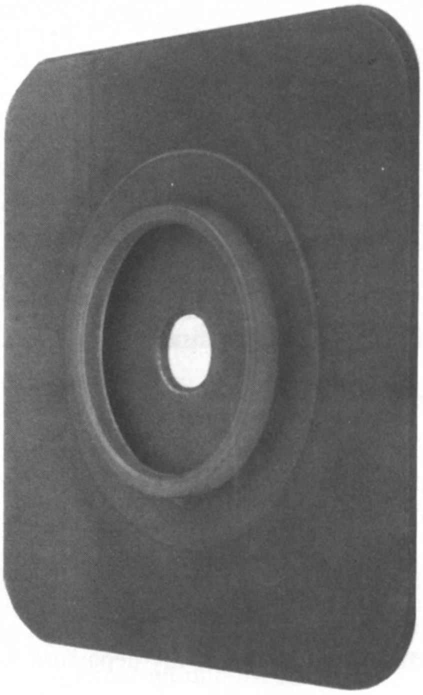

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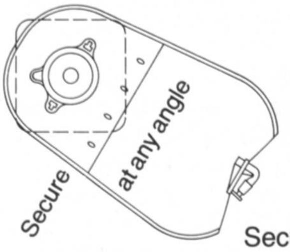

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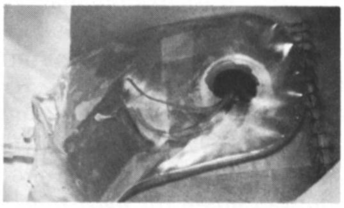

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Susan Seager, 37, of Pickering, Yorkshire, is a wife and a mother. She also has spina bifida and is confined to a wheelchair. Her life has been a struggle against physical handicap and illness (altogether she has spent about five years in hospital), and against ignorance and indifference, but it has been a full and varied 37 years.

LINK is pleased to carry in this issue some of the highlights of her life, taken from a full-length story written by Susan, herself.

Living with spina bifida

. . . for 37 years

"I made my entrance into the world in York in 1942. It must have been a terrible shock for my parents when they were told I had spina bifida. After all, very little was known about this disability in those days . . .

"Whenever possible, my mother took me to see specialists but she was given little hope of any improvement. They usually suggested that it would be a waste of their time doing anything to help me as I was unlikely to survive more than five years. However, one doctor, more adventurous than the others, agreed to see what he could make of me."

"At five years of age, I left home for my first visit to hospital . . . I knew something was afoot and sat watching the preparations for my departure with wary eyes."

Susan as a little girl in hospital

She spent the next three years undergoing many operations and dogged by childhood illnesses at a TB hospital in Kirbymoorside where the wards were open to the elements on three sides.

"Visiting was once a month for two hours so we soon forgot to cry for our parents."

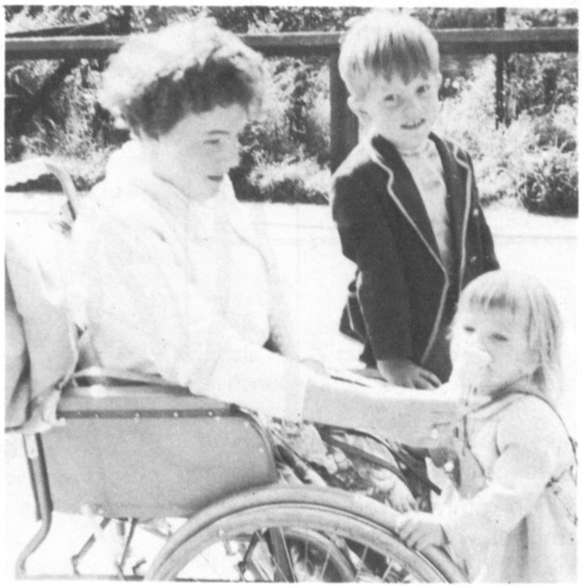
Home for the holiday

After recovering from one operation she was allowed home for Christmas.

"I remember being confused by the many people present who were strangers to me after being away from home for so long. I found I missed the other children and my familiar surroundings, so I wasn't upset when I went back into hospital . . ."

Susan left hospital to go to school at Welburn Hall in Yorkshire.

"Our headmaster believed the most important thing he could teach us was to be independent, and I am grateful to him for this . . .



Growing up

After school it was decided that as she had shown some aptitude for sewing she would go to the School of Stitchery and Lace down in Bookham, Surrey.

A car of my own

"As soon as I was eligible I applied for an invalid car and . . . once I had passed my test I decided to drive home for my next holiday, taking two days over the journey. My first go-it-alone attempt was very successful. I stayed at a hotel in Grantham overnight and arrived home to be greeted with admiration from my family.

"When I had just about completed my three year training, I decided to leave and try my luck at getting work nearer home . . . Now at last, I was going to lead a normal life. Well, that was my intention anyway. I soon found out my mistake. It was one thing to be trained for a particular type of work, but to find employment using that training was another matter . . ."

She was eventually told of a vacancy at Remploy in York . . . knitting endless stumps to be used by people with artificial limbs. It didn't make use of her training, but it was a start. Unfortunately she had to start at 7.30 in the morning and this meant that she had to look for accommodation in York itself.

Somewhere to live

An article in the local paper resulted in an offer of accommodation from a couple called Jim and Joyce. Susan moved in with them and came to regard them as her second family.

Susan applied to go on a three-week holiday in France after reading about it in a magazine, and this gave her the travel bug. In the coming years she visited Belgium, Holland and Denmark.

Down, but not beaten

When she was 21, Susan was again laid low by pressure sores and eventually had to go back into hospital for a skin graft.

"It is amazing and rather frightening how quickly one becomes hospitalised. In a very short time I was quite content with my lot, not even bothering to ask when I could go home. What I had expected to be a short visit began to stretch into a five month stay.

"Then came the day when the surgeon settled down for a heart-to-heart talk which left me speechless. 'I don't think, said he, 'that there is any need for you to go out to work. Why not stay at home and knit, or something?' I was furious. I was out of hospital and home to my parents in less than three weeks."

Susan managed to get a different job, working in the sewing room of Claypenny Hospital. When work started on building some new council bungalows at Easingwold, she applied for one and to her surprise was successful.

"I had always dreamed of having my own home . . . a goal to work towards."

Marriage

"Over the years I had had my share of boyfriends, some serious and some not. One person, though, had moved into and out of my life frequently—his name, John."

Wedding day happiness

In 1974 when they met again, John asked Susan to marry him and she accepted.

"I would like to be able to say that the first few weeks of our marriage were heaven, but it wouldn't be exactly true. I had been my own boss for a long while. Frequently I found I was resenting the demands on my time and privacy. John had the knack of being able to calm me down when I got into too much of a state though . . . he still can, thank goodness . . . and I soon sorted out a routine and was able to settle down and start to enjoy married life.

Proud parents with little Anna

"Towards the end of June I began to suspect that I was pregnant . . . We both wanted a baby and we were sure we could cope with one.

"I knew even before I got married that there was a test to check whether an unborn child has spina bifida . . ."

It revealed that all was well, and Susan's pregnancy continued normally, though in the last couple of months she suffered from swollen legs and blisters. It was also decided that she would have to have a caesarian operation.

At five minutes past eleven on Sunday 15 February, 1976 Anna Marie was born—all 6lb 4ozs of her.

And baby makes three.

"Now I had to learn to look after Anna . . . I soon got the hang of how things were done and it wasn't long before I could pick her up with one hand without either of us having any qualms.

"Bathtime meant carrying a bucket of water into the bedroom to be tipped into the baby bath when all was set up. I sat with the bath on one side of me and an ottoman covered with Anna's changing mat on the other; that way I could reach everything.

"Family outings required some thought but we found that if we balanced the carrycot on our chair arms, put the nearest handle around the neck and held the other in the teeth, it was possible to carry Anna to the car.

"Pushing the pram around the house was easy but we had to find a way to manage outside. We solved the problem by tying a length of cord to the pram handle and fastening the other end to my chair.

"Anna took her first unaided steps on the day she was fourteen months old. I was alone with her at the time and had been watching her carry her toys from one chair to another—the long way round. Suddenly she let go and began to walk backwards and forwards without holding on. I wanted to shout and tell the whole world. Instead I simply sat quietly and watched a small child do something that I would never be able to do myself.

Across the Channel —by parachute!

IN THESE days of space travel and science fiction coming true, there are very few things that one can do that have not already been achieved by someone else, but ASBAH has been lucky enough to benefit from just such a first.

At the beginning of June six members of the Armed Services will parachute jump across the channel! The team, consisting of four men from the Army and two from the Royal Marines, will jump out of a plane 25,000 feet above Dover Castle and glide down to St. Guette on the French coast, just outside Calais.

The jump will take place in the early morning and approximately ninety airliners will have to be diverted in order to clear an air passage. The costs of the event are being paid for by Courages and ASBAH is likely to make in excess of £50,000 as a result of commercial companies sponsoring one or more of the parachutists at a rate of £3 a mile each for each of the 22 miles. At the time of writing the promised income already stands at £10,000 and a team of thirty telephone sales persons are working very hard to bring us the maximum possible return.

As the exact date of the jump will be subject to favourable weather conditions, it is impossible to be precise as to timing, but I have no doubt that you will be hearing more of this exciting project through the national media, in June.

Perhaps we don't need a channel tunnel after all!

Can you milk a cow?

LOCAL Associations have already received letters concerning the Sponsored Initiative which is being backed by Esther Rantzen and organised by Jane Evans, Madeleine Legg and myself.

About 2,000 schools and youth clubs all over England and Wales have been contacted so far and I must thank those Local Associations who have written back to me with information on schools to approach in their areas.

The 'Initiative Tests' take the form of challenges, ranging from spending 30 minutes on a submarine to milking a cow! Participants are sponsored per challenge attempted.

I think the scheme is going to be very successful, especially among school children, and if it is, we shall turn it into a yearly event.

If anyone would like further details please contact Jane, Madeleine or myself.

GARRY LOCKWOOD
Education Appeals Organiser

A jewel of an evening

ON APRIL 16 the Crown Jewel Ball was, once again, held in aid of ASBAH at the Dorchester Hotel in Park Lane.

Our Patron, HRH the Duchess of Gloucester was unable to be with us following the birth of her baby, but we were honoured by the presence of Their Royal Highnesses Prince and Princess Michael of Kent.

The Evening was a great success even though the organisers were a little nervous on hearing that £5 million worth of jewels were on the premises. The jewels were lent by Chaumet, for use in the Fashion Fantasia cabaret spot. Furs and jewellery were paraded by ballet dancers from leading companies and Mr Alan Jay Lerner compered the show to background music from My Fair Lady, which was a fitting tribute to him.

After dinner, guests played Bingo for a top prize of a P and O luxury cruise. The game alone raised £1,300 thanks to the efforts of our toastmaster Mr Bryn Williams.

It is anticipated that the ball will have raised a net profit for ASBAH of £6,000.

Miss Helen Bryant presenting a bouquet to Princess Michael of Kent. Helen was certainly a great social asset that evening and entertained both our royal visitors and the celebrity guests with her lively conversation.

Let's make it a bumper year

AS WE embark upon a new fiscal year all of us concerned in raising funds both at Tavistock Square and around the country are determined to make this a bumper year for ASBAH, this being a matter of necessity as well as a challenge and I hope very much that you will be prepared to back us with your support and encouragement during the months that lie ahead.

JUDY KAY
Director of Appeals

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Adverts for the next LINK (July/Aug) should be in by June 5. Send to the Editor Mrs Susan Gearing (or telephone her on Langton 3351).

HOLIDAY ACCOMMODATION

HEYSHAM, Nr Morecambe: Purpose built 6-berth fully equipped mobile home. Convenient and accessible for the largest wheelchair. Large bathroom. Details: Mrs H. Campbell, 9 Belton Road, Whitchurch, Salop. Tel: Whitchurch 3691.

MABLETHORPE, Lincs.: 2 well-equipped 6-berth chalets, self-contained, at Mablethorpe Chalet Park, Links Road. Details: Mr. B. Guest, 57 Bloxwich Lane, Walsall. Tel: Bloxwich 31725.

MABLETHORPE, Lincs.: Well-equipped holiday chalet, sleeps 6. Colour TV. Details (s.a.e. please): Mrs. G. Foster, 47 Almond Avenue, Lincoln.

MILLENDREATH, Nr Looe, Cornwall: Well-equipped holiday chalet (sleeps 6). Easy access. Details (s.a.e. please): Mr T. Gardiner, 72 Dale Valley Road, Oakdale, Poole, Dorset. Tel: Parkstone (0202) 744873.

WINTERTON-ON-SEA, Nr Gt Yarmouth: 6-berth chalet. Indoor swimming pool, shop, play areas. Details: Mr R. Morris. Tel: High Wycombe 32184.

FOR SALE

Leisure Wear: White cotton **Tee Shirts** with green Family symbol and words 'Support Spina Bifida' £1.60 each size 22″–30″, £1.85 each small, medium, large. Also quality **Sweat Shirts** with reverse colours in all sizes including extra large adults. All at £4.50 each plus postage. From Mrs M. Humphreys, 27 Orchard Way, Holmer Green, Bucks.

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NEW RATES

THE RATES for subscribers to LINK who obtain their copies direct from national office have had to be raised due to the increased postal charges and the recent price rise of LINK to 15p per copy.

The rates now are:

U.K.	£1.85
Europe (surface mail)	£1.75
USA, Canada (surface mail)	£3.85
USA, Canada (air mail)	£8.25
Elsewhere (air)	£4.10

The rates are per annum, and inclusive of postage and packing.

ASBAH booklets etc . . .

Your Child with Spina Bifida, by J. Lorber, MD, FRCP	25p
Your Child with Hydrocephalus, by J. Lorber, MD, FRCP	20p
Children with Spina Bifida at School, Ed. P. Henderson, CB, MD, DPH	30p
The Care of an Ileal Conduit and Urinary Appliances, by E. Durham Smith, MD, MS, FRACS, FACS, and others	15p
Aids and Equipment	60p
Sex and Spina Bifida by Bill Stewart	£1 (75p to LIFT members)
The Handwriting of Spina Bifida Children by Joan Cambridge and Elizabeth M. Anderson ...	£1
The Nursery Years by Simon Haskell & Margaret Paull	35p
Information leaflets	100 for £1.30

All available from ASBAH, Tavistock House North, Tavistock Square, London WC1H 9HJ. (Special rates available to Local Associations.) Please note that postage is extra. Allow minimum of 15p per booklet.

Scottish Spina Bifida Association Booklets

Growing up with Spina Bifida	30p
The Spina Bifida Baby	30p

both by O. R. Nettles, McSP, ONC.

Available from: The Scottish Spina Bifida Association, 190 Queensferry Road, Edinburgh EH4 2BW (at special rates for bulk orders).

FUND RAISING AND PUBLICITY MATERIAL

Posters

Best Foot Forward 20 × 30 in.	**10p each**
Best Foot Forward 15 × 10 in.	**10 for 40p**
For local publicity 15 × 10 in.	**10 for 40p**
Car Stickers	**2p each**
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All available from Appeals Dept.—postage extra.

Film 'Appeal for ASBAH' 10 mins 16 mm Colour/Sound	**£4 Hire**

The Appeals Dept. carries a range of fund-raising items, i.e. pens, key rings, kits, games, etc. Send for list and order form.

Flag Day equipment can be obtained direct from: Angal, 48a Holmbush Road, London SW15 3LE (01-788 5464).

FREE SERVICE

THE DISTRICT Advertising Company of EMI Elstree Studios, Shenley Road, Boreham Wood, Herts. WD6 1JG, offers a special service to Charities. They produce Telephone Address & Notebooks. These are a unique way of raising funds, also Fundraising Charts with Socks attached for Donations. These also help promote your cause and recruit new members, and are displayed in public houses, restaurants, on factory notice boards and other prominent places. Calendars, Diaries and Programmes for Fetes, Donkey Derby's, Bazaars, Charity Football Matches, etc., can also be obtained, all completely free of charge. For further information contact: Mr J. A. Alter at the above address or tel: 01-953 1600 Ext. 171.

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