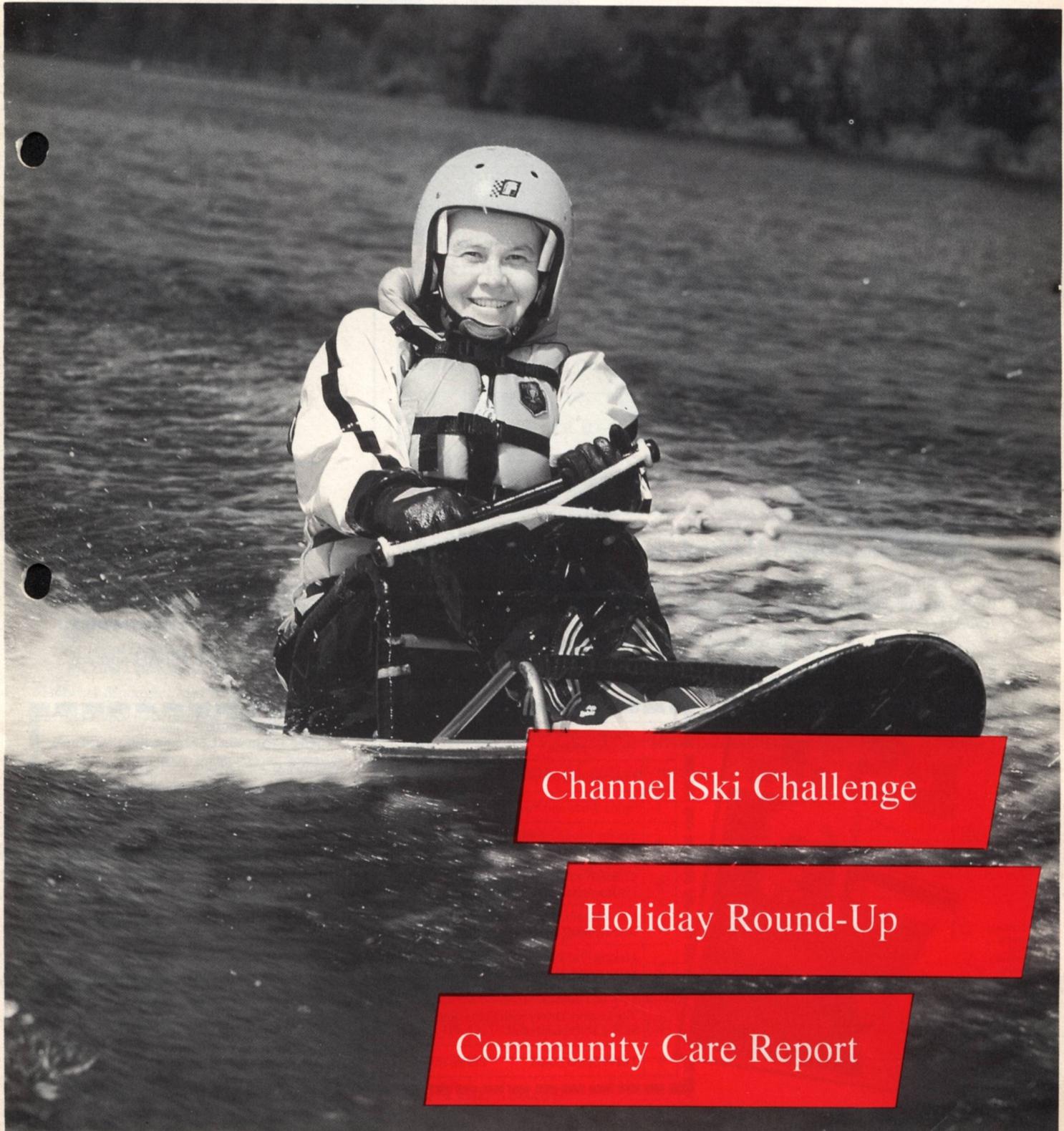


February 1990 No. 126 30p

The magazine for people with spina bifida and/or hydrocephalus

# Link

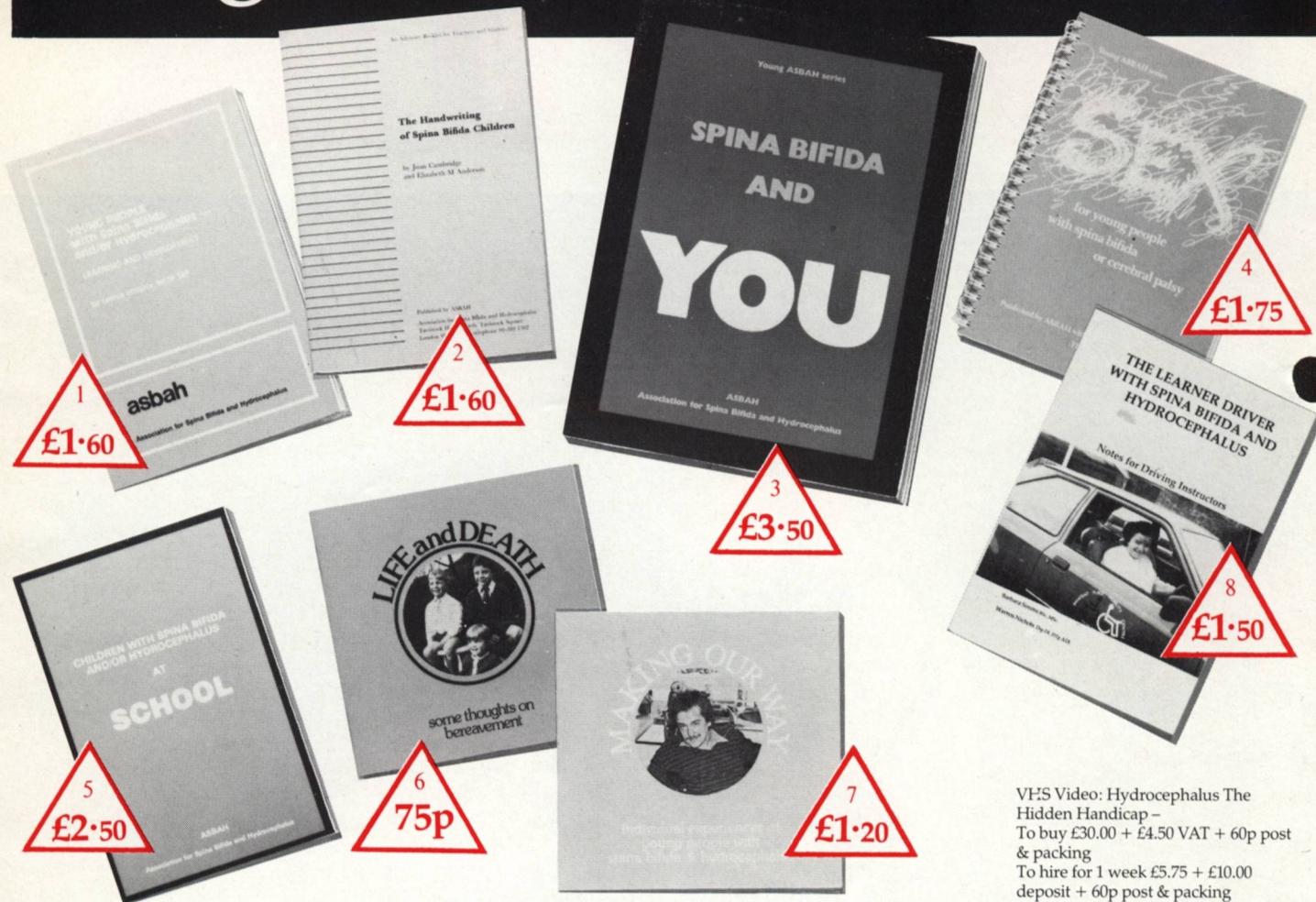


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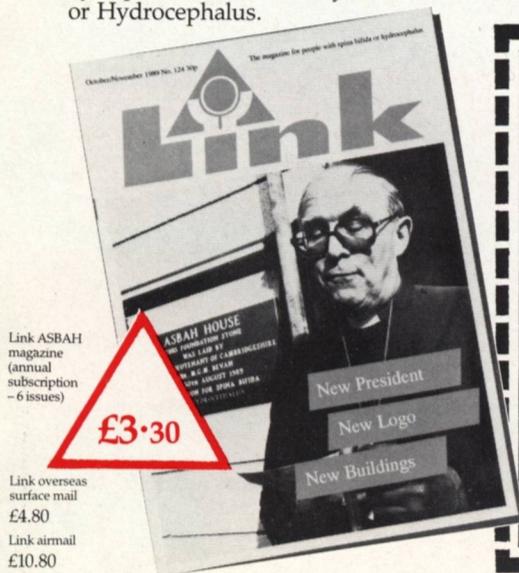
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FEBRUARY 1990

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**Cover Picture:** 23 year old Denise Smith, international swimming champion and medallist. Photograph: Richard Ansett courtesy *You Magazine*.

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## HOLIDAYS AT HOME OR ABROAD

### Los Christianos—an accessible resort

**L**os Christianos in the south west tip of the Canary Island Tenerife used to be a quiet fishing harbour. Today, with the clear blue sea strumming against the rocks, the resort has an appeal for tourists from all over the world. Cafés beckon at every corner. Specially selected photographs of culinary expertise entice the tourist and remove the language barrier. Food is beautifully decorated with flags and umbrellas whilst ice-cream arrives lit with sparklers.

Once the harbour lights burn low, live entertainment begins with a mixture of comedy and music, which often leads to dancing in the streets and every café has its own style of entertainment. Traders just arrived from Morocco invite innocent tourists to purchase anything from jewellery to wooden elephants or toys to tempt the youngsters.

Hidden a few streets back from the sea-front along a quiet pathway is the Mar y Sol Hotel. To date the complex boasts that it is the only fully accessible apartment style hotel in Europe for people with



Photographs: Paul Loosely

disabilities. It is constructed in a square around three swimming-pools, with a mixture of 240 studios and apartments although not all overlook the recreation area. One of the pools is heated and has hydrotherapy massage fountains that can pummel away at tired muscles, whilst a hoist encourages everyone to enjoy the fun in and out of the water.

The apartments can be bought outright, or on a co-ownership basis for a minimum of four weeks per year, or simply rented for holidays. They are tastefully designed and furnished with cane and floral patterns. Wherever possible natural materials have been employed. Doors are all extra width for wheelchair accessibility and the balcony which is reached via a gentle slope also has a table and chairs. Each apartment consists of a twin bedded room, as well as a main living area with a settee which doubles as twin sofa beds, to accommodate up to four persons. The dining-room table and chairs, a kitchen unit with refrigerator, cooker and sink unit with cupboard space are also situated in the living-room. The bathroom is fitted with hand rails and has both a shower and bath, a wash-basin and WC. (Wash-basins and cooking facilities are not height adjustable.)

Le Ro, a separate company under the umbrella of Mar y Sol, supply, at extra cost, hoists and wheelchairs as well as bathroom adaptations.



Le Ro also operate a small coach which is fully accessible and offers transfers to and from the airport. It has only been more recently that Le Ro have been allowed to meet individuals with a disability as they arrive on the other side of customs.

Under the supervision of a State Registered Nurse Le Ro offers 24 hour medical and personal care. Prices vary depending on whether you require injections or assistance with dressing. Their facilities are extensive and a comprehensive list is available on request. A doctor visits the site twice a week for consultations. The Mar y Sol Hotel is an ideal choice if one member of the family were to have a disability and/or require some extra health treatment. Each apartment is fitted with an emergency cord and alarm light system and there is a hospital nearby.

SolarMed is the third company on site under the umbrella of Mar y Sol. Here guests are offered an individually tailor-made health, fitness and physiotherapy programme. A Finnish sauna, group gymnastics or a massage are just some of the excellent but expensive extras on offer. A massage costs approximately £16 for a 30 minute session but is well worth the treat.

Mar y Sol boasts an international clientèle and an ability to speak English. Most of the guests come from Germany and a lot of the information material is written in that language.

You could spend an entire vacation within the grounds of the Mar y Sol with the pool side bar offering refreshments and a daily menu. The complex is still under construction and shops as well as squash courts and a larger restaurant are planned to open within six months.

Los Cristianos has considered and incorporated the access needs of people with disabilities within the design of the growing resort. Only the sandy beach does not have a

**Here is a useful directory of companies and voluntary organizations who specialize in holidays to suit people with a disability.**

**Accessible Travels**

13 St Paul's Square, Birmingham B3 1RB. Tel: (021) 233 0055

This tour operator has reserved wheelchair-accessible hotel rooms for their clients and can give access information on 100 hotels in Spain, Balearic Islands and Canary Islands.

**Assistance Travel Service**

1 Quarry View House, Tank Lane, Purfleet, Essex RM16 1TA. Tel: (0708) 863198

Organises tours to Florida and throughout the United Kingdom. Keen to help families with a disabled member.

**British Ski Club for the Disabled**

c/o Hubert Sturges, Springmount, Berwick St John, Shaftesbury, Dorset SP7 0HQ. Tel: (0747) 88515

Organises skiing holidays to the Alps and Norway as well as dry ski slope sessions in the United Kingdom.

**Carefree Holidays**

64 Florence Road, Northampton NN1 4NA. Tel: (0604) 34301 or (0604) 30382

Arranges holidays to venues with easy access. Specializes mainly in the United Kingdom but can offer holidays by air to Tenerife, Minorca and Canada, as well as coach holidays to Switzerland and Berlin.

**Chalfont Line**

4 Medway Parade, Perivale, Middlesex UB6 8HA. Tel: (01) 997 3799

Arranges tours to Europe, America, Hawaii and Egypt in specially adapted coaches.

**Churchtown Farm Field Studies Centre**

Lanlivery, Bodmin, Cornwall. Tel: (0208) 872148

A centre belonging to The Spastics Society providing adventure holidays for children and adults.

**Country Holidays**

Spring Mill, Earby, Colne, Lancashire BB8 6RN. Tel: (0282) 445566

Also Disabled Person's Helpline manned from 9.00 am to 5.00 pm on (0282) 445340. Have a range of self-catering properties in the United Kingdom.

**Disaway Trust**

2 Charles Road, Merton Park, London SW19 3BD. Tel: (01) 543 3431

Arranges a limited number of holidays in Britain, Corfu and the Holy Land. Can provide helpers—volunteer helpers are welcome.

**Homeshare Holidays**

3 Main Street, New Elgin, Moray IV30 3BQ. Tel: (0343) 48118

Will arrange home exchanges for both tenants and home owners to destinations throughout the United Kingdom as well as Europe, Canada and America. There is a reduction in price for people with a disability. A brochure is available.

**John Grooms Association for the Disabled**

10 Gloucester Drive, Finsbury Park, London N4 2LP. Tel: (01) 802 7272

Has a wide selection of hotel and self-catering accommodation in England and Wales. Can also make reservations at reduced prices for wheelchair-accessible rooms at the London Tara Hotel.

ramp, but can be negotiated via a couple of steps. Some of the streets are narrow and steep in parts of the old fishing port but there are ramps throughout the town. Walkways are even and the promenade is easily negotiated. As one guest suggested "whilst many British towns, cities and resorts have not woken up to the needs of people with disability, in Tenerife the yawning is over and people with disabilities are being made welcome." There are several supermarkets near the complex where you can purchase daily provisions. Eating out though can be less expensive and a cheaper option to self catering.

Le Ro also organise excursions within the island. The north of Tenerife is far richer and greener in foliage than the south, with banana plantations, orange groves and vines on the terraces at the foot of the mountains.

A day trip is recommendable, and car hire reasonably priced if you fancy going it alone. There do not seem to be any local companies offering cars with hand controls, so unless you drive a conventional vehicle perhaps an excursion would be a better option. Book your car early and try not to travel between noon and about 2.30 pm to avoid the hottest part of the day.

It seems that every village on the island is in the process of building new homes and apartment blocks for tourists. The coast of Tenerife is a maze of concrete just waiting for holiday makers and the distinct aroma of their sun-tan lotion. Foliage in the south of Tenerife is sparse on the exposed volcanic rock bed. Palm trees stand like soldiers in the still air. Cactus plants cling to the crevices in the rocks and offer for admiration their startling deep purple, red or yellow flowers.

As you leave the sunny coast and climb the steep winding road you reach the light mist of the mountains and the air becomes cooler and fresher. Los Cristianos with its allergy-free healing climate and

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**Jubilee Sailing Trust**

Test Road, Eastern Docks, Southampton SO1 1GG. Tel: (0703) 631395  
Voyages in traditional sailing ship for crews of mixed physical ability starting from UK and European ports and the Canary Islands. No experience is required.

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**Kielder Adventure Centre**

Kielder Water, Hexham, Northumberland NE48 1BS. Tel: (0434) 250232  
The Centre is accessible to people in wheelchairs.

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**National Trust**

36 Queen Anne's Gate, London SW1H 9AS. Tel: (01) 222 9251  
As well as easy access to all their properties, they also have adapted self-catering accommodation in Cornwall, Isle of Wight, Lake District and Yorkshire. Publish a free booklet *Facilities for Disabled and Visually Handicapped Visitors*.

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**Park House Hotel**

Sandringham King's Lynn, Norfolk PE35 6EH. Tel: (0485) 543000  
Run by the Leonard Cheshire Foundation and suitable for people with disabilities. Financial assistance may be available.

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**Project Phoenix Trust**

68 Rochfords, Coffee Hall, Milton Keynes MK6 5DJ. Tel: (0908) 678038  
Are organising two study tours in 1990. The first is to Belgium by special coach in August; the second by air to Spain in September.

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**Sailability**

Ian Harrison, 16 Church Road, Wanlip, Leicester LE7 8PJ. Tel: (0533) 677138  
Promotes recreational and competitive sailing for people with disabilities. Opportunities for sailing in large or small boats, either on inland waters or on the coast.

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**Sportstart Holidays**

British Paraplegic Sports Society, Ludwig Guttman Sports Centre, Aylesbury, Bucks HP21 8PP. Tel: (0296) 84848  
Organises short low-cost holidays at the purpose-built sports centre, with a large number of sports available.  
Although aimed mainly at those with recent spinal injuries, people with other disabilities are welcome.

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**Stackpole Trust Centre**

Home Farm, Stackpole, Pembroke, Dyfed SA71 5DG. Tel: (0646) 81425  
Self-catering holiday centre providing holidays for people with a disability.

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**Threshold Travel**

80 Newry Street, Banbridge, Co Down, BT32 3HA. Tel: (08206) 23954  
Arrange holidays to Florida, Malta, Portugal and Tenerife as well as Ireland. All accommodation is fully accessible.

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**Venture Caravan Park**

Langridge Wsy, Westgate, Morecambe, Lancashire LA4 4TQ  
Tel: (0424) 412986  
Has two caravans which are accessible to wheelchair users.

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**Winged Fellowship**

Angel House, 20-32 Pentonville Road, London N1 9XD. Tel: (01) 833 2594  
Run purpose-built holiday centres in Essex, Nottingham, Southport and Surrey, as well as organising holidays overseas. Can provide helpers—volunteer helpers always welcome.

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lack of insects encourages one to return to its sandy beach, the street traders and cafe life, where you can eat drink and be merry, or just watch the world go by.

If you were thinking of going to Tenerife, and like the sound of the facilities of Mar y Sol, then a studio for two will cost about £15.00 per person per night with a £5.75 single supplement. An apartment for four is £21.00 per night for the first two people and £18.50 per night for the third and fourth people.

For further information please contact Lynne James, 7 Overpool Road, Ellesmere Port, LL66 1ZW. Tel: 051 39 5316, who can also arrange flights.

### Major tour operators making special provision for people with disabilities include:

#### Charity Link Holiday Service

Retail Travel Ltd, P.O. Box 44, Peterborough PE1 1JF. Tel: (0733) 555225

Launched by Thomas Cook and works with major tour operators to help clients on an individual basis to find suitable accommodation both in the United Kingdom and overseas.

For every booking made through the scheme, Thomas Cook will make a donation direct to a chosen disability organisation.

#### Thomson Holidays

Greater London House, Hampstead Road, London NW1 7SD. Tel: (01) 387 9321

Their Client Welfare Department is happy to deal with enquiries. Most resorts have accommodation suitable for people with a disability.

## STOP PRESS STOP PRESS STOP PRESS STOP PRESS



Mr James McKinnon recently joined The Disabled Living Foundation (DLF) as Director. The DLF was founded 20 years ago by Lady Hamilton and has grown to be the leading National Information resource on disability with an enormous fund of experience and expertise.

### Calling All Playwrights

GRAEAE, the only professional theatre company of disabled people in the United Kingdom, would like to perform work written by disabled people. So if you are disabled and write drama and would like your work

to be considered, or would like to learn how to write scripts, please contact Graeae Writers Project, 10 Woad Lane, Great Coates, Grimsby DN37 9NH before April 1990.

### Start Saving for Sweden

The 6th International Congress organized by the International Federation for Hydrocephalus and Spina Bifida will be taking place between 14-18 August 1991 in Stockholm. The Congress will be held at the PTK Training Centre in the beautiful Archipelago of Stockholm. This is an ideal opportunity not only to exchange knowledge but also to organize a family holiday. A special camp programme will be provided for children and young people.

Further information: Congress Secretariat, RBU, David Bagares, gata 3, S-111 38 Stockholm.

The new British Rail leaflet offering information to disabled travellers, including station addresses, itinerary services and fare facilities has now been published and should be available at most mainline stations or through an ASBAH Fieldworker.

### Come Dancing

Since 1968 when wheelchair dancing began, it has spread throughout the country. The Wheelchair Dance Association has over 2,500 members who span from Scotland to Cornwall, whilst Holland and Hong Kong have their own teams. Some fifty new dances, from ballroom to disco, are created each year.

If you would like to join an existing team or form your own, all you need is a cassette player and a reasonably sized room. Scripts and cassettes can be supplied.

For more information contact either Mr Dave Phillips, 70 Cherwell Road, Westoughton, Bolton BL5 3DX (Tel: 0942 815193) or Mr Les Catlow, 25 Essex Avenue, Heap Bridge, Bury BL9 7JD (tel: 061 764 8508).

The Midland Association are collecting petrol vouchers, Green Shield Stamps, Co-op Stamps, money-off coupons, foreign coins or notes. Please send any of the above to Mrs McCabe, 14 Court Road, Sparkhill, Birmingham.

## COMMUNITY CARE—THE NEXT DECADE

The long awaited White Paper on Community Care was finally published towards the end of November. Less than one week later its proposals were incorporated into the National Health Service and Community Care Bill giving no time for consultation or comment on the contents of the White Paper.

The voluntary sector has generally criticised the government's proposals for community care as being full of the right rhetoric but failing to provide the mechanisms and resources to deliver appropriate services. The Bill itself gives very little substance to the proposals which will mainly be introduced under directions from the Secretary of State. There is considerable pressure on the government to ensure adequate debate is given to their proposals for community care. During the second reading debate on the Bill the Secretary of State for Health gave no coverage to this part of the Bill, concentrating entirely on the proposals for the NHS. It is evident that detailed consideration needs to be given to many aspects of the government's proposals and it is hoped this can take place during the Bill's committee stage.

**In the first of a series of articles on the government's proposals, Fidelity Simpson outlines the contents of the White Paper 'Caring for People'.**

The government outlined six key objectives in their White Paper 'Caring for People—Community Care in the Next Decade and Beyond'

1. to promote the development of domiciliary, day and respite services to enable people to live in their own homes wherever feasible and sensible;
2. to ensure that service providers make practical support for carers a high priority;
3. to make proper assessments of need and good case management a cornerstone of high quality care;
4. to promote the development of a flourishing independent sector alongside good quality public services;
5. to clarify the responsibilities of agencies and so make it easier to hold them to account for their performance;
6. to secure better value for tax-payers' money by introducing a new funding structure for social care.

Good community care, as far as the government is concerned, means providing the right level of intervention and support to enable people to achieve maximum independence and control over their activities. The White Paper dwells on the contribution of carers and states that helping carers is both right and a sound investment.

Help may take the form of providing advice and support as well as practical services. The government recognises that some people will continue to need residential or nursing home care but for those who live in the community the primary health care team will have a vital role to play. The government recognises that there are significant variations in need between different groups of people and wishes to

promote particular priorities for elderly and disabled people and people with a mental handicap. The Paper states that community care should not be seen as the prerogative of public services; that people like to take responsibility for their own needs wherever possible; and the thriving voluntary sector and the rapidly growing private sector should be encouraged.

The government wishes Social Services Departments to have the following key responsibilities:

1. carrying out an appropriate assessment of an individual's need for social care (including residential and nursing home care), in collaboration as necessary with medical, nursing and other caring agencies, before deciding what services should be provided;
2. designing packages of services tailored to meet the assessed needs of individuals and their carers. The appointment of a 'case manager' may facilitate this;
3. securing the delivery of services, not simply by acting as direct providers, but by developing their purchasing and contracting role to become 'enabling authorities';
4. establishing procedures for receiving comments and complaints from service users;
5. monitoring the quality and cost effectiveness of services, with medical and nursing advice as appropriate;
6. establishing arrangements for assessing the client's ability to contribute to the full economic cost to the local authority of residential services.

To discharge these responsibilities each local authority will need to ensure that it has in place an integrated system for assessment and decision making within a clear budgetary framework.

### Assessment

The government proposes that the responsibility for ensuring that an assessment is made should be a specific duty of the local authority. This does not mean that other agencies should be excluded, nor that local authorities can or should make decisions on services managed by other agencies. A single individual should be responsible for ensuring that each case is dealt with effectively.

There are a number of ways in which an individual may seek help, for instance he or she may apply for local authority home care services or may request services under the Disabled Persons (Services, Consultation and Representation) Act 1986. Local authorities should aim to provide a common process for all these situations.

Local authorities should make public criteria of eligibility for assessment and the way in which their assessment processes will work. Assessments will have to be made against a background of stated objectives on priorities determined by the local authority. Priority must be given to those whose needs are greatest and decisions on service provision will have to take account of what is available and affordable.

### **Case management**

Where an individual's needs are complex or significant levels of resources are involved, the government sees merit in nominating a 'case manager'. The case manager will often be employed by the social services authority, but this need not always be so and he or she will take responsibility for ensuring that individual's needs are regularly reviewed, resources are managed effectively and that each service user has a single point of contact. The government thinks a range of backgrounds from which the case manager should be drawn could be possible, although social workers, home care organisers or community nurses may be particularly suitable. The government sees advantage in linking case management with delegated responsibility for budgetary management.

Social services authorities will be expected to indicate in their community care plans how they propose to apply case management techniques and develop clear budgetary systems.

### **Securing the delivery of services**

The government expects social services authorities to take all reasonable steps to secure diversity of provision, and that use should be made wherever possible of services from voluntary, 'not for profit' and private providers so far as this represents a cost effective care choice. The government envisages that the statutory sector will continue to play an important role in backing-up, developing and monitoring private and voluntary care facilities, and providing services where this remains the best way of meeting care needs. Local authorities will be expected to make clear in their community care plans what steps they will be taking to make increased use of non-statutory service providers. The government has decided against extending compulsory competitive tendering to social care services. It will be essential for local authorities to develop purchasing systems for private, residential and nursing home care.

### **Quality**

Authorities should establish procedures for receiving comments and complaints from users of services and these should be publicised. Local authorities will be expected to retain the ability to act as direct service providers if other forms of service provision are unforthcoming or unsuitable.

### **The voluntary sector**

The government will expect public funding agencies to develop an increasingly contractual relationship with the voluntary bodies they fund. The voluntary sector should be involved at an early stage in negotiation over the content of the contract. It will be important to allow scope for the emergence of large well established voluntary bodies. For both these purposes, health and local authorities may continue to make grants towards the administrative expenses of voluntary organisations.

### **Housing and community care**

Social services authorities will need to work closely with housing authorities, housing associations and other providers of housing to develop a plan for a full and flexible range of housing. Where necessary, housing needs should form part of the assessment of care needs and the occupational therapist may have a key role here.

### **Domiciliary and day care services**

Recent work undertaken by the Social Services Inspectorate has revealed considerable variations in the level of resources allocated to homecare services and poor targeting of available resources. There is great scope for establishing a clear policy framework and guidance for resource use and for increasing the provision of more flexible and intensive personal care services for people who would otherwise require institutional care. Growth should be stimulated in the independent sector by delegation of responsibilities for resource management to local level and the encouragement of tendering for certain services.

### **Residential and nursing home care**

From April 1991 local authorities will be responsible, in collaboration with health care professionals, for assessing the needs of new applicants for public support for residential or nursing home care. Social services departments will be expected to make maximum possible use of independent providers of residential and nursing home care. There will be no nationally set limits to the level of fees which may be met by local authorities who will negotiate with local providers of such care. Authorities will be required to assess the ability of each individual to contribute towards the cost of the care they will be receiving.

### **Roles and responsibilities of the health service**

Health authorities will continue to be responsible for community health services and ensuring that discharge procedures are in place and agreed with the local authority so that people can return home with the support they need. They will be expected to make the necessary contribution to assessments carried out under the responsibility of social service authorities and to prepare plans (which will be public documents) setting out their community care policies and the provision they intend to make for community services and community care.

The government recognises that community nursing services will be essential in future and sees community nurses making the following contributions: in assessment procedures; the development of care arrangements; and the provision of care once a package of services has been designed. Health authorities will retain the responsibility for providing care for people who cannot be supported in their own homes and will work with local authorities to develop comprehensive and compatible arrangements for the care of discharged patients. Health authorities may continue to offer lump sum payments or continuing grants to local authorities or voluntary organisations in respect of people moving from hospital to community care.

## ACHIEVING HIGH STANDARDS OF CARE

### Local authority community care plans

Local authority care plans should enable social services authorities to carry out the following:

1. set out strategic objectives and priorities and set specific targets in collaboration with relevant agencies;
2. take account of the needs of people who have been in hospital a long time and need help to re-establish themselves away from large institutional settings;
3. assess other local needs, taking account of the results of assessments in individual cases;
4. organise their move away from the role of exclusive service provider to that of service arranger and procurer;
5. ensure that service arrangements respect and preserve individual independence, include adequate quality control systems, offer freedom of choice and provide services in a sensitive and responsive way;
6. monitor performance and inform the public.

Authorities should consult with and take account of the views of private and voluntary sector service providers and representatives of service users and carers in drawing up their plans which should be public documents intended to communicate an authority's policies and plans to the widest possible audience in as straightforward a manner as possible.

### Inspection of residential care and nursing homes

Local authorities will be responsible for establishing independent inspection units for residential care homes. The Social Services Inspectorate will also be strengthened to advise and monitor social services departments in setting up and operating their own registration and inspection units.

## COLLABORATIVE WORKING

The government believes its aims for the NHS and its proposals for community care no longer fit in well with the mechanics of joint planning and joint finance, and the government will be reassessing the part played by joint finance.

### The new context for collaboration

The government proposes that collaboration of health and social services authorities will be based on the increasingly important distinction between the purchase and provision of health and social care; and accountability for budgetary decisions. It is envisaged that health and local authorities will need to decide locally about how they share objectives, responsibilities and funding of different services. There will be scope for the private sector and voluntary agencies to offer 'mixed' health and social care services. Service providing agencies will be accountable to buying authorities through contractual agreements.

### Services for people with a mental illness

Three key initiatives are proposed to improve the provision of community services to mentally ill people:

1. As from 1 April 1991 all district health authorities will be required to have instituted, in collaboration with social services authorities, a care programme for mentally ill people.
2. Regional health authorities are being asked to identify sites where partnership with the private sector could enable earlier provision of new forms of service. For instance, an envisaged possible solution is for authorities to enter into agreements with developers to build community facilities for those with a mental illness in return for vacated mental illness and mental handicap hospitals.
3. The government proposes to make a specific grant to social services authorities from 1991/92 to increase the social care available to people with mental illness. Separate guidance will be issued in due course on the size, distribution and monitoring of the grant.

The government does not intend to implement section 7 of the Disabled Persons (Services Consultation and Representation) Act 1986. The need to do this will be reconsidered in the light of several years' experience after the introduction of the specific grant.

## RESOURCES FOR COMMUNITY CARE

### The government's proposals for funding residential and nursing home care

The government proposes to introduce a single unified budget to cover the costs of social care, whether in a person's own home or in a residential care or nursing home. The new budget will include the care element of social security payments to people in private and voluntary residential care and nursing homes. Local authorities will be responsible for managing this budget and making best use of funds available in the light of an assessment of an individual's needs. Consequential changes will be made to the way in which Income Support is paid to people in residential care and nursing homes.

### Funding for local authorities

The government will transfer to local authorities the resources which it would have otherwise provided to finance care through social security payments to people in residential and nursing homes. The transfer of funds will be phased to reflect the declining proportion of residents in independent homes previously eligible for income support who continue to be supported entirely by social security and the aggregate amount of transferred resources will allow for the projected growth in the numbers of people needing support. Final decisions on resource issues will be taken in next year's Public Expenditure Survey following discussions with local authority associations.

The additional provision for local authorities will be distributed through the Revenue Support Grant taking account of the Standard for Suspending Assessment for the Personal Social Services. Health authorities will continue to fund mainstream community care activity from within their overall allocation of resources.

### The social services workforce

Social service authorities will need to review their training strategies for all sections of their workforce in the light of the White Paper's proposals. The government has begun to develop a programme of training improvements.

### Help from social security

The government intends to preserve the present scheme of special Income Support limits for existing claimants who are in residential care and nursing homes when the new funding structure is introduced on 1 April 1991.

The funding of respite care is affected by the new arrangements only in so far as it is currently provided through Income Support. Future arrangements for funding respite care will need to reflect the primary responsibility of local authorities in facilitating and funding it as part of the package of care.

### Attendance allowance

The proposed changes in funding community care will not alter the present arrangements for paying attendance

allowance to people in private households or to people who go into independent residential or nursing homes without any other assistance from public funds (other than state benefits). The transfer to local authorities of responsibility for assisting with the care costs of residents in independent homes will however require a change in the current rules intended to prevent double provision. After 1 April 1991 attendance allowance will not be paid to residents in independent homes who are assisted by the local authority. This rule will not make any difference to the resident's entitlement to attendance allowance which can be activated once a person leaves residential care.

### Independent living fund

The government says there would clearly be an overlap between the independent living fund and the intended responsibilities of local authorities which would need to be reviewed.

*Community care proposals for Scotland and Wales are outlined separately but reflect those above.*

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## DENISE SMITH—SHE'S GOING TO SKI THE CHANNEL

**H**er legs are useless and she can't feel her arms but she's going to ski the Channel—both ways.

"But she's only got spina bifida"! The exasperated cry is followed by a muttered "and some stupid doctor has said she can't water-ski". Now, to most people, spina bifida would be a perfectly acceptable reason for not attempting to play table tennis let alone be pulled behind a speeding boat on a narrow plank. Clearly they haven't met Denise Smith.

"It's just life. It's an achievement, nothing more nor less. You could do the same. I just think you've wasted your life. But that's your problem." And she scoots off to sort out why some doctor is creating such a fuss over a spina bifida problem.

We are at Heron Lake near Staines, the national training centre of the British Disabled Water Ski Association, where 34-year-old Denise is a qualified volunteer instructor.

Having contracted polio at the age of

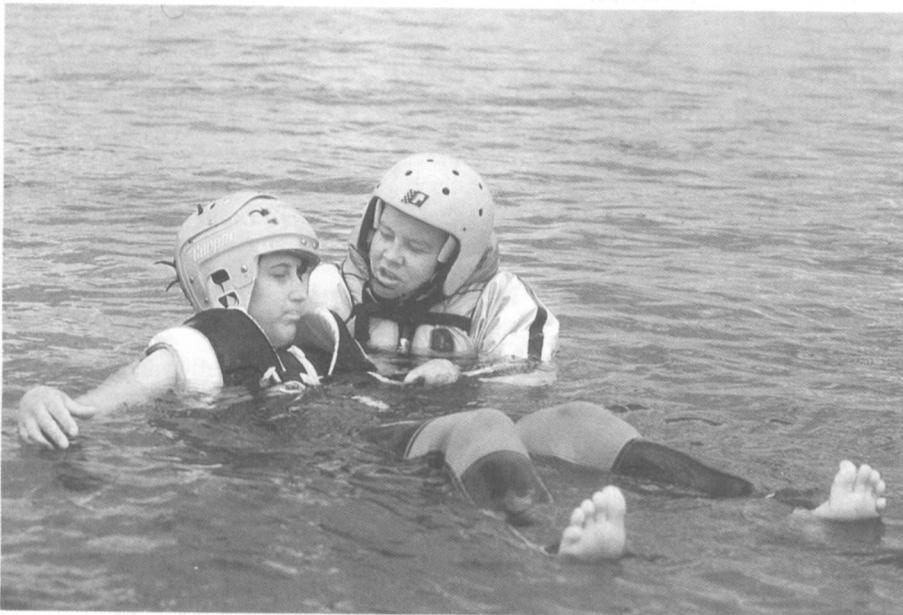
At the next Olympics she collected a treasure trove of swimming medals, then thought winter sports might be a bit of fun and went on to scoop up armfuls of medals for skiing, downhill luge and speed-skating at the following winter Olympics and world championships. In 1986, someone suggested water skiing. . . she was the first, and current, ladies' world champion despite the fact that she managed to break her neck last year while snow skiing so she now has no feeling from the neck down.

After the accident, the first thing she asked was how soon she could get back to skiing. "Well," she says briskly as though it were a perfectly reasonable question in the circumstances, "I was skiing across the Channel in a few months' time and needed to get my training in." (Only one way on that occasion.) "The doctors thought I was mad but I thought as they'd made a good enough job of putting me back together it was such a waste if I didn't make use of it." The one concession she has made—and she makes it clear it's done reluctantly—is to wear a life jacket that has a special high collar to protect her neck.

Denise skis, sitting down, on what looks like a surf-board. Suggest this is nothing more than sledging on water and hardly as skilled as real water skiing and she invites you to think of that limp feeling when you've sat awkwardly on your legs and they've gone to sleep. Then imagine your whole body feels like that yet, somehow, you've got to balance yourself on a narrow piece of wood without any idea where your centre of gravity is.

"You've also got reduced muscle strength in your arms—you only know what they're doing by looking at them—and you're only able to grip the bar because you're wearing a pair of gloves that are too small and force your fingers to curl.

"I'm nowhere near Karen Morse's standard (the current European slalom champion who also coached Denise before last year's Disabled World



If there was a wheelchair terrorist organisation, I have no doubt Denise would be its guerrilla leader. Rebellious, anarchic, bloody-minded, to Denise the system, any system, is there to be beaten. Her own is pretty daunting. With useless legs and no feeling from her neck down, she's a tetraplegic, confined to a wheelchair. Denise dismisses this as a mild irritant, "I've got an able body, it just doesn't work." "So what?" hangs in the air.

So nothing. Denise skis, water-skis, swims, marathon runs, has done speed-skating, fencing, basket-ball and archery and is planning to ski across the Channel next summer—there and back, that is. Tell her how wonderful she is, how courageous, and she's likely to run over your foot with her wheelchair.

four, she was told she would never walk again. She did. "And without the aid of callipers. I managed that just before I broke my back, which was a real pain," she adds. She was hit by a drunken driver while waiting in her car at traffic lights. Her back was broken and her neck dislocated rendering her legs useless and leaving her with no feeling from the mid-chest down. Now confined to a wheelchair, her one thought was to get back to sport.

Initially taken up as physiotherapy for her polio, she was by now at 23, an international swimming champion, including double silver medallist at the 1976 Disabled Olympics. "The doctors advised me to give it up, but my argument was that the fitter I was the better I could protect myself."

Championships in Australia) but I'd give the average club skier a good run for their money.

"Oh, and I do trick skiing" she lobs in casually as though she's talking about macrame or cake decorating. Tricking, she explains, is things like skiing backwards or 360-degree turns. "It's a bit difficult because I can't tell where my centre of gravity is and if I turn over I have to wait until someone comes along to right me." She is, naturally, world champion.

Denise, however, makes it quite clear she's not out to prove any points. "When I'm doing my sport, I want people to think of me as just someone who's doing their sport. The disability shouldn't count." It works. The effect she has when leading a group of disabled snow skiers down the pistes is extraordinary. In their 'ski-bob' machines—a seat that sits on a ski like a ski boot, the skier using elbow crutch mini skis to balance—they pass stumbling ski schools and she has been delighted to hear a ski instructor bawl at his class; "Look, they're doing it. Now you lot do that." "That's great! They just see us as ordinary skiers. It helps disabled people realise that they're good at something."

But Denise is candid enough to realise that, apart from the sheer exhilaration factor, one of the reasons she chooses snow- and water-skiing is because she can leave behind the visible sign of her disability—her wheelchair. "I become like everybody else. I suppose I am trying to recapture something of how I was."

Denise's bedroom is dominated by her mini-gym. Every morning after a quick speed push to the paper shop as a warm-up, she 'chucks some weights around' for half an hour, ie gives her arms a severe workout with cross-lateral pulls, reverse bench presses, triceps strengtheners and wrist curls, using two 6kg weights. She has extremely powerful shoulder muscles and biceps but needs to build up her triceps which were weakened after she broke her neck. The nerves that control

these muscles are below the break point.

Three times a week she's down at the lake training and teaching, each Tuesday she goes swimming, clocking up a religious two and a half miles. To prepare for the cross-Channel event she will step up the pressure on the slalom course—"I encourage the boat drivers to drive hard and make it rough"—and do some endurance skiing down on the coast.

Usually she doesn't arrive home until eight o'clock in the evening but will always do half an hour of flexibility work to keep the joints supple and prevent injuries. One of the biggest dangers is that she can tear a ligament, even break a bone and not be aware of it. "When I broke my leg in Australia", she casually remarks, "there was just a burning sensation and then nothing. And with my wrist, I didn't know anything was wrong until it went rather black and blew up. (That was doing the hoovering; she fell out of her chair.) You have to use your head to tell you things. If you feel sick, that's quite a good indicator. Or, after a fall, you look at yourself to check everything's at the right angle."

Denise likes to make life difficult for herself. She believes that's the only way to get the best out of it. "People saying 'it would be nice' really frustrate me. You can change things. Life's for living, not sitting around. But you've got to make things happen."

Lying in hospital after she broke her neck, she knew she was in danger of losing her strength. "Basically, I had to make life tough for myself." Three weeks lying around was quite long enough, she decided. The hospital tried to dissuade her by putting her in one of their independent living flats. "They wanted to show me I couldn't manage. But they got it wrong. When they came in the next morning, I was already up



and having breakfast!" she says triumphantly. Fighting words but Denise admits she was shaken when she realised just how much she had to re-learn.

It's taken her a year to come to terms with her new body and has only now agreed, reluctantly, to allow some help into her fiercely independent life. She lives alone with her two cats, Dusty and Mitten. Ironing, she conceded, could be dangerous—after the iron fell on her lap—and, yes, it was a chore cleaning the bath after she'd broken her leg, yet again, as she leaned over too far. "I suppose there is a point where safety comes first," she mutters grudgingly.

She justifies it to herself by pointing out that the energy saved can be better spent helping others. As well as teaching skiing, she also coaches athletics and is involved in Back-up, a charity which encourages spinally injured people to rediscover their motivation through sports. The cross-Channel attempt is to raise money for the organisation.

Had she not been disabled, she says, she wouldn't have discovered her sporting talents. Nor would she have gone further abroad than a holiday in Spain. "Now I've been to Europe, Scandinavia, America, Australia, New Zealand, Dubai. It's almost a case of, 'break your neck and travel the world'."

*Reprinted by kind permission of You Magazine, The Mail on Sunday.*

## A DAY IN THE LIFE OF AN ASBAH FIELDWORKER



**T**he Association for Spina Bifida and Hydrocephalus employs 41 Fieldworkers throughout England, Wales and Northern Ireland. They are all highly knowledgeable about spina bifida and hydrocephalus. They offer practical help, information on benefits, housing and medical issues as well as emotional support to individuals and their families.

Gina Broughton has been an ASBAH Fieldworker for over five years. Gina is based in the north of London with a catchment area which spans from Harrow and Hemel Hempstead in the north to Dagenham in the east. It was the diagnosis of a young relative which led her to apply for the post as a Fieldworker. Gina is supported through a head-office information resource unit as well as a manager and regular training days. Gina is in contact with over 400 families and plans to average five visits a day but, as she explains, three visits would be preferable...

"By 8.30 a.m. the 'phone usually starts ringing. Just listening to someone is a means of offering support and

reassurance. By 9.30 I will have reached my first client. A lady who is waiting for a visit from her GP in order to be assessed for Attendance Allowance. It is reassuring having someone present who not only knows the procedure but is aware of the strain of looking after a young son with spina bifida at home. For instance, constantly changing soiled sheets can become a way of life, so a devoted mother might forget to mention the stress involved. An ASBAH Fieldworker can offer the support of someone who does not feel intimidated by authority.

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**"ASBAH appears to be the only organisation offering continuous support..."**

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"From there I am off to a local hospital where a Social Worker had informed ASBAH of the diagnosis of a new baby. In recent years social

service departments have welcomed the help of ASBAH Fieldworkers. We have the time to listen and specialized knowledge to impart to families.

"This baby turned out to be a little boy. The early scan had not revealed any abnormality so the parents are devastated. I had taken an armful of information, but I am then selective in how much I will hand over. In a state of shock there is a limit as to how much anyone can absorb. I will always explain that ASBAH is there to support and help, but often find myself rejected. Involvement from ASBAH means accepting that a baby is born disabled and that is often too great a step for a family to acknowledge from the outset.

"There are so many ways in which ASBAH can help. A small grant might make all the difference for fares to and from hospital if a baby is likely to be in hospital for anything up to four months. It may be that the parents wish to learn more about spina bifida and/or hydrocephalus and ASBAH can arrange for a visit from one of their Disabled Living Advisors or put them in contact with another family. We always try to talk about the positive side of the disability. I usually leave my telephone number with the parents and allow them to phone me day or night. If I have not heard from them within a week, I will make contact again.

"Leaving the maternity ward it is time to visit a lady who wishes to talk over the possibility of terminating her pregnancy. She has just had a scan which has revealed spina bifida. I am not in a position to advise anyone or make decisions for them. I can only offer information about the disability and assure her that whatever her decision ASBAH will be supportive. I did, though, suggest that she has a second scan for accuracy and left her in the knowledge that I would arrange one for her at Guys Hospital.

"A visit often results in a great deal of paper work and correspondence and it is usually well into the evening before I have time to turn my attention to it.

## ASBAH FIELDWORK IS STRENGTHENED IN THE NORTH WEST

The last call of that day is to a single parent with an only child. ASBAH appears to be the only organisation offering continuous support to this seven-year-old lad. He can walk without aids, yet has always had problems with his right leg. More recently though, his left leg has started to give him trouble.

During my visit I try to reassure him as he is due to visit the hospital the next day. He attends a mainstream school, yet it transpires that the other boys are making fun of his having to wear incontinence pads. Fortunately, I have brought along a book which he can show to his teachers and classmates in order to help them understand his disability. An application for mobility allowance has failed but I am now supporting his mother's attempts to get them rehoused into a flat or bungalow.

"Whilst I am there we also discuss an application to the Social Fund for a grant for extra trousers and shoes. I promise that I will write a supportive letter to accompany the grant application before setting off for home, where the answering machine holds new referrals who require help."

Gina's workload is already over-stretched. The only way additional Fieldworkers can be appointed is through a sponsorship arrangement between ASBAH and corporations or businesses who wish the community to receive this service.

Alan Langshaw has been appointed on a part-time basis to St Helen's. A fully qualified social worker, Alan has a great deal of experience of disability through his

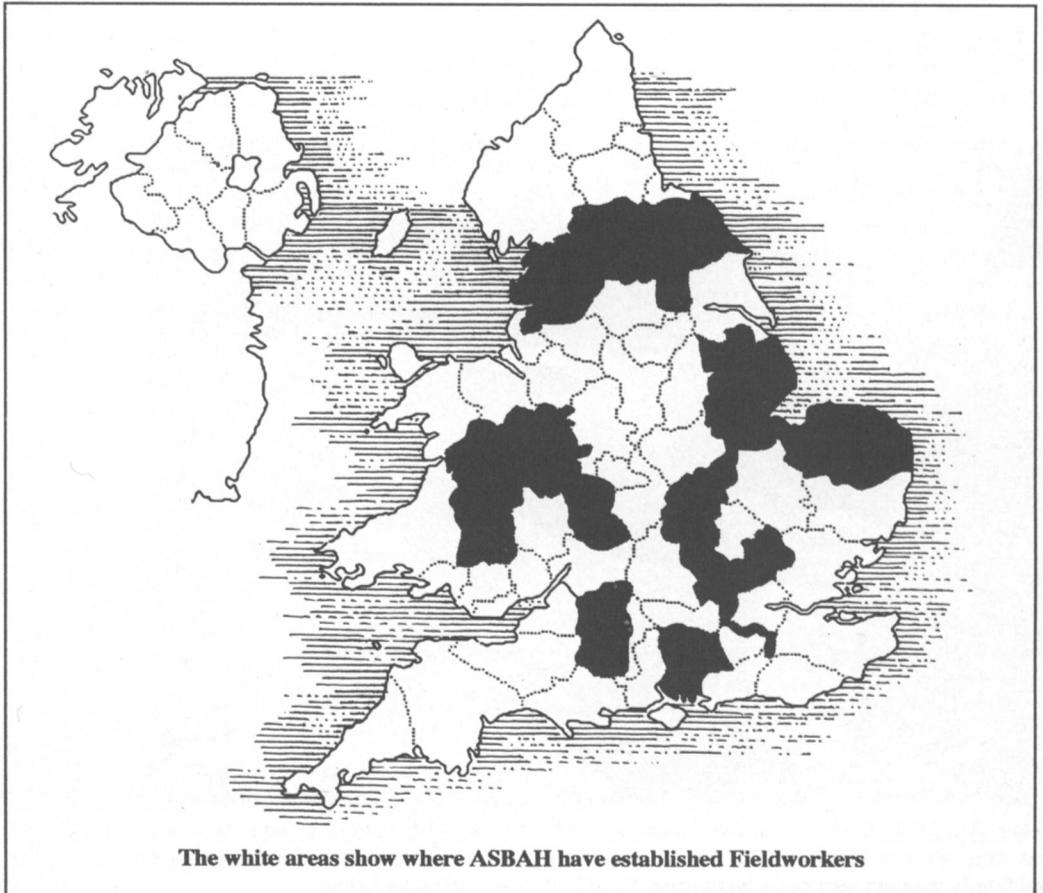


training in remedial drama. This led to his involvement in setting up a centre for children with special needs. It was the birth of a friend's child with hydrocephalus which brought him to ASBAH. Alan is interested to hear from individuals and/or families. Tel: 051 677 4450

Val Cushing is returning part-time as a Fieldworker to Liverpool after a break of several years. Val is a fully trained physiotherapist with enormous knowledge of spina bifida. She will be



concentrating on the under-16 age group and is hoping to be able to contact new referrals. If you would like to contact Val Cushing her telephone number is: 051 427 8500.



## FIVE OAKS—INDEPENDANCE TRAINING

**F**ive Oaks leads the way in combining understanding and patience with knowledge in the field of independence training. During 1990 Five Oaks will provide courses to children and young people, from the age of seven upwards.

Part of each programme focuses on spina bifida and hydrocephalus in order to gain better personal insight about the disabilities. As spina bifida not only causes limited mobility but also incontinence, personal care is an important part of self-management. There are also hidden difficulties to be considered, particularly for young people with hydrocephalus, and these can include initiation, organisation, memory, orientation, perception and numeracy.

Shorter Independence Training Courses usually run from Monday to Friday, but they may be increased up to a month, and are available to:

- Children from 7 to 15 years of age. These mini-training programmes give insight into disability and offer help and advice with practical problems.



Photograph by Chris Morton

- School and college groups with their own staff who can call upon the expertise at Five Oaks to plan the course.
- Schools and colleges who can make use of the assessment facilities of Five Oaks when planning a realistic

curriculum for an individual pupil who has spina bifida and/or hydrocephalus.

- Sixth form students nominated by a school, college or social services department, as part of a leaving programme.
- Individuals, where programmes can be adapted to meet specific needs or circumstances. For example, a young person may want to gain experience before moving into his/her own flat; a disabled parent may need practical guidance with a new baby; parents may need help in supporting a disabled child.

Dates for independence training periods will be offered when Five Oaks receives completed application forms. We will endeavour to match up suitable pairs or groups to work together on the course.

*For an application form and prices please contact:*

Joan Pheasant,  
Manager,  
Five Oaks,  
Ben Rhydding Drive,  
Ilkley LS29 8BD  
Tel: 0943 609468



*Below:* The HELIOS Housing Award arrives at Five Oaks with Manager Joan Pheasant and some of the residents. This European award was given in recognition of Five Oaks' care and family support services. *Photograph:* Bradford Telegraph and Argus

## FIVE OAKS PROGRAMME FOR 1990/1991

**Activity and Holiday Weeks:** Five Oaks is offering exciting activities in a friendly environment for you to develop your skills or just relax.

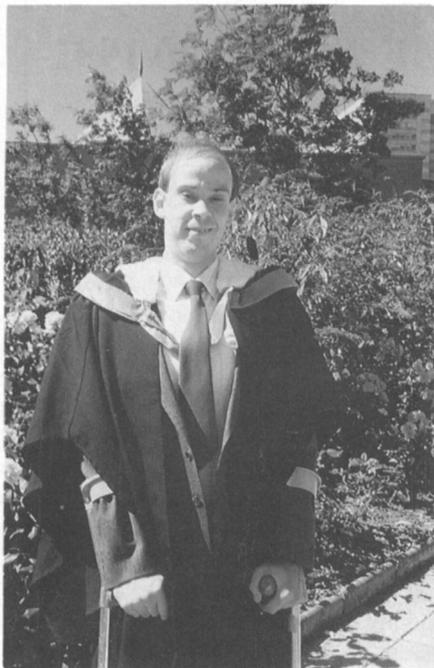
7 April–14 April	Holiday Week	25 August–1 Sept.	Holiday Week
14 April–21 April	Holiday Week	1 Sept.–8 Sept.	Outdoor Pursuits
22 April–28 April	Driving Course (as this is the 10th Course, to celebrate there will be a party on Sunday 22nd)	23 Sept.–29 Sept.	Driving Course
29 April–5 May	Fashion Course	5 Oct.–13 Oct.	International Fashion Course. This year the course starts with two nights in London before travelling north to Ilkley
6 May–12 May	Daytripper Week	21 Oct.–27 Oct.	Holiday Week
26 May–2 June	Holiday Week	12 Nov.–16 Nov.	Driving Assessments
2 June–8 June	Daytripper Week	30 Nov.–2 Dec.	Winter Wildfowl Weekend
8 June–10 June	Fishing Weekend	5 Dec.–9 Dec.	D J Course
16 June–23 June	Wildlife Course	22 Dec.–29 Dec.	Holiday Week
30 June–7 July	Outdoor Pursuits	29 Dec.–5 Jan. '91	Holiday Week
15 July–21 July	Outdoor Pursuits	16 Feb. '91–23 Feb. '91	Holiday Week
28 July–4 August	Holiday Week	4 Mar. '91–8 Mar. '91	Driving Assessment
4 August–11 August	Holiday Week	17 Mar. '91–23 Mar. '91	Daytripper Week
18 August–25 August	Holiday Week		



Paul Dean and Lisa Castle take a shopping trip in the Austin Montego Estate generously given to Five Oaks by the Wellcome Foundation who totally refurbished and serviced it before offering the car to ASBAH.

Photograph: Phillip Bambridge.

## ACHIEVERS



22 year old **Gary Slater** who has spina bifida was recently awarded a Degree in Ancient History at Sheffield University. He has now returned to complete a teacher training course.

16 year old **Simon Foster** is the first table tennis champion of South Derbyshire. He has recently won top honours in the UK championships, with a Gold Medal.

**Richard Kilburn** and **Christopher Xifaras** recently returned from Miami for the Second World Games for Disabled People. Both young men received a Gold Medal, Richard for table tennis and Christopher received a

Gold, Silver and Bronze Medal for swimming. Christopher also has received a top prize in the sports category of the 1989 Barnardo's Champion Children of the Year Awards.



**Linda Edwards** from Cwmbran, who has spina bifida, is also blind. Linda has recently knitted a multi-coloured blanket which was sold for charity.



42 year old **Roger Elliott** was partly funded by ASBAH when he was selected to join Operation Raleigh in Queensland, Australia. Operation Raleigh, founded by Colonel Blashford-Snell, aims to give young people the opportunity to explore remote corners of the world. Roger Elliott was personally asked by the Colonel to join the expedition, where tasks include the restoration of a 19th century Post Office and jailhouse in Burktown.

Have you seen the lift?



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## PROFESSOR ZACHARY FUND OPENS CULTURAL DOOR

19 year old Rachel Bowcock from Shrewsbury has recently returned from a concert tour of the USA and Canada. Together with The Methodist Youth Brass Band, Rachel, who plays the cornet, appeared on stage in Hamilton in Oakville and Scarborough in Ontario and in New York, Bloomsburg, and Bernus Point in Pennsylvania and New York State. The band consisted of young people between the ages of 13 and 25 who came together from all over the British Isles. They were sponsored in America by five Churches and Methodist members offered accommodation in their own homes. "The hospitality was enormous. The church halls doubled up

as restaurants and all 45 members of the brass band ate together with their adopted families, which created a great atmosphere," Rachel explained.

Although fearful of travelling overseas and well equipped with antibiotics to fend off expected infections, "people were very helpful". In fact, Rachel had to admit that access to buildings in the USA was particularly good. It was a bumpy boat trip around the Niagara Falls which proved one of the highlights of the trip. "It is not just the beauty of the water which is so spectacular but the sound of the cascade. My main fear came true when one of my wheelchair tyres went flat on top of the Empire State Building,

but for me the most important aspect of the trip was being able to join in and try everything my able-bodied friends were experiencing."

ASBAH was able to assist Rachel through a £200 grant from their Professor Zachary Fund which supports young people with projects initiated by themselves. The Bursary Fund provides funds for people wishing to attend training courses approved by ASBAH. Additionally, the Professor Lorber Fund helps young people who are attending courses run by ASBAH.

All Funds, particularly the Bursary Fund, are open for applications. Please apply to ASBAH.

## APPEALS REPORT

At the invitation of Charterhouse Enterprises, ASBAH and Unicef had stalls at Charterhouse's Direct Marketing exhibition and conference at the Novotel, Hammersmith on 7 and 8 November. The ASBAH stall provided light relief from the more severe proceedings, and ran a trivial pursuit type quiz for various prizes including champagne.

ASBAH provided a stall in Kensington High Street on a pre-Christmas Edwardian evening thanks to Joan Chapman and the 1st Southall Girls Brigade Company. On this occasion the 1st Southall Girls Brigade Company sang carols and ran the tombola.

Over the years, the 1st Southall Girls Brigade Company have given valuable and unsung help at various events. They helped prepare and serve food at the Conversationalist of the Year events, packed and despatched the various appeals and Christmas cards and, recently, thoroughly enjoyed taking their band to play in Ealing Broadway shopping centre to help raise funds for the North West London Association.



HRH The Duchess of York with Dame Vera Lynn (left) and Jennie Whiting (right).  
Photograph: Doug Mackenzie.

Because of this, we were delighted that they, other staff and friends could attend a reduced priced matinee of 'Me and My Girl'. As well as enjoying the performance, the girls were thrilled to be able to meet the stars of the show, Gary Willmott and Jessica Martin.

Jennie Whiting, ASBAH's Appeals Director, was recently presented with a cheque from the proceeds of the Nightingale Ball on behalf of the Hampshire North, West Surrey and South Berks Association.

I am pleased that ASBAH is, in conjunction with its impending move to Peterborough, adopting a new bright logo, and I like the fact that it incorporates the name in full. I do, however think it's a pity the colour has changed from green.

I am sure we are all delighted that the highly acclaimed conductor, Jeffrey Tate, has agreed to become the Association's President. Music is a medium which can, in its many different forms, provide so much pleasure for disabled or non-disabled alike, either as participants or as audience. It is so nice that we have someone with considerable experience of life with Spina Bifida. We hope that Mr Tate's association with ASBAH will be a long and very happy one.

We welcome the great emphasis which ASBAH is now placing on counselling for its members. We are quite sure that this will have an important impact on the work of the Association for many years.

*Alan Twyford,  
Surrey*

I was interested to read Dr McKinlay's excellent article on Epilepsy in the October/November edition of *Link*. But he might have added that one of the best drugs for epilepsy—sodium valproate/Epilim can actually cause spina bifida if taken during pregnancy. Any woman taking valproate during the early months of pregnancy has a 1–2% risk of having a baby with spina bifida.

All teenage girls and young women with epilepsy who are being treated with valproate should consult their GP. Unfortunately, many GPs are unaware of the risk and may need encouragement to consult their medical books.

If a young woman has not had fits for two years their doctor may be able to gradually stop valproate before they become pregnant. But most women taking valproate will not see their doctor until they are already pregnant. They should not stop taking valproate as having fits while pregnant could damage the baby. They should also be referred to a good hospital where they can have blood tests, detailed ultrasound and amniocentesis when they are about 16–18 weeks pregnant to make sure the baby is alright.

*Pippa Oakeshott MRCP*

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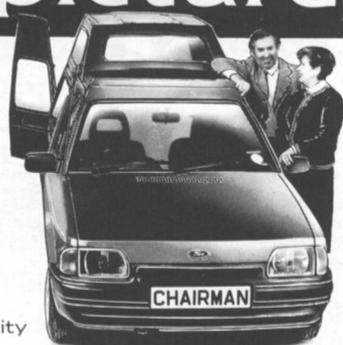
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### A change for the better!

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Carelink is especially for people who find ordinary buses or the Underground difficult to manage (you might be carrying luggage, for example). And at Victoria and Euston, Carelink becomes an air link, meeting up with the frequent Airbus services to and from Heathrow. These buses, too, are now wheelchair-accessible.

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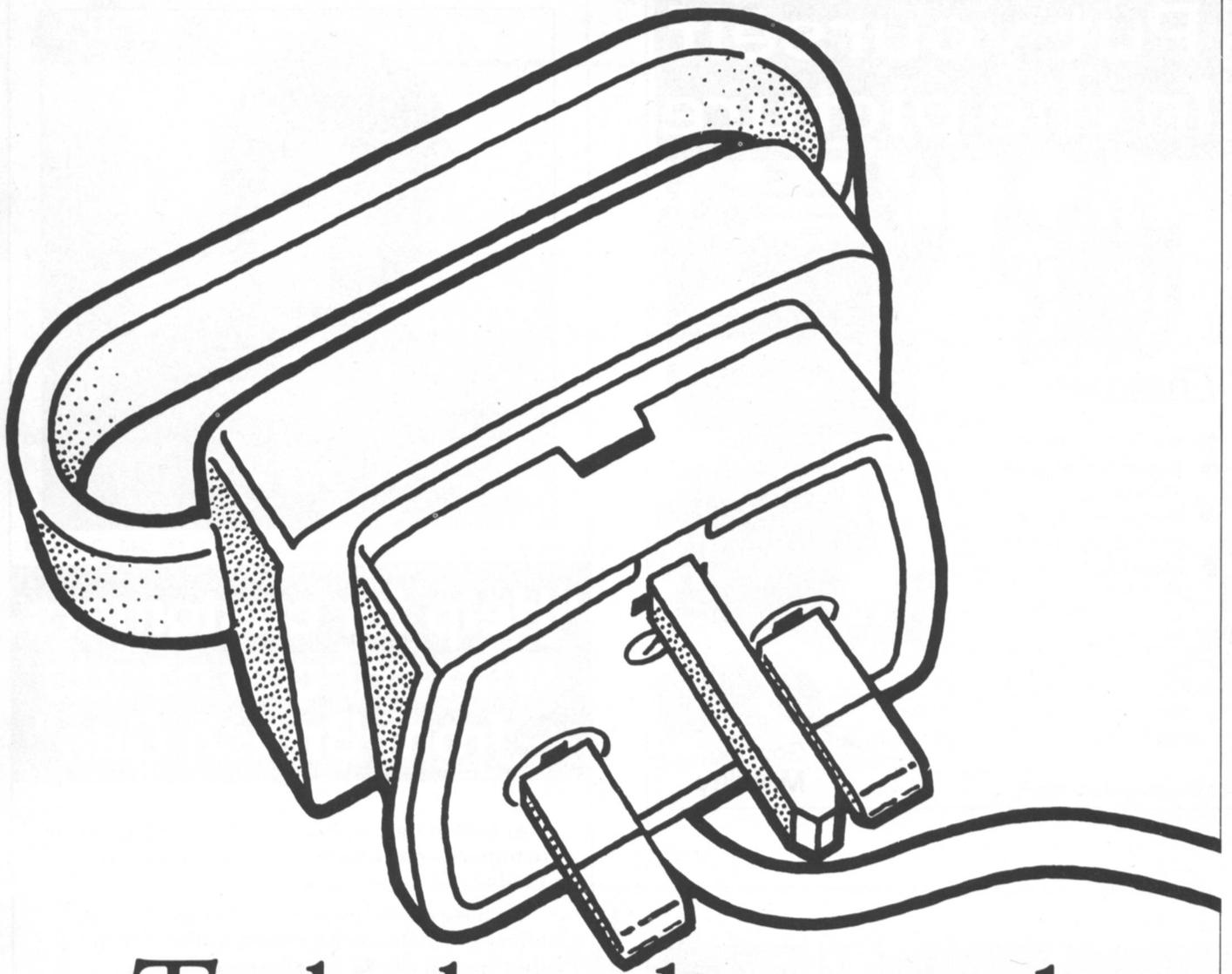
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Rates: £3 for 30 words max; £4.25 for 30-45 words;  
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Adverts for the next issue of *Link* (April) should be in  
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Upper Woburn Place, London WC1.

## HOLIDAY ACCOMMODATION

**RED CROSS HOUSE, INVERNESS** offers respite care/  
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**LOOE, CORNWALL.** Fully equipped, self catering two  
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Cycle hire. Snack bar and take-away food.  
Further details:- Mr. F Simmonds. Tel: 0628 783413

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