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# TAKING A BREAK

A guide for people caring at home

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# INTRODUCTION

Over a million people in Britain today are caring for elderly, ill or disabled relatives at home. Carers are wives, husbands, parents, sons or daughters, other relatives, friends and neighbours — ordinary people without special training or skills who take on the responsibility for someone who cannot manage alone. Many of us will care for someone at some time in our lives, and women are especially likely to do so.

People need looking after for a variety of reasons, perhaps because they are elderly, frail or confused, or because they have developed a disease or had an accident which has left them mentally or physically disabled. Some people who are born with serious disabilities will need help all their lives.

Whatever the circumstances, it is likely that, as a carer, you may need to spend long hours carrying out tiring and demanding tasks. You may have to undertake household and personal tasks, as well as nursing the person, keeping them company and just generally looking after them — sometimes both day and night. Caring can easily become a full-time job.

Unlike a paid job outside the home, though, you cannot automatically expect breaks and holidays away from the responsibility and demands of caring. This doesn't mean that you need them less or are any the less entitled to them. On the contrary, for most carers a rest is essential to enable them to carry on caring. And there is probably no other job you, or anyone else, would dream of doing so intensively without a break.

There are, of course, many reasons why you may want or need a break from caring. You may need to go out

to work, or want to pursue an interest. No less importantly, you may want to take a holiday, relax with the rest of your family or friends, or have some time to yourself for the sheer pleasure of not having to do *anything*.

Many carers are concerned about an emergency — their own ill health, or an accident, or some other family event which makes it impossible to carry on caring. A break in such circumstances may be unavoidable and most carers want to be prepared for such an event.

A break means a few hours or a few days away from the usual routine of caring. It may be a regular arrangement, or something that happens only occasionally. Often it is other family members or friends who take over, but if that is not possible, or not what you want, it may mean someone new comes into your home to care for the person while you go out. It can mean the person you look after goes away from home — perhaps to a special centre, or a hospital, or someone else's home. Whatever the case, most carers who have breaks are enthusiastic about the benefits for themselves, the person they care for, and for the rest of their family.

If you are caring for someone who is unable to look after themselves because they are elderly, ill or disabled, this guide has been written for you. If you are already having successful breaks it is intended mainly for reference. If you have been frustrated in your attempts to arrange breaks, it is hoped you will find some new ideas and feel encouraged to try again. For those who are new to caring, or on the brink of taking a break, it is hoped the book will give you the information

and the confidence to go ahead. The overall message is look for the break that suits both you and the person you care for.

*Taking a Break* has been written drawing on the advice of carers — all of whom are well aware that arranging a break is rarely just a matter of finding a suitable place and simply 'fixing it up'. They know that you and the person you look after will have very strong feelings and anxieties which must be considered carefully and sensitively as well. So this guide acknowledges these feelings too and suggests some ways of coping with them.

And of course, it is important to be realistic. It can be difficult to arrange a suitable break and some carers may feel they have no choice at all. Even so, the booklet encourages you to be optimistic. It aims to help you make the most of the options that are available — by giving you information and advice, by acknowledging your feelings, and by encouraging action — in the hope that you, and the person who depends on your care, can make the best possible decision.

Part One of *Taking a Break* looks at carers' concerns and feelings. The second part describes the various kinds of breaks that are available and points to some of their advantages and disadvantages. Part Three gives you information about arranging breaks. The fourth part summarises advice on how to make breaks successful, and the final part describes how to start bringing about improvements to services by making your views known and joining with other carers.

\*The asterisk means the address of the organisation can be found on page 33

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# YOUR CONCERNS ABOUT TAKING A BREAK

Many carers have successful breaks and gain immense benefits. Yet these have often not been achieved easily. It's likely that you are going to experience some difficulties.

Of course the range and strength of your concerns and feelings will vary according to individual circumstances. Even so, there are some common experiences amongst carers. You are probably not alone with your particular worries — someone else will have felt them too.

The major issues seem to be similar for all carers — their own mixed feelings about whether they should have a break at all, and worries about the effect of a break on the person they look after.

## YOUR OWN MIXED FEELINGS

Most carers, even those taking breaks, are unsure about whether having a break is the right thing to do. You may want a break yet feel guilty for wanting to get away, even for a short time. You may believe that you should be able to cope and that to let someone else take over is an admission of failure. Sometimes it can seem that a relief carer copes better than you do, and this can make you feel inadequate:

**'This woman was coping so well with Karen yet she was driving me mad. I thought 'What am I doing wrong?' It took me a long time to realise that she only had her one weekend a month and, of course, it's quite easy to cope then.'**

You may think your family should help more, or find it difficult to turn down family help if it doesn't work out:

**'For the first nine years we struggled on with family help — which my husband seemed to resent. He didn't feel it was right that my Mum and Dad should look after him and we had battles every time I wanted to go anywhere.'**

Many carers don't like to make a fuss, or believe that others are worse off than they are, and so tell themselves that they don't need a break. After several years of caring, some people even forget what it's like to have time for themselves and feel at a complete loss when they eventually do take a break:

**'We didn't have a break for a very long time, then when we went out one evening we didn't know what to do or where to go ... we'd forgotten what it was like to do anything together as a couple.'**

It is also not unusual for carers to become frustrated and angry because breaks are difficult to arrange, too infrequent, or unsuitable. You may feel that the professionals who should assist you are unconcerned and unhelpful. Some carers feel that they have to 'fight' for everything including services that the person they look after is entitled to. Many just don't have the energy to take on the additional work of arranging a break on top of what can be the day-to-day exhaustion of caring.

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### THE FEELINGS OF THE PERSON YOU LOOK AFTER AND THE EFFECTS OF A BREAK

You may tell yourself that you can't take a break because the person you look after won't like it and will refuse to cooperate. Indeed, it is not unusual for people to resist the idea of being looked after by someone else. This can exert a lot of pressure on you, which may leave you feeling resentful towards the person you look after and very indecisive about having a break.

It's probably true that most carers worry about the effect a break will have on the person they look after. But you are likely to be most anxious the first time, especially if they are going away from home. You may worry in case the person is unhappy without you and that they will be homesick. And, of course, you will be concerned in case others are not able to look after them as well as you do. You may fear their particular needs will not be seen to — whether it's giving practical help with feeding or toileetting, or showing patience and understanding towards those who have problems in communicating or are confused, or respecting people's specific cultural, language or religious needs. Parents of young children and carers of confused or mentally disabled people may be especially concerned because the person may not be able to tell you what happened during the break or how they felt:

**'It's very difficult to know what he's thinking. You have to judge by how he reacts in a situation; you just have to wait until he's been there and come back to find out. Fortunately, we think he's been quite happy.'**

You may also be worried in case the break makes the person's condition worse, or that the disruption to regular routines might make their behaviour more difficult to handle when you take over again. These

sorts of worries can cause so much stress and anxiety for a carer that the break is ruined.

### COPING WITH THESE ANXIETIES

It's normal for a carer to have these feelings. And of course, some of your concerns may be justified — services and standards of care sometimes are inadequate, and there can be disturbing effects on people. This may lead some carers to question the value of a break:

**'He's been going there for a year now and I still don't know if it's right. I feel very guilty about him being there and when he comes home he makes my life hell, and when we take him back he's very spiteful. I'm not sure that the break is worth it.'**

On the other hand many carers find that things eventually improve:

**'The first time I sent him to the school residential centre he wouldn't speak to me for two days, and when he came home he ignored me. He said, 'I hate you! You sent me away!' He put it down to something really wrong at home — but I just needed a break. But now he loves it, and he asks to go, and that's really lovely.'**

Although it is difficult to replace the personal attention that you give, particularly as most relief care cannot be given on a one-to-one basis, many carers are more than satisfied with the standard of care:

**'The geriatric wards at ... hospital are wonderful. The staff and facilities are excellent.'**

**'I was very reluctant at first. I couldn't believe anyone could cope with mother's little ways. But this young man who comes, he's absolutely marvellous, and I know she likes him — she talks away to him and tells him all her secrets.'**

Of course, there are no simple answers to any of these dilemmas but there are some things you can try. It is not always easy to admit to having

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some of these feelings, but they are common and often it can help just to voice them. If possible, discuss how you feel with the person you care for and encourage them to join in resolving the problem. You may feel that this will be difficult and that it might be easier to talk to others first — your family, friends or any one else you feel supports you. Often carers groups can be most supportive as you can talk with people who share the same problems as yourself and draw on their experience and advice:

**'This group ... we know we're always going to be here. We're each other's crutches. We've been together six years and we're still talking!' (Contact a Family group)\***

**'I don't know what I'd have done without this group. I've learnt more from all these people than from any professional.' (Alzheimers Disease Society group)\***

On the other hand, some professionals can be very experienced and offer a lot of help and reassurance:  
**'You need to go to the right person who can help you fix it all up. I've got my social worker — she's fantastic.'**

You should, in any case, try to involve the person you care for as much as possible. It's very important how the idea of a break is put to them as they may misunderstand your reasons for wanting a break and feel insecure, or fear that you are trying to get rid of them because they are a burden. Indeed, they may not fully realise the demands they make on you until you discuss them together. Perhaps you can separate how you feel about the person you look after from how you feel about all the tasks you have to carry out for them. Explain to them how you need a break from the *work* not the *person*. You may be surprised when you do talk about it — many people who are being cared for want a change as much as you do, but don't like to say so until you bring it up.

Carers have described various appeals that work for them when dependants won't cooperate, such as this one from a mother talking about her physically disabled teenage son:

**'We pointed out that his sister had a social life and went out by herself, and we said if you don't want one it's up to you. He crawled off into the other room and lay there for half an hour and thought about it. He came back and said 'I'd like to give it a go'... We didn't plead with him. Pressure wouldn't have worked.'**

Sometimes a blunt statement about your need for a break works:

**'I told my mother that I would be ill myself unless I got a break.'**

Some people may protest loudly but cooperate when the time comes:  
**'Mother refused to go every time I mentioned the day centre. Yet when the ambulance came, she smiled charmingly at the driver and gave me a regal wave as she went off.'**

It may be easier for an outsider, such as your doctor or a social worker, to talk to the person you look after. Often they can say things you cannot and can 'defuse' an otherwise explosive situation.

And of course the benefits of a break may outweigh many of the difficulties and disadvantages:

**'If only carers could be persuaded that it is acceptable to feel the need for a break. I cared for my child (multiply handicapped from birth) for twelve years without a break because I would have felt guilty doing otherwise. Now we are into taking regular, short breaks I realise we all benefit — not least my son who enjoys his 'holidays' immensely.'**

Many carers come to feel that having some sort of break is imperative in spite of the difficulties:

**'We all need a break — whatever shape or form it takes!'**

A break will prevent you from becoming too exhausted to carry on

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caring. In some cases it can make the difference between you continuing to care for someone at home, if that's what you want to do, and having to consider a permanent alternative. And there are many other good reasons for taking a break. A break will be good for your own health and can make you feel a 'new person':

**'I had a fortnight's holiday – it was beautiful! Just going out for a walk in the hills every day kept me sane.'**

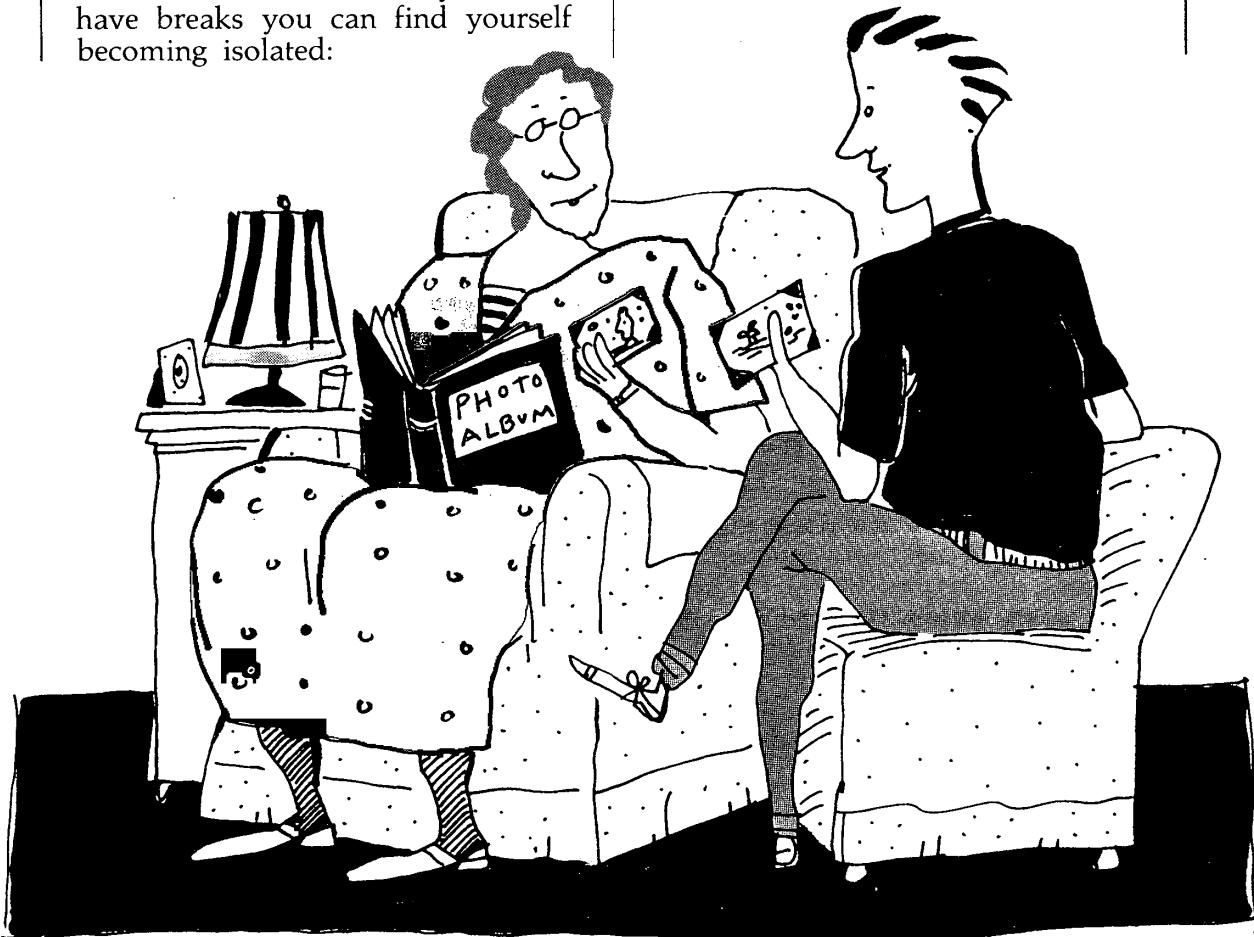
A break can prevent you from becoming too wrapped up in caring and give you some independence and a chance to keep up with your interests and friends. If you don't have breaks you can find yourself becoming isolated:

**'My friends and family stopped asking me to go anywhere as I always said I couldn't because of Dad.'**

But there are benefits for others too. Carers stress the importance of considering the rest of your family: **'It's for the sake of the family – it's so nice to have half an hour to sit down with your husband or play cards with your kids.'**

Many emphasise how caring without breaks may even damage family relationships:

**'Clare was 12 by the time I got a break and my other children were almost grown up – we hadn't done**



**"I COULDNT BELIEVE ANYONE COULD  
COPE WITH MOTHER'S LITTLE WAYS.  
BUT THIS YOUNG MAN...  
HE'S ABSOLUTELY MARVELLOUS."**

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**anything families normally do — go to the pictures, that sort of thing. I think you've got to think of the rest of the family even if it's not what you really want.'**

**'When Dad first had respite care my daughter was 21, and it dawned on me that we'd never been out together, we'd never been to a pub or the pictures.'**

**'We didn't go out for five years. We couldn't get anyone in for Mother. Our marriage was on the rocks.'**

It's also important to realise that there can be some real benefits for the person you look after as well:

**'Mother finds the lively conversation at the dinner centre really stimulating.'**

**'Father didn't like it at the first home because there were only old ladies, but at this other place now he's met a gentleman who likes reading and chess too.'**

**'We knew there were other children in the family and so she would have more company and new playmates.' (A father talking about his mentally disabled daughter staying with another family).**

**'My husband has more freedom in the...home to wheel himself around the various rooms and the gardens, whereas at home there's no space.'**

**'I send Tracey there as much for herself as for me. After all, one day she's going to have to cope without me.' (Mother talking about her multiply disabled daughter).**

Some carers manage to arrange breaks with little difficulty. They are probably the exception rather than the rule, but their tales are encouraging. Indeed, once into the system it seems it's often easier to get more care if you need it:

**'I've always been very well supported and when mum has been too ill for me to cope at home she's been taken into hospital to give myself and my family a break.'**

**'When I was caring for my father and my back gave out my very**

**supportive GP arranged for him to go into hospital.'**

**'I spoke to the day care worker on Monday who contacted Social Services. The social worker came on Friday. By Friday night he was packed, and off for two weeks holiday — it all happened just like that!'**

**'Although I retired early to look after my wife I've always used relief care. The sort of care, and the amount, has been worked out to fit as my wife's condition deteriorated. We started off with someone coming in one evening a fortnight and my wife going two days a week to a day centre. We progressed to a day hospital, then the help extended to an overnight bed, and gradually longer stays until she is now in semi-permanent care in a special unit.'**

Of course, no one can decide what's best for you, although it is hoped that some of these other carers' experiences may have shed light on your own situation. You're probably involved in a delicate balancing act trying to satisfy everyone's interests. Perhaps sometimes the scales will need to be weighted more on your side — you may have to put yourself first occasionally and take a break if you want to continue caring. If, however, you feel you don't want or need a break now, it is still worthwhile finding out what is available in your area, especially as breaks can often take a long time to arrange. You could look on this as a kind of insurance in case of an emergency or for if your circumstances change. You may also be able to inform other carers and so help them to take a break.

The next two parts describe types of break and how to make arrangements. You will probably want to dip into the sections that are relevant for you. Part Four 'Making Breaks Easier' contains advice for all carers. It highlights some practical things you can do to make breaks easier for everyone.

# TYPES OF BREAK

This part describes the different sorts of breaks available, and highlights some of the benefits and drawbacks discovered by carers who have used them. Although every attempt has been made to give you a comprehensive picture, the system of relief care is complicated and can be confusing. Three general points may help to clarify things.

**There are many different types of break available** These range from small scale sitting schemes offering a break of an hour or two, to services offering day care in your own home or a special centre, to those offering a week or two in a residential home or hospital.

The names used to describe these breaks vary. Sometimes the same kind of service will have a different name from one area to another. You may come across the terms **relief care**, **respite care**, **short-term care**, **phased care**, **programmed care**, **shared care**, **holiday care**, **emergency** or **social admission**, and possibly more.

And the names of specific services will differ in the same way, for example a **lunch club**, a **social club** and a **dinner centre** may sound different but they probably all offer much the same thing.

**There is not enough relief care available and it is unevenly distributed** How much relief care is available will vary according to where you live, and according to the age and particular needs of the person you look after. Some areas have only minimal services for all groups of people needing breaks; others are well provided with services for some groups, but have virtually nothing for others.

Sometimes services are restricted to particular groups of people and exclude many others who need them. For example, a service might be limited to people in a particular area, or to a particular age-group, or to people with certain disabilities, or only be available to individual carers for a set period of time. Occasionally the service providers may offer only one kind of scheme rather than providing a range of different ones, so choice is limited.

In many cases existing services are provided for the person who needs looking after rather than the carer. The main purpose is to help the dependent person, and your 'break' is only a side-effect. However, it's gradually being acknowledged that carers need support too, and services that also take their needs into account are beginning to be provided. This means that some existing services are trying to become more flexible and that sometimes carers are consulted before new services are set up. There are also organisations of carers working to establish carers' rights and campaigning for improved support services.

## **Relief care is mainly provided by three different sectors.**

**Statutory** which means services provided by Local Authority Social Services Departments, Education Authorities, and Health Authorities.

**Voluntary** which means services provided by charities and voluntary organisations, on a non-profit making basis.

**Private** which means services provided by individuals, commercial

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organisations or companies, on a profit making basis.

(There are also schemes under government job creation programmes which may be run by the statutory or voluntary sector.)

In practice these may all provide very similar services, and sometimes the statutory and voluntary sector may provide schemes jointly. Indeed, many carers receiving relief care may be unaware which sector is helping them. Nor does it necessarily affect the sort of staff and the quality of care provided. 'Voluntary' does not mean 'volunteer'. Voluntary organisations often employ trained and professional people, as well as using volunteers. On the other hand, statutory services may rely on volunteers for certain things. And of course, volunteer help does not mean help of inferior quality — volunteers are generally competent, and some are trained and paid an allowance.

However, *who* provides the service can make a difference to how you find out about what's available, who can use it, how you actually get the service, and whether you will have to pay.

## **CARE AT HOME**

### **SITTING SERVICES**

These will provide someone, often a volunteer, to come into your home for a few hours during the day or evening to 'sit' with the person you care for. Some schemes offer this help to any carer that needs it, others will be aimed at particular groups such as carers of older people. The schemes also vary as to how often they can help — some try to provide regular breaks, others can cope only with occasional breaks.

Volunteers, although on the whole untrained, have often had experience

of caring for their own relatives and some have been nurses or home helps. The kind of help they offer varies: some will keep the person company but not carry out any personal or household tasks, others may prepare a meal or get the person up and wash and dress them.

These schemes are run by Social Services Departments and voluntary organisations. Local carers' or parents' support groups may also organise their own sitting services. They come with all sorts of names ranging from 'granny sitting' to 'family support' or 'bridge-in' schemes, so it won't always be clear from the name exactly what is being provided. The service may be free or you may have to pay a small charge. Some private agencies also provide sitters, but you will, of course, have to pay, and rates can vary greatly.

### **CARE ATTENDANT SCHEMES**

There are many schemes offering similar services. You may come across any one of the following:

**Crossroads Care Attendant Schemes**  
**Home Care Attendant or Assistant Schemes**

**Domiciliary Care Attendant Schemes**  
**Extended Home Help Schemes**  
**Neighbourhood Care Attendant Schemes**

**Family Support Services**

The main aim of these schemes is to provide relief for carers. So they try to fit in with carers' needs by providing a very flexible service that suits them and the person they care for. Some of these services are intended to help particular groups of people, but many are available for carers looking after people of all ages and disabilities. They are available on a regular basis, providing care for a few hours on one or more days a week, and in some schemes during the night as well.

Care Attendants usually do everything that the carer does. They are trained and employed by the scheme.

However, they are not meant to replace other services such as home helps or district nurses.

Such schemes may be provided by Health or Local Authorities and voluntary organisations. They are often free, but sometimes there may be a small charge. Some private agencies also provide care attendants, and their charges will probably be higher. It may also be possible to employ someone directly to help you care in your home. (See Hiring your own Helper, page 22).

### NIGHT SERVICES AND LIVING-IN HELP

Night time can be very difficult if the person you care for disturbs you or needs attention. There are, however, very few Social Services or voluntary schemes which provide relief care in your home during the night. Some

care attendant schemes do, and a few Health Authorities will provide district nurses for occasional cover, but most do not. You can employ someone from a private agency although night rates can be expensive. If you need regular help during the night it may be easier to try to arrange some overnight stays or short breaks away from home for the person you look after.

A few care attendant schemes will provide someone to 'live in' for a few days. Some voluntary organisations will also arrange this for you, but you will probably have to pay. Most private agencies can arrange for 24 hour cover, if necessary, or for someone to live in your home for several days while you go away. This can be expensive although you may be able to get financial help (see page 22).

### 'The care attendants I've come across are absolutely fantastic'

For many carers having someone come into their home to take over from them is the most satisfactory arrangement.

- It means least disruption for the person you care for which may be especially important if the person is confused, needs to use special equipment, or prefers to stay at home.

### 'The Bridge-In Scheme is perfect for younger children. The person comes into your house and helps out and it doesn't disrupt the whole family. But you can only have it for two years.'

- You don't have to worry about transporting your relative and any equipment away from your home.
- It means you have more control over what happens. If you have a weekly or other regular arrangement the care can be worked out in close cooperation with you, and once in a scheme you can usually arrange for someone to come in fairly quickly if you need help suddenly.
- The care is given on a one-to-one basis so you don't have to worry that the person will be left unattended.
- Care attendant schemes try to attach one or two care attendants to your family so that you get to know them well. Sitting services try to do the same if you use them regularly.
- Care attendants in schemes (and some volunteers) are trained and supported in their work so that the standard of care provided is generally very high.

There are however some possible drawbacks to care at home:

- It means that you can't have the house to yourself. That's fine, of course, if you want to go out, but if you want to stay in it can be difficult to relax properly even if you've got the space to move to another part of the home.
- These schemes are ideal for fairly short periods of care, but many of them

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cannot offer more than a few hours a week. Overnight care may present problems too — some care attendant schemes provide this but sitting services usually don't.

**'You want a real break — a couple of hours is nice, but you want a longer break away from the responsibility and the pressure you're under.'**

- Care attendant schemes are heavily used and you may find there is a waiting list. Sometimes there is a limit to the length of time you may use the service.
- Sitting schemes may offer different things — some will carry out all the things that you do, including personal tasks and housework, others provide minding only — so it's important to know what you're being offered.
- It is most important that carers and the people they will be looking after are well matched, and on the whole placements are made very carefully. Sometimes however mistakes may occur and clashes of personality or disagreements may arise. If this happens the schemes will try to find you someone else, though this may not always be possible because of the demands on the service.

## CARE AWAY FROM HOME DAY CARE FOR CHILDREN AND YOUNG PEOPLE

These days every attempt is made to integrate disabled children with other children. This means that it is often possible for a disabled child to attend an ordinary school. But for some children this will not be appropriate and for others it will become increasingly difficult for them to manage as they get older. In these cases the Education Authority is required to make an *Assessment* of the child's educational needs. You have a right to this assessment for your child (no matter what age or disability), although it does not always happen automatically. You can ask for this process to be started by contacting the Education Officer for Special Education (at your Local Education Authority). Parents, health professionals, social workers, and teachers all contribute to producing a *Statement* describing your child's

needs and how these can best be met. If you feel unhappy about any suggestions made for your child's schooling you can appeal.

Your child may be offered a place in a special or residential school, or in some cases a teacher may visit your home. Whatever arrangement is agreed for your child, it means you will have some kind of break during school hours.

For many parents the difficult times are the pre-school years, and the evenings, weekends and holidays. The help that's available at these times varies. Local Authorities and Education Authorities are not obliged to provide any services at these times, although some do. You may find some voluntary organisations arrange clubs, groups and activities too.

The following gives you some idea of what might be available:

### DAY NURSERIES AND CHILDREN'S CENTRES

Nurseries provide care and play facilities part-time or full-time for children under five while their parents are at work. Those run by Local Authorities may provide places for disabled children. Private nurseries may be willing to take disabled children too but you will

## DAY CARE FOR CHILDREN

have to pay. Some voluntary organisations or local parents support groups form their own nurseries. Your Social Services Department may run Family or Children's Centres which will have special provision for disabled children and their families. Contact the Under-5s Adviser at your local Social Services office for more information about these and any other day care schemes which may exist in your area.

### NURSERY SCHOOLS AND CLASSES

These provide pre-school education for children from age 3, often on a part-time basis. Education Authorities do not have to provide nursery education, but those that do will admit disabled children subject to certain conditions. Many special schools have nursery classes and will take children from 2 years. You should contact the Education Officer for Special Education who will be able to advise you.

### PLAYGROUPS

Playgroups provide supervised play for children from age 3-5 for a few hours on one day or more a week. They are run by Local Authorities, voluntary organisations, or may be attached to local community organisations or churches. They will vary in their ability to take disabled children. You may find that some parents' groups and local voluntary organisa-

tions will form their own playgroups for disabled children. All playgroups have to be registered with the Social Services Department who will be able to tell you what's available where you live. The Pre-School Playgroups Association\* will also advise on local playgroups.

### PLAY SCHEMES AND CLUBS FOR SCHOOL AGE CHILDREN

Some Education Authorities arrange clubs before and after school, youth clubs for evenings and weekends, and play schemes for the holidays. These will vary as to their suitability for disabled children. You will have to check locally, either with the head-teacher or the organiser.

Staff and parents of special schools often organise their own schemes which may be open to disabled children who live in the area but don't attend the school. Some voluntary organisations such as **Physically Handicapped and Able Bodied (PHAB)\*** and **Gateway\*** provide clubs and activities for physically and mentally disabled young people, often together with able-bodied young people. Many other voluntary organisations, such as **Dr Barnardo's\*** and **MENCAP\***, run holiday and leisure schemes, workshops and weekend breaks. Local parents' support groups may get together to provide play schemes, clubs or other activities often with financial help from the Local Authority.

If you can find a scheme locally that will occupy your child out of school hours there are likely to be several benefits:

- Disabled children and young people can mix with others, including sometimes able-bodied children. They can learn new skills and develop an independent life.
- Parents can often join in activities, so parents who feel isolated may meet others who share many of their experiences.

On the other hand:

- Nurseries, playgroups and clubs which in theory can accept a disabled child in practice may not have sufficient trained staff.
- Transport and access may be a problem, especially for children with wheelchairs or other special equipment.

# CARE AWAY FROM HOME DAY CARE FOR ADULTS

### LUNCH AND SOCIAL CLUBS

These clubs provide company and recreational activities. Lunch clubs, as their name suggests, provide a meal as well. They are often run for particular groups of people, such as older people, or those sharing a specific culture or religion. On the whole they do not cater for people who need a lot of personal assistance. They are generally very informal and locally based. Sometimes transport may be provided. They are open for a few hours on one or possibly more days a week. The scheme will probably be staffed by volunteers.

These types of clubs are organised

by Local Authorities, Voluntary organisations, and religious and other cultural groups. There is usually a small charge.

### DAY CENTRES

Day centres provide an opportunity to meet people and offer organised activities such as craftwork, games, singing, and quizzes. Some are set up to provide rehabilitation or teach skills to particular groups of people. These centres vary greatly in terms of services offered and people accepted. They may have professionals and volunteers working in them, they may take people across a range or with specific disabilities, and they may be available every day or only on certain days. (Some people may attend more than one day centre). They are usually open for the whole day and provide all meals in that time. Many provide transport too.

These centres are run by Local Authorities and voluntary organisations. Some may be attached to residential homes. There may be a charge for meals and transport.



Photo Co-op

## DAY CARE FOR ADULTS

Contact your local Social Services office for more information.

### DAY HOSPITALS

These are centres for patients who are ill, or disabled, but who live at home and require regular medical treatment or specialised care. Some are used to assess patients and provide different kinds of rehabilitation treatments. Most arrange recreational activities as well. They too vary as to when they are available and who can use them. Often people attend for a set period of time and then their progress is reviewed. These centres are staffed by nurses, doctors, social workers and other health and welfare professionals. They are run by Health Authorities so there is no charge for

using them nor for transport by ambulance to and from them.

### EDUCATION, TRAINING AND WORK CENTRES

The help available for education, retraining and job advice varies from place to place. Some colleges and Adult Education Institutes provide courses for disabled people. There are some workshops for those unable to take up an ordinary job or return to their usual jobs but capable of working in special or sheltered conditions. You might also come across Work Project Centres and Employment Resettlement Centres. Contact your local Job Centre and ask the Disablment Resettlement Officer for details of what's available in your area.

### **'Mother's been a lot better and cleaner now she's at the Day Centre, and it means I get a few hours of peace at home!'**

Many carers and the people they look after do find day care very suitable. It may take a while for the person to get used to it, but you can make things easier by introducing care away from home gradually.

- Many people enjoy going to day centres where they make friends, take part in new and stimulating activities, and retain a sense of independence.
- If you want to continue part-time paid work, you may be able to arrange sufficient day care for the person you look after (possibly combined with some care at home) to enable you to do this.
- Some day centres are attached to residential homes so you may be able to introduce gradually an overnight stay in a familiar environment.

There are advantages and disadvantages to every sort of care, and day care away from the home may present certain difficulties for some carers and the people they look after:

- Some people do not find the sorts of activities offered in day centres to their taste, and some feel that the age or social mix is not one they feel comfortable with.
- There may be transport problems getting to and from the centre. When transport is provided, it is not always reliable or punctual and the number of places may be limited. Public transport is not always available or convenient. This can make it difficult for you to arrange your day and uncomfortable for the person who has to wait around.
- Day centres cannot provide one-to-one care and you may feel the person you look after needs this. Some carers find that particular or personal needs are not sufficiently well taken care of and dependants sometimes return home tired or dirty.
- Staff may change frequently so that the person you care for may not be able to develop longstanding relationships with their relief carers.
- In some areas there are not enough centres or places to meet demand and there can be long waiting lists. People with severe disabilities may not be accepted.

# CARE AWAY FROM HOME RESIDENTIAL BREAKS FOR CHILDREN AND YOUNG PEOPLE

### A SHORT STAY IN A SPECIAL HOME, HOSTEL OR UNIT

In some places there are special centres which offer short breaks to children with similar disabilities. These centres may be run by Local Authority Social Services departments, Health Authorities, or voluntary organisations. They may be purpose-built units attached to Special Schools for disabled children, or to hospitals, or they may be old residential homes which have closed and been converted into short stay homes. A growing number are ordinary houses in the community, where children and young people will lead as normal life as possible, with special support.

They vary greatly in terms of what they offer and how they are organised. Most are available for emergency and regular use, which might mean anything from one night a week to every other weekend, or just two weeks in the summer. Some allow you to choose how much relief you want, and when; others will let you know when it's available and you have to fit your arrangements in with this. You will probably be allocated a certain amount of care free, but you may have to pay for any extra care you want. Parents may be encouraged to visit the centre first, and to 'share-care' for some of the child's stay — perhaps to maintain familiar activities such as putting them to bed. These

centres are usually small, well-equipped, comfortable, and staffed by qualified people.

### A SHORT STAY IN A RESIDENTIAL HOME

Residential homes are mainly intended for disabled children who live in them permanently. Local Authority homes are gradually being phased out, but those that remain often reserve places for children who need a short break. Some voluntary organisations will take children for short breaks in residential homes designed specially for children, or in homes for people of all ages sharing a common disability. A growing number of private residential or nursing homes will also take children for short breaks.

These homes will vary as to who they can take and in the length and



Sally and Richard Greenhill

frequency of breaks that they offer. Because they are *homes* they try to provide a friendly and comfortable environment, although there will probably be set routines that your child will have to fit in with while they are staying there.

### A SHORT STAY IN A HOSPITAL

Your child may be offered a bed for a

## RESIDENTIAL BREAKS FOR CHILDREN

short break in a general, paediatric or mental handicap hospital. This may be available for emergency use only, for a few weeks a year, or on a more regular basis such as in a share-care scheme in which your child has regular stays in hospital alternating with periods at home. Some hospitals provide special wards, others only have beds available in regular wards. Exactly what you are offered will vary from area to area depending on

facilities and current policies for admitting children. Your doctor should be able to give you information about what happens in your Health Authority.

### **A SHORT STAY WITH ANOTHER FAMILY**

There are some schemes where children can stay with another family on a regular basis. These are described more fully on page 19

**'Elaine goes to ... Hospital every other weekend. It's been going on for a year now, but I don't know how long it will last. I love it! It's fabulous ... I'm happy with ... Hospital. She was born there and she's been in and out ever since with her bits and all the rest of it ... and the paediatrician is the same one, and the staff know her very well, and because of her medical problems I'm very happy she goes there. What bothers me is that she actually shouldn't be in hospital because she is mentally disabled, she isn't an ill child. So that's not really the right place for her, but there isn't an alternative for us at the moment.'**

The comment above sums up many of the contradictions that parents feel about residential breaks for children. It can work very well for some children and families especially if it is used with other forms of care in their own home, such as a sitting service or care-attendant scheme. It seems to work best when there is good preparation and follow-up. This would include such things as introducing children gradually to being away from home, letting parents make informal visits beforehand, and allowing regular opportunities for parents to discuss their feelings and any specific worries. There are some additional benefits:

- Many children enjoy breaks away from home as they make new friends and can take part in different activities.
- Staying regularly in a familiar environment away from home can help to build a young person's confidence and prepare them for a more independent adult life.
- Parents have time to spend with their other children.

Yet it is not an ideal solution for all families:

- Many parents experience great anxiety and unhappiness separating from their children.
- Parents and children who get used to a particular sort of residential break may worry about what will happen at the cut-off point when their child reaches school-leaving age:

**'It takes ages to adjust to it, and then all of a sudden, 18. It's gone.'**

- Some hospitals and residential homes may seem to be impersonal places without the security and comforts of the child's own home.
- Children cannot be given one-to-one care and many parents feel that their children's special, personal and emotional needs are not given adequate attention.
- Hospitals are sometimes unsuitable places for healthy disabled children to stay. They do not have the same needs as sick children. Also the hospital may be a long way from the child's home, and in some general or mental handicap hospitals there may be few special facilities for children.
- Staff may change frequently, be very busy, and unable to spend sufficient time exchanging information about or discussing children's needs with their parents.

# CARE AWAY FROM HOME RESIDENTIAL BREAKS FOR ADULTS AND OLDER PEOPLE

### A SHORT STAY IN A SPECIAL HOME, HOSTEL OR UNIT

A few special centres have been set up to provide short term care for adults and older people with specific disabilities. They provide specialised facilities and general care often in small, comfortable centres. Staff will be trained but are unlikely to provide nursing care unless it is a unit attached to a hospital. Some Health Authorities provide Younger Disabled Units, for people between the ages of 16 and 55, which have permanent residents as well as catering for short breaks. The length of the break and how frequently you can have one will vary in all these centres, as will any charges payable.

These centres are run by Local and Health Authorities and voluntary organisations.

### A SHORT STAY IN A RESIDENTIAL HOME

Residential Homes are intended for permanent residents but many will take people for emergency breaks or planned short breaks.

**Social Services Departments run homes for older people** often referred to as 'Council' or 'Part III' homes (called after Part III of the National Assistance Act 1948), but increasingly now called Residential Care Homes.

These homes are mainly intended for older people who live alone and have no support, but some have short-term places for people whose regular carers need a break. They provide general care and supervision but not nursing care. Staff are on duty all day and there's help at night for those that need it. Any local resident can apply directly to the Social Services Department, but there are likely to be long waiting lists. People are assessed to establish how much they should pay.

**Voluntary organisations run Residential Care Homes and Nursing Homes.** Such homes are often open only to certain groups of people such as older people, or people with specific disabilities or conditions, or those sharing a particular religion, trade or profession. General care is provided in all these homes and nursing care by qualified staff in Nursing Homes. The homes have to be registered with the Health or Local Authority and are regularly inspected.

There may be long waiting lists for short breaks. There will usually be a standard fee and there are some sources of financial help for those who cannot afford to pay the full amount. (See page 23).

**Private organisations run Residential Care Homes and Nursing Homes.** Homes which have four or more residents must be registered with, and inspected by, the Local Authority (for Residential Care Homes) or District Health Authority (for Nursing Homes). Residential Care Homes provide general care and supervision but not nursing care. Nursing Homes provide qualified nursing care as well. All these homes vary as to who they can accept depending partly on how much care the person needs and whether they can afford the fees. There may be a waiting list if the home is very

## RESIDENTIAL BREAKS FOR ADULTS



Photo Co-op

popular. There are various organisations that can help you choose a suitable private home (see page 22), and you may be able to get help to pay for it (see page 23).

### A SHORT STAY IN A HOSPITAL

Breaks can be arranged for young and older adults in some general, mental handicap, psychiatric and geriatric hospitals. All of these will have different arrangements for breaks. Some will admit a person for a two week period once a year while the carer takes a holiday, others can cope with regular relief breaks. Some run 'shared-care' schemes in which the care is divided between you and the hospital so that the person spends, for example, two weeks in each place. There may be heavy demands on places at different times of the year and you may have to wait. You should contact your doctor about arranging this sort of relief care. There is no charge for hospital care but sometimes benefits and allowances can be affected so you should check this at your local Social Security office.

In many cases relief care in residential homes or hospitals may be the only option open to you if you want a break of several days. But this type of care may present certain difficulties for some carers and the people they look after:

- Residential homes may not have the right facilities for someone who is severely disabled or who needs a lot of personal help or constant supervision.
- Mentally disabled, or confused elderly people may be disturbed or made worse by leaving home.
- Hospitals are, on the whole, set up to nurse sick people rather than physically disabled people who are not ill. They may not be able to provide recreational activities and people staying there may become bored.
- Hospitals can be large, impersonal and far from where you live. The standard of care and the overall atmosphere can vary from ward to ward.
- Staff may change frequently and there will be different night and day staff who will all need to learn about the person's needs. When staff are very busy or under pressure you may feel that they don't have time to do this and cannot provide the personal care that you would give.

On the other hand:

- Many carers find that if residential breaks are planned carefully and introduced gradually they work very well.
- Many people enjoy breaks away from home as they get a change of environment and the chance to meet new people and do different things. Most people come to feel secure if they have regular breaks in a familiar place.
- A period in a hospital can provide the opportunity for reassessment, treatment or therapy.
- A period of residential care for the person you look after may be the only way you can have the break you need to enable you to carry on caring.

### CARE AWAY FROM HOME HOLIDAYS

You may want to take a holiday with the person you care for, or you may want to do something else while they have a holiday without you. In either case there are several options open to you and many organisations, guides and directories can help you to find what you want — it need not be as difficult as it may seem.

Some Local Authorities provide or subsidise holidays for disabled or sick people. Several voluntary organisations, specialist agencies and some ordinary holiday companies, provide holidays for people with disabilities — either on their own or with friends or families, or with provided escorts, attendants or nurses. The accommodation ranges from ordinary guest houses and hotels with suitable facilities to specially designed hotels, and self-catering accommodation in adapted houses, caravans and even boats. There is always a great demand for these holidays and you need to book early.

There are many organisations offering information and advice on holidays for disabled people. **The Holiday Care Service\*** gives free advice to carers tailored to individual needs, and can help you find solutions to most holiday problems. **The Royal Association for Disability and Rehabilitation (RADAR)\***, provides an information service and publishes guides covering all aspects of arranging holidays in this country and abroad. Many voluntary organisations for specific conditions and disabilities, travel and tourist organisations such as the Automobile Association and the various National

Trust Boards also provide information and guides.

If you want help towards paying for a holiday and you are not eligible for help from the Local Authority there are several charities which make grants. You will be able to find out about sources of funding from one of the organisations offering holiday advice.

### CARE AWAY FROM HOME A STAY IN A HOSPICE FOR CHILDREN AND ADULTS

#### A SHORT BREAK IN A HOSPICE OR CONTINUING-CARE HOME

Hospices and Continuing Care Homes are run by voluntary organisations such as the **Marie Curie Memorial Foundation\*** and the **Macmillan fund** (see Cancer Relief)\*. They provide home care, day care and residential facilities for sufferers from cancer and some other serious illnesses. This help is offered to people of any age. They aim to relieve patients' symptoms and help them to enjoy life for as long as possible, and to give carers a break from the stresses of looking after a sick relative twenty four hours a day. The care is very flexible and worked out to suit the needs of each patient and their family.

Hospices employ qualified nursing staff specially trained to advise and counsel individual patients and their families. Most of the homes are set in peaceful surroundings and they provide a relaxed environment with recreational and social activities as

## STAYING WITH ANOTHER FAMILY

well. You can ask your doctor about what's available near you, or contact the Hospice Information Service.\*

# CARE AWAY FROM HOME STAYING WITH ANOTHER FAMILY FOR CHILDREN AND ADULTS

Family Support Schemes

Family Placement Schemes

Family Link Schemes

Special Fostering Schemes

In some parts of the country schemes

have been set up which enable people to stay in the homes of other families. At the moment these schemes are run mainly for children (although there are a few for older people and adults). Although the scheme may be called 'fostering', children are not taken into care, and you retain your full rights as a parent whilst your child is being looked after.

All these schemes vary slightly but usually someone can stay with their 'foster' family for an hour or two, a weekend, or a few days up to a maximum of two or three weeks. Sometimes the total amount of care you can have over a year is limited.

Families are selected very carefully from those that volunteer (and it is not only families who want to help in this way—single people, childless or retired couples can offer different but equally valuable support). Families are trained in the basics of coping



## TYPES OF BREAK

with disabled and frail people, and are generally supported in various ways while they are caring.

Usually all families meet together informally before they are matched. Children are generally placed near their own home so that they can continue at school and with their other regular activities. After the first visit, you will probably make

arrangements directly with your exchange family. The scheme organiser will however keep an overall check on what is happening.

These schemes are run by Social Services Departments, sometimes together with Health Authorities or voluntary organisations. They are usually free for children, but adults will probably have to pay a small fee.

**'My husband didn't like the idea of 'fostering'—it's not easy to say—he felt it was a bit of a stigma. But now, five years on, it's fine.'**

**'The 'foster' mother does a lot of things with Zoe that I don't have the time or the energy to do. She can get Zoe doing it...She can stimulate her. She gets more attention in that respect that she does at home.'**

Most of these schemes are fairly new and considered to be 'experimental', but they seem to be successful—nearly everyone involved likes them. Parents who said 'Never' when the idea was first put to them have become regular and appreciative users, and older people who were very reluctant to leave their own homes have been equally reluctant to go back to them at the end of their stay.

The main advantages of these schemes seem to be:

- They are flexible, local, and informal. They provide the benefits of residential care without the drawbacks of staying in a residential home or hospital. Care in someone else's home may be the nearest thing to care in your home.
- Families can get to know each other well and develop strong friendships and supportive networks.
- Disabled children derive many benefits from being part of an ablebodied family — they can make friends, gain in confidence and become more independent.

However there can be some problems:

- Some schemes cannot accept people who are severely disabled or who need special nursing care (although they will accept people who have regular assistance from District Nurses or other community health staff—and these services should be maintained during the period with the support family).
- Support families can become very involved with the families they are helping. This can be upsetting for everyone if the family has to stop caring for some reason. The organisers of schemes need to keep a careful check on how things are progressing between families to make sure that they don't become too dependent on each other.
- Families who are happy using the schemes for children should ask what will happen when their child reaches the cut-off age at 16 or 18. Many Local Authorities are developing schemes for young adults.

# MAKING ARRANGEMENTS

## FINDING OUT WHAT IS AVAILABLE AND MAKING CONTACT

Finding out what relief care is available can be a difficult and lengthy process, as this carer's experience bears out:

**'It took me ten months of searching, asking and 'digging' around and when I was on the verge of a nervous break-down there was a breakthrough!'**

Unfortunately there is no one professional whose job it is to inform carers or the people they look after about the breaks that are available. On the whole, professionals do not volunteer information and, when asked, often they only know about things they can provide. Nor is there a central reference point for carers to find out about what's available. In fact, many carers get their information from other carers or by accident — they just happened to see a notice somewhere or read something in a newspaper or magazine.

You may have to try on several fronts. So even if you don't want a break now, find out what is available for the future or an emergency. Try to get as much information as possible about every type of service you are considering. The following check list probably covers most of the things you will need to know:

- who is it for?
- what sort of help does it offer?
- what facilities does it have for people with particular needs?
- who is it staffed by?
- where does it take place?
- when is it available and for how long?
- is transport provided?
- are there any charges?
- how do you arrange it?
- is it possible to visit first?

### BREAKS PROVIDED BY HEALTH AND LOCAL AUTHORITIES

You can ask the people you are directly in contact with such as a **social worker**, **doctor**, **health visitor**, **district nurse**, or **specialist** (if you're under one), your child's teacher or **playgroup leader** and so on. Other people you may not already be in touch with but who can help are:

**Children:** Under 5's Adviser, Special Education Officer.

**Adults and Older people:** Hospital Social Worker, Mental Health Social Worker, Community Occupational Therapist, Community Psychiatric Nurse, Community Mental Handicap Team, Disablement Resettlement Officer.

To get in touch with any of these people you will need to find the right department of your Local Authority, Local Education Authority or District Health Authority. (Look in the Phone Book under the name of your City, County, Borough or District.) It may take a few calls to contact the right department or person. Some of them may be able to give you information about voluntary and private services too, but will probably expect you to follow it up.

A few Local Authorities produce information sheets or guides for carers listing all kinds of local help. You can ask at your Town Hall, or Social Services Department to find out if anything like this is produced in your area. All Health and Local Authorities keep a list of private residential homes. To get this ask your doctor or Social Services department.

### **BREAKS PROVIDED BY VOLUNTARY ORGANISATIONS**

There are many charities and voluntary organisations which can give you information about breaks, or which provide services themselves. If the person you care for has a particular condition or disability you should check whether there is a national voluntary organisation providing information and relief care. Some exist for particular age groups or religious or occupational groups so check these as well. You can contact a national voluntary organisation directly. They will give you advice over the telephone or put you in touch with the local branch if there is one.

You will find the addresses of several national voluntary organisations at the back of this booklet. In addition, your library or your Citizens Advice Bureau (CAB) will keep directories listing the addresses of all national and local voluntary organisations.

Several 'umbrella' organisations coordinate and keep information about voluntary groups in local areas. Among these are Councils for Voluntary Service, Rural Community Councils, Voluntary Service Associations, Voluntary Centres or Bureaux, and Disablement Associations. Look them up in the phone book and in the Yellow Pages phone book under 'Charitable and Benevolent Organisations'.

Some voluntary schemes are publicised on the TV, or local radio and in the press.

### **BREAKS PROVIDED BY PRIVATE ORGANISATIONS**

There are many private agencies that employ sitters, care attendants, and qualified nurses. Anyone can apply directly to one of these agencies for someone to work in their home. Look in the Yellow Pages phone book under 'Nursing', or in the local paper. A recommendation from a friend who has used an agency is probably a good guide to choosing one.

You can find addresses of private residential homes in the Yellow Pages phone book under 'Nursing' or 'Residential Homes'. By law any residential care home which takes four or more people must be registered with, and inspected by, the Local Authority. Nursing homes must be registered with the District Health Authority. You can get a list of registered homes from either Authority, but it will not tell you what they are like.

There are some private and voluntary agencies, such as **GRACE\***, **Counsel and Care for the Elderly\***, and **Carematch** (for people under retirement age), that will give you advice on choosing a home that suits your requirements. Some of these agencies also visit and assess homes — but do your own checking as well. Ring any homes you think you may like and book an appointment to visit. You may be eligible for assistance with the fees and you should go to your local Social Security office (DHSS) as soon as you have decided on a home.

## **HIRING YOUR OWN HELPER**

You will not necessarily need a qualified nurse to look after the person you care for. Many people

have the experience and skills to care for sick, disabled or frail people and would be competent to work in your home as a paid helper. Although it may seem that employing someone would be too expensive for most people, this is not always the case. For example, the cost of hiring someone to look after a retired person may be no more than the pensions and allowances they are already receiving. A local branch of the **Association of Carers\*** has produced a useful leaflet on how to hire a helper in your home. The main points are summarised here.

**Planning** Work out what sort of care is needed by the person you look after and what you can afford to pay. In certain circumstances you may be eligible for financial help from the DHSS or a charity. Think about the sort of person you want to employ. It may help to draw up a check list based on what other carers have found important when selecting a paid helper. For people with certain disabilities you may want to get additional advice from a professional or voluntary organisation.

- How easily and quickly can you contact the person and can they get to your house — are they on the phone, do they live nearby, do they drive?
- Have they had relevant experience? — perhaps they've looked after someone in the past.
- Are they in good health and of a suitable age?
- Do they like people of the age and sex of the person you look after?
- When are they available — what hours and time of day or night?
- What sort of tasks are they able to carry out — will they do everything you do?
- How committed will they be to you and the person you care for — what other commitments do they have, are they being realistic?

**Finding your helper** Try your local

contacts, your friends or church, or place advertising cards in local shops. You must ask for references and take them up.

**The Interview** Have the person you look after with you, and if it's possible a friend or relative too. Go through your check list of requirements — although it's unlikely you'll find someone who matches them all. Make it clear exactly what you will expect the person to do and how much you are paying.

**Working together** Arrange a trial period and introduce your helper gradually. Much of the advice on page 28 about introducing a relief carer into your home will be relevant.

**Practicalities** You may have to sort out tax and insurance for them, but this will depend on how much you pay them and how many hours they work for you. Don't be put off — it's quite simple and the Tax Office will help you.

## SORTING OUT MONEY MATTERS

When the person you look after starts day care or has periods of residential care your finances may be affected in several ways:

- You may have to pay for the relief care
- You may be entitled to State help in paying for it
- You may want or need to seek out other sources of help to pay for it
- Benefits received by you or the person you look after may be affected

### PAYING FOR RELIEF CARE

Relief care provided by Health Authorities is free.

Some services provided by Local

## MAKING ARRANGEMENTS

Authorities or voluntary organisations have to be paid for. Whether, and how much, you will have to pay varies according to the kind of care, where you live, and your own resources.

There is usually a small standard charge for day care in centres or lunch and social clubs, which the person receiving the care will be expected to pay for out of their allowances. Some sitting and care attendant schemes are free but others charge according to means.

Payments are rather more complicated for periods of residential care. Children will probably be allocated a certain amount of free care, but for adults there is more likely to be some form of assessment to establish how much of the full cost the person can afford to pay. You need to find out how the assessment is made, so that you can help them query it if necessary. Generally it is the person who will be receiving the care who is assessed rather than the carer but you may be expected to contribute as well in some cases.

You will have to pay for any sort of private care, and the cost can be high. The hourly rate for agency nurses and care attendants may often seem inexpensive but if you have to pay a registration fee, and have to pay for a minimum number of hours as well, this can put the cost up considerably. Private residential homes, and especially nursing homes, can be expensive. Sometimes it can work out cheaper to pay for living-in care. You may be able to get state or charitable help towards the cost of private relief care.

### STATE HELP TOWARDS PAYMENTS

The state system of making payments towards relief care is complicated. This guide can provide only basic information and you will need to seek advice about your particular case. The Department of Health and

Social Security (DHSS) provides leaflets and a telephone answering service called Freephone DHSS. (You will find your local Social Security Office in the Phone Book under 'Health and Social Security'.) The Disability Rights Handbook available in your library, provides clear information for disabled people. Various other voluntary organisations including Age Concern produce guides, or can help you over the telephone. Your local Citizens Advice Bureau (CAB) will also be able to advise you.

You can make a claim on behalf of the person you look after if they are unable to do this for themselves. You can ask the DHSS for help towards paying for periods of residential care in a rest or nursing home if the person's savings are less than £3,000. (If they own their home its value *may* be taken into account.) If they are receiving certain state pensions or allowances they will be expected to contribute these towards the cost. There may still be a short fall as there is a maximum amount that can be paid for each type of residential care. (In these cases you may want to apply to a charity to make up the difference—see below.) You must apply to the DHSS before admission for relief care as they won't pay afterwards. Sometimes the DHSS will make payments towards relief care in the person's own home.

Social Services Departments can sometimes pay for periods of residential relief care, and can make grants towards holidays for certain disabled people. It may take a long time and there are always long waiting lists, so apply early.

### CHARITABLE HELP TOWARDS PAYMENT

There are several sources of charitable help towards payment for relief care, whether it's to pay someone to come into your home, or to pay for your dependant to stay

somewhere else. Some voluntary organisations provide small grants for this purpose. Several will give you information and advice about how to find out what is available. These include **Counsel and Care for the Elderly**\*, **Age Concern**\* and the **Family Welfare Association**\*. Libraries also keep directories of charities and voluntary organisations.

### HOW YOUR BENEFITS MAY BE AFFECTED

Regular relief care in residential homes or hospital may affect the payment of allowances — both those paid to the person you look after and any which you claim for looking after them. It depends on how frequently the breaks take place, and how long they are. You can avoid losing any benefits if the timing is checked carefully. Contact your local DHSS office for more information.

## FINDING OUT ABOUT TRANSPORT

### LOCAL JOURNEYS

If the person you look after is unable to use public transport, a scheme offering personal door to door transport may be an alternative. These schemes vary greatly as to when they operate, how much they cost, and how you book them. You will need to check these details directly with the scheme. (Look under 'Disabled' in the Yellow Pages phone book or contact a Council for Voluntary Service or Volunteer Bureau.) **Dial-a-Ride** is an example of this kind of service. It now operates in several parts of the country, using specially adapted vehicles. Volunteer driver schemes mostly offer lifts in

private cars and are run by many local organisations such as **Women's Royal Voluntary Service**\*, **British Red Cross**\* and **Lions** or **Rotary Clubs**.

Local Authorities provide some transport to their day centres, but there may be a waiting list and charges vary. Health Authorities provide free transport to day hospitals. Your doctor or specialist will arrange this. The most common complaint about these services is that they don't operate to a regular timetable, and there may be a long wait to be taken or brought home. Some voluntary organisations have adapted minibuses which they use for their own centres or clubs as well as outings.

Some bus companies now have buses with hydraulic lifts on selected routes. To find out if any special transport schemes are run in your area you can contact the Transport Coordinating Officer (name varies) in the Planning Department of your Local Council. Don't forget that the person you look after may be eligible for a concessionary fare — contact your local Social Services Department to find out.

### LONGER JOURNEYS

Provision for elderly and disabled people to travel by train, coach, plane or ferry is improving steadily, although many routes and interchanges are still poor. Journeys need to be planned in advance so that help can be arranged, and you must still find transport from your home to connect up with the long distance services.

Sometimes local volunteer driver schemes are able to undertake longer trips to help you and the person you care for to take a break. If a wheelchair lift is necessary they may be able to put you in touch with an organisation that can help.

There are a number of national and local guides giving details about all aspects of travel for disabled and elderly people. Transport operators

such as British Rail produce their own leaflets and RADAR\* publishes several directories and guides. RADAR can also send you the booklet *Door to Door*, published by the Department of Transport, which gives details of many national and local schemes.

### FINDING ALTERNATIVES TO A BREAK

Most carers will find that their need for support fluctuates. You may not always want, or indeed be able to arrange, regular relief care. However, you may be able to draw on other kinds of help to assist you with different aspects of caring. Carers have found the following services and schemes most useful.

**Help in the home** Home Helps, Meals on Wheels, community nurses and many others can give you help at home with household tasks, general caring or specialist nursing. This booklet can't go into details but you should check whether you or your dependant are entitled to help from any of these. Contact your local Social Services office and ask your doctor.

**Escort schemes.** Some voluntary organisations such as the WRVS\* and the British Red Cross\* will provide escorts to accompany the person you care for on an outing or to a course or centre.

**Neighbourhood schemes** (They have many other names too) These schemes are usually run on a local basis attached to a voluntary organisation or a community centre. Their aim is to help elderly, ill or disabled

people who need help with certain tasks or at certain times of the day. They are sometimes set up to keep an eye on people who have recently returned home from hospital. A neighbour or volunteer will call round to light a fire, heat up a meal, and generally check that the person is safe. Ask at a local advice centre or Social Services office.

**Carers' support groups** These groups are usually run by carers for carers. They are self-help groups that meet regularly once or twice a month and give you an opportunity to talk about and share experiences with others in your position. Some are affiliated to a national voluntary organisation and may be involved in campaigning and other activities as well. Most carers find such groups very supportive and feel that, even if they can only arrange relief care for these meetings, they've had a valuable break. A local advice centre such as a CAB will be able to tell you if one exists in your area.

**Advice and Counselling** Some voluntary organisations run telephone advice schemes. A few provide trained counsellors to help carers who are depressed and overwhelmed by caring, or who are unable to make decisions about what to do. Some carers find that ministers of religion can fulfil this personal supportive role.

**Courses for carers** A few Health and Local Authorities, and some voluntary organisations, run short courses which aim to help carers with some of the problems of caring. Topics include lifting and moving people, dealing with incontinence, home nursing techniques and other issues relevant to caring for people with different problems. So far only a small number of carers have taken this training but they have found it useful.

# MAKING BREAKS EASIER

## CHOOSING THE BREAK THAT WILL SUIT YOU AND THE PERSON YOU LOOK AFTER

In some cases it will be possible, with the cooperation and support of others involved, to maintain the normal ways of being apart—the person you care for can continue to go to work, follow their usual activities, meet friends and so on. But when this isn't possible, or as circumstances change, you will have to decide about other sorts of break.

It's important to remember that breaks can prevent a carer from reaching 'breaking point'. A real risk if you are not very well supported and perhaps have money or other worries as well, or if the person you look after is especially demanding. If you experience any of the following symptoms, even occasionally, then a break is strongly recommended. Do you:

- frequently lose your temper?
- sleep badly for no obvious reason?
- feel tired all the time?
- find that even small things which once didn't bother you seem to get on top of you?

In any case, there can be other advantages to starting breaks early on:

- Both the carer and the cared-for person get used to the idea that each has a life of their own.
- If an emergency arises the person you care for will not have to be looked after by a stranger.
- If the person you look after has a condition which is likely to deteriorate, the relief carer can learn to cope with each stage of the disease or disability. Relief care might be refused if it is requested later on.

Of course, you're going to be limited by what's available, but it may be that one sort of break on offer will suit you more than another. Do you want an occasional afternoon or evening out or a regular daily break? Will relief care be most suitable at home or away from home? Some factors to take into account when trying to decide are:

- your age and state of health
- the length of time you have been caring
- the kind of practical support you are already getting
- the emotional support you get
- the particular needs and problems of the person you look after
- their views about having a break
- the views and needs of others you live with
- your financial situation
- your plans for the future

Many carers and the people they look after find that different sorts of break suit them at different times, and that often a combination of care is most useful.

# CARE IN THE HOME MAKING THINGS EASIER

Many carers find that relief care in the home works well. Experienced carers suggest that there are several things you can do to get the arrangements off to a good start.

**Find out as much as you can about the service first** Make sure you know exactly what's being offered, services vary greatly. A lot of schemes insist on a home visit to see that the scheme is suitable for your family.

**Prepare yourselves for the break** This means, wherever possible, involving the person you care for in planning the break, and talking together about the potential benefits for you both, as well as your anxieties. Some carers find that an understanding 'outside' person, such as a social worker or a nurse who has come across this sort of situation before, can help you both to see things more clearly. They can often calm a tense situation.

**Introduce a new carer gradually** Arrangements often work best if you are able to have one or two regular relief carers so that you can get to know each other well. If possible, the relief carer should spend some time with you both before taking over. You might like to stay with the relief carer for the whole of their first visit, and gradually reduce the time you're around on later visits. If the person you care for can't understand clearly what is happening it is of course even more important that you are with them when someone new appears.

You will probably want to stay with them until you are sure they are not distressed with the relief carer.

**Provide full information** When the relief carer first visits your home talk through with them the particular needs of the person you care for. It can help the relief carer to take over smoothly if important details are written down. This would include such things as medication, diet, likes and dislikes, habits and routines and so on. It might also be helpful to demonstrate how you carry out certain tasks. And of course, make sure they are familiar with your home and any special equipment they will need to use.

**Keep up regular services such as home helps and district nurses** Let them know there will be a relief carer in your home and make sure the relief carer knows when to expect them. Sometimes it is even possible to increase this help if you're going to be away for a few days. You should ask for extra help well in advance.

**Allow time for everyone to get used to the new arrangement** At first you may feel that having someone come into your home causes you more work rather than giving you a break. You have to get everything ready beforehand — set out medicines, equipment, clothing and so on — and you have to clear up again afterwards. This probably will be so at first but your relief carer will gradually be able to take over more of these tasks. And it will probably take a while for the person you care for and the relief carer to get used to each other and settle into a comfortable relationship. Don't be too hasty to conclude it's not working if there are 'teething' problems.

**Recognise that your needs may change** When relief care in the home

has been working well for some time it may be that you, and the person you look after, will want to introduce some day care away from home, or a period or residential care. This doesn't mean that you should give up the help at home, indeed many carers find a combination is ideal. If, on the other hand, after a few breaks things really don't seem to be working out, and you can't sort things out with the relief carer, contact the organiser and find out if it's possible to have someone different.

### CARE AWAY FROM HOME MAKING THINGS EASIER

Carers who are used to having breaks suggest there are several things you can do to make care away from home easier.

**Start breaks away from home gradually** Many carers find it's easier to begin with some kind of day care and gradually build up to an overnight stay somewhere, or a longer period of residential care. Try to avoid introducing residential care at a time when the person is experiencing other major changes such as starting school, moving house, or stopping work. Often a combination of day and residential care works well once you're started. Some special schools have residential units attached and some day centres are in residential homes or hospitals and in these cases it can be a fairly easy progression to a break of a few days.

**Discuss your feelings with the person you look after** Carers emphasise how important it is, wherever possible, to plan the break together and to talk together about your feelings and anxieties. Obviously this needs to be done as honestly as possible — it can make things worse if you pretend that everything will be absolutely wonderful from the start. Some carers find that involving a sympathetic outside party can help as well — sometimes they can say things that you can't.

**Get full information about the service** Make sure you know what you're getting — services vary greatly. Sometimes you may have to rely on what your doctor or social worker can tell you. However, it's worth trying hard to visit a place first, with the person you look after if that's possible. Many carers find that it is extremely valuable to do this. It gives you a chance to talk to the staff and the people using the centre and to have a look round in a fairly informal way. You should be able to get a general impression of the place as well as finding out specific things that you want to know about. Even if the person you look after can't accompany you, a visit can at least give you confidence in the standard of care and you can pass on this reassurance to them.

**'This was the fifth home I'd been to, but I could tell it was right. It didn't look as smart as the others from the outside...but when I went in I noticed immediately how warm it was, it didn't smell, and I was invited to have tea with the residents.'**

**Sort out practical arrangements in advance** This may mean working out arrangements for travel, sorting out finances, checking medication, arranging diets, and making sure that

any other special needs the person may have are dealt with.

**Prepare well for the first break** It's very important how the person you care for is introduced to the place and how they are made to feel welcome. You can find out whether there are any particular procedures for doing this so that they know what to expect. If you are using a day centre you can often arrange to stay there with them for the first time (or two) — but don't forget the idea is for you to have a break so they will have to go on their own eventually. If the person you look after cannot communicate everything for themselves, this also provides an opportunity for you to show the care staff how you do things for them.

**Provide full information about the person you look after** Some places encourage you, or the person you look after, to prepare a 'biography' detailing likes and dislikes, habits and routines, and any special points that will help in their care. Even if this is not standard practice, many carers find it's a good idea to do it. Make two copies — one for the staff (make sure someone responsible gets it and knows what it is), and one for the person you care for to keep with them.

**Maintain links with home and familiar things** Make sure that children, and adults who may be confused or disturbed, take a favourite possession and some reminder of home with them, especially if they are going to be away for a few days. You may want to ring to check that they're all right, although some places discourage this. Opinions are mixed as to whether it's a good idea or whether it can make things worse. For example, if you ring and they sound unhappy you may feel you have to give up your break without having given it much of a

try. Some carers feel that for this sort of reason it's simpler if you don't ring or visit. On the other hand, some carers and the people they look after are reassured by keeping in touch and the break works better for them.

**Allow time for the person to settle in** It may take a few weeks for someone to get used to going to a day centre. If the break is for a week or two it may take them a few days to adjust. It's only to be expected that most people will feel strange and homesick at first. You should wait a while before deciding whether the break's right or not.

**Get as much feedback as possible about the break** Some people are unable to give their usual carer a full picture of what the break was like for them. And it's a common complaint from carers that staff do not tell them enough about how the person they care for has got on. If there are no standard procedures for doing this, make a point of letting the staff know that you will expect some feedback. Some places encourage the use of 'diaries' which note the persons progress through the break. Whatever method is used, you should find out whether you can see any records kept and whether your views will be included in them.

**Recognise that your needs may change** Don't assume that the sort of care you start off with is necessarily what will always suit you, and don't let professionals make these judgements for you. If your circumstances change, or there is a change in the person you look after, you may need something else. If things really haven't worked out well, or you feel the standard of care has not been good enough, you may need to make a complaint (page 31 gives more advice on this).

# MAKING CHANGES

## WHAT TO DO WHEN THINGS GO WRONG MAKING COMPLAINTS

Sometimes standards of relief care are inadequate. Common complaints are that dependants' particular needs are not seen to. This means that they might return in a distressed state, or have an accident while being cared for, or return without personal possessions such as false teeth and clothing or come back with someone else's.

If you are unhappy with the standard of care it is very important that you don't accept it but that you try to get things put right. Quite often the providers of services may be unaware that there is a problem and may be very concerned to improve things. And even if your own problem cannot be immediately resolved, your action may help others in the future.

There are various ways of going about this depending on the nature and seriousness of your complaint and the type of service you are using.

In many cases it may be possible to start with the individuals concerned and try to sort things out directly with them. It's best to do this as soon as the problem arises, while the person is still using the service, although it's understandable why you may be reluctant to do this. It is important how you make the complaint. Obviously, you want to

avoid making a criticism in such a way that it rebounds on the cared-for person, or the carer or both. Often a bit of praise can make a critical comment easier to take, and encourage remedial action. If this fails you should then think about making your complaint through more formal channels.

For all services, irrespective of whether they are statutory, voluntary or private, the next level of complaint is to the manager, organiser or proprietor of that service (titles vary greatly). You may at the same time inform your doctor if the complaint is against the Health Authority, or your social worker if it's against the Local Authority. Sometimes these professionals may be able to take up the complaint for you, or advise you on what to do.

If you feel that none of these channels is adequate, or that you don't get much response, you can contact the officials whose job it is to represent the interests of consumers:

**A local elected councillor** should be able to help with any problems arising from Local Authority services. Libraries keep a list of councillors and you can write to one directly at the town hall.

**The Community Health Council (CHC)** will help with problems about health services. You will find the address in the telephone directory.

**Your MP** can sometimes follow up complaints that you can't get resolved in any other way. You can get the name of your MP from the library and write directly to him or her at the House of Commons, London SW1A 0AA.

For complaints against private

agencies contact the Licensing Authority at your Local Authority or Department of Employment.

For private residential homes contact the Registration Officer (name may vary) at the Local Authority. For private nursing homes contact the Registration Officer (again, the name may vary) at the District Health Authority, who will investigate the complaint.

If your complaint warrants any kind of legal action, in that you want to obtain compensation or prosecute for negligence, you must seek legal advice before going ahead. You could become entangled in expensive and drawn out negotiations. A Citizens Advice Bureau, (CAB), law centre or solicitor will be able to advise you on how to proceed.

## CAMPAIGNING AND PLANNING

Most carers would like to have a say in the type of relief care that is available and how it is organised. There are different ways of going about this depending on how much time you have and what you feel you are able to do.

Of course, a great many carers are not able to become 'active' themselves. But you can let your views be known by talking to people and writing letters so that other people can act on your behalf. You can find out what is on in your area, and what plans there are for relief care services by contacting your local Community Health Council or Council for Voluntary Service.

If you are able to become more involved you can get together with others by joining a carers' support

group, or a voluntary organisation. The Association of Carers\*, Age Concern\*, Mencap\*, The Alzheimer's Disease Society\*, are just a few who are encouraging carers to become involved in planning. Groups of carers can often set up Associations with the staff at Special Schools, hostels and special centres, and try to influence the running of these services. Some carers' support groups campaign locally to try to increase and secure funding for the sorts of support services that carers actually want, such as care attendant schemes, and small locally based residential units. Some national carers' groups are campaigning for carers' entitlement to support services and financial assistance.

If you want to be more active it is possible for a carer to become directly involved in the planning of local services. You could become a representative of a voluntary organisation on a formal planning committee such as a Joint Consultative Committee (JCC).

JCCs are a means for the Health and Local Authority to coordinate certain existing services and discuss proposals for future services. The voluntary organisations in the area can nominate three members.

These committees are also responsible for allocating funds to new projects which the Health and Local Authority agree to pay for together for a certain time. (This is known as Joint Finance.) Many schemes to help carers, such as some Crossroads schemes, sitting services and day centres, are funded in this way. It is therefore of crucial importance to carers how the decisions to spend this money are made.

To become a member of a JCC you do not have to have professional status, nor do you have to be an employee of a voluntary organisations. However, you would be a representing the interests of voluntary organisation in your area as a whole,

## MAKING CHANGES

not your own personal concerns. So although it might be your desire to improve things for carers that motivates you, you would be expected to have an interest in all issues of concern to the voluntary sector.

You may feel that your time is better spent with a group of carers organising relief for yourselves. Although it demands a lot of time, effort and long-term commitment, it is possible for carers' groups to do this. Sitting and befriending schemes, Crossroads schemes, day centres and hostels have all been set up in this way.

**The Association of Crossroads Care Attendant Schemes\*** will help groups to set up their own local schemes. It will advise on all stages of development from forming a Steering Committee to applying for funding and running the organisation. It also publishes a guide giving fuller information for anyone thinking of taking this step.

**The Association of Carers\***, and some other voluntary organisations, have information about carers' groups which have set up various types of relief care, and may also be able to help you get started.

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### Alzheimers Disease Society

Bank Buildings, Fulham Broadway,  
London SW16 1EP. Tel. 01 381 3177

### Arthritis Care

6 Grosvenor Crescent, London  
SW1X 7ER. Tel 01 235 0902

### ASBAH Association for Spina Bifida and Hydrocephalus

22 Upper Woburn Place, London  
WC1H 0EP. Tel. 01 388 1382

### Dr Barnardo's

Tanners Lane, Barkingside, Ilford,  
Essex IG6 1QG. Tel. 01 550 8822

### BLESMA British Limbless Ex-Service

### Men's Association

Frankland Moore House,  
185/187 High Road, Chadwell Heath,  
Essex RM6 6NA. Tel. 01 590 1124

### British Red Cross

9 Grosvenor Crescent, London  
SW1X 7EJ. Tel. 01 235 5454

### Cancer Relief Macmillan fund

Anchor House, 15/19 Britten Street,  
London SW3 3TY. Tel. 01 351 7811

### urematch

286 Camden Road, London N7 0BJ.  
Tel. 01 609 9966

### sociation of Carers

1st Floor 21/23 New Road,  
Chatham, Kent ME4 4QJ.

Tel. 0321 813981

### eshire Foundation

aunsel Street, London  
QN. Tel. 01 828 1822

### t and Stroke Association

k House North,  
k Square, London WC1H 9JE.  
87 3012

### Association to Combat

### Huntington's Chorea

34a Station Road, Hinckley,  
Leicestershire LE10 1AP.  
Tel. 0455 615558

### Contact a Family

16 Stratton Ground, London  
SW1P 2HP. Tel. 01 222 2695/3969

### Counsel and Care for the Elderly (CCE)

131 Middlesex Street, London E1 7JF.  
Tel. 01 621 1624 (10am-4pm)

### Association of Crossroads Care

### Attendant Schemes Ltd

94 Coton Road, Rugby,  
Warwickshire CV21 4LN.  
Tel. 0788 73653

### Down's Syndrome Association

12/13 Clapham Common Southside,  
London SW4 7AA. Tel. 01 720 0008

### Disability Alliance

25 Denmark Street, London  
WC2H 8NJ. Tel. 01 240 0806

### Family Welfare Association

501/505 Kingsland Road, Dalston,  
London E8 4AU. Tel. 01 254 6251

**GRACE**  
PO Box 71, Cobham, Surrey KT11 2JR.  
Tel. 09326 (Cobham) 62928

**John Groom's Association for the Disabled**  
10 Gloucester Drive, London N4 2LP.  
Tel. 01 802 7272

**Headway**  
200 Mansfield Road, Nottingham  
NG1 3HX. Tel. 0602 622382

**Help the Aged**  
St James's Walk, London EC1R 0BE  
Tel. 01 253 0253

**Holiday Care Service**  
2 Old Bank Chambers, Station Road,  
Horley, Surrey RH6 9HW.  
Tel. 0293 774535

**Hospice Information Service**  
St Christopher's Hospice,  
51-59 Lawrie Park Road, Sydenham,  
London SE26 9DZ. Tel. 01 778 9252

**Invalids-At-Home**  
17 Lapstone Gardens, Kenton,  
Harrow HA3 0EB. Tel. 01 907 17061

**Jewish Welfare Board**  
221 Golders Green Road,  
London NW11 9DW. Tel. 01 458 3282

**Marie Curie Memorial Foundation (Cancer Care)**  
28 Belgrave Square, London  
SW1X 8QG. Tel. 01 235 3325

**MENCAP Royal Society for Mentally Handicapped Children and Adults**  
123 Golden Lane, London EC1Y 0RT.  
Tel. 01 253 9433

**MIND National Association for Mental Health**  
22 Harley Street, London W1N 2ED.  
Tel. 01 637 0741

**Motor Neurone Disease Association**  
61 Derngate, Northampton NN1 1UE.  
Tel. 0604 22269/250505

**Multiple Sclerosis Society**  
25 Effie Road, Fulham, London  
SW6 1EE. Tel. 01 736 6267

**Muscular Dystrophy Group of Great Britain and Northern Ireland**  
Nattrass House, 35 Macaulay Road,  
London SW4 0QP. Tel. 01 720 8055

**National Association of Disablement Information and Advice Lines (DIAL UK)**  
Victoria Buildings, 117 High Street,  
Clay Cross, Chesterfield,  
Derbyshire S45 9DZ.  
Tel. 0246 864498

**National Council for Carers and their Elderly Dependents**  
29 Chilworth Mews, London W2 3RG.  
Tel. 01 724 7776

**National Federation of Gateway Clubs**  
Mencap National Centre,  
115 Golden Lane, London EC1Y 0RT.  
Tel. 01 253 9433

**National Schizophrenia Fellowship**  
78 Victoria Road, Surbiton, Surrey  
KT6 4NS. Tel. 01 390 3651

**Parkinson's Disease Society**  
36 Portland Place, London W1N 3DG.  
Tel. 01 323 1174

**PHAB Physically Handicapped and Able Bodied**  
Tavistock House North,  
Tavistock Square, London WC1H 9HX.  
Tel. 01 388 1963

**Pre-school Playgroup Association**  
61-63 Kings Cross Road,  
London WC1X 9LL. Tel. 01 833 0991

**The Richmond Fellowship**  
8 Addison Road, London W14 8DL.  
Tel. 01 603 6373

**RADAR Royal Association for Disability and Rehabilitation**  
25 Mortimer Street, London W1N 8AB.  
Tel. 01 637 5400

**RNIB Royal National Institute for the Blind**  
224 Great Portland Street, London  
W1N 6AA. Tel. 01 388 1266

**Sue Ryder Foundation**  
Cavendish, Suffolk CO10 8AY.  
Tel. 0787 280252

**Sense The National Deaf-Blind and Rubella Association**  
311 Gray's Inn Road, London  
WC1X 8PT. Tel. 01 278 1005/1000

**Shaftesbury Society**  
2a Amity Grove, Raynes Park,  
London SW20 0LH. Tel. 01 946 6635

**The Spastics Society**  
12 Park Crescent, London W1N 4EQ  
Tel. 01 636 5020

**Spinal Injuries Association**  
76 St James's Lane, London N10 3DF.  
Tel. 01 444 2121

**Voluntary Council for Handicapped Children**  
8 Wakley Street, London EC1V 7QE  
Tel. 01 278 9441

**WRVS Women's Royal Voluntary Service**  
17 Old Park Lane, London W1Y 4AJ.  
Tel. 01 499 6040

### **WHERE TO GET MORE COPIES**

Carers who want one copy free of charge should write to Taking a Break, Newcastle-upon-Tyne X, NE85 2AQ. Please write your name, address and postcode clearly. Health Authorities, Local Authorities, voluntary organisations and other bodies who wish to purchase copies in bulk should write to the same address.