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YOU AND CARING

AN ACTION PLAN FOR CARING AT HOME

PENNY MARES

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BY

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by Penny Mares

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The King's Fund Centre

The King's Fund Centre is a health services development agency which promotes improvements in health and social care. We do this by working with people in health services, in social services, in voluntary agencies, and with the users of their services. We encourage people to try out new ideas, provide financial or practical support to new developments, and enable experiences to be shared through workshops, conferences, information services and publications. Our aim is to ensure that good developments in health and social care are widely taken up.

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INTRODUCTION

If you are caring for someone at home - someone young or old, perhaps someone who is ill, disabled or elderly - you are a 'carer'.

You may not see yourself in this way - it may seem a natural part of being a parent, child, spouse or partner to take on the responsibily of looking after someone who depends on you to care for them. You may feel uncomfortable about labelling one part of your life when you are also many other things; none of us has a single role, and most of us feel we are different things to different people.

But seeing yourself as a carer can help to encourage the people around you to recognise that caring is a demanding job, often done in difficult circumstances. As with any demanding job, you have a right to expect help and support. Seeing yourself as a carer may also help you to realise that you are not on your own. Over six million people in Britain - around one in eight adults - look after someone at home and are likely to share some of your experiences, needs and feelings.

What sort of things would help to make a difference to people who are caring, or being cared for at home? One in three carers get less than five hours a week to themselves. One in four carers has been caring for over ten years. Here are just a few of the needs that carers often mention:

I'd like to be able to take a break more often.

I would like to be asked what I think, not just told what's been decided.

I'd like to be able to get flexible help in the home, as and when we need it.

We need more information about all the different professionals and services that are available.

You and Caring is a book of ideas and suggestions based on the experiences of carers, the people they care for, and those who work with and support carers. It is about organising things to make day-to-day living as manageable as possible for you and the person you are looking after. It doesn't claim to offer easy answers. It does try to give you some space to stand back and think about how you are doing, and about what you need most to help you, in difficult circumstances, to get the best out of life for both of you.

You will find some practical information, but You and Caring isn't a reference book. It is designed so that you can dip into any section that takes your interest. It is about the 'how to' of caring - how to organise your own support, how to organise your time, how to cope with the system, how to deal with professionals. These are everyday things that everyone has to do, and many of the ideas and suggestions in this book apply to all kinds of situations, not just to caring for someone else. The difference is that when you also have responsibility for someone else's needs, many of these tasks can become mentally and physically exhausting.

How to use this book

The important thing is to use this book in whatever way you find most useful.

Every caring situation is different. Every carer is an individual, and individuals do things in different ways. What works for one person may not work for another, so it's up to you to pick and choose the sections that you want to look at. Some suggestions and activities will not be appropriate to your needs or circumstances. The book is designed so that you can pick up and read any short section that you want to - most take between ten minutes and half and hour. Sections are marked so that you can easily find the start and finish.

Each section contains questions and activities for you to try out. There are no 'right' or 'wrong' answers to these - they are there to help you think out about your own ideas, views and feelings. Different activities will suit different people. Some you may not feel like doing, and others may not be relevant, so pick out the ones that interest you most. You can use the space provided to make notes and work out your response to a particular question or activity, or you may prefer to just read and think about them, without writing anything down.

Action plans

Throughout the book you'll also find action plans. These are to help you review what you've read and decide whether you want to take further any of the ideas or suggestions that you've found useful. If you want to try out some of the action plans, start with something that you think will be easy to achieve: don't try to do too much or too many things all at once.

You may find it helpful to read this book or do certain sections or activities with someone else, perhaps the person you care for, other family members or another carer. It may be useful to do different parts with different people.

If you belong to a carers' group, it might be a good idea to discuss some of the questions or do some of the activities with that group. Feel free to adapt or adopt the ideas you find here in whatever way best suits your group.

Organisations and publications mentioned in this book

Full details of all the organisations and publications mentioned in this book are given at the back on pages 66 to 72.

CHAPTER ONE

BEING A CARER

Every person is an individual who is unlike any other. Being a carer makes you special. Someone who isn't a carer can't really understand what it's like. Other carers may have been through similar experiences, and may share some of your feelings, but each of us deals with these things in our own way. There is no right or wrong way to care for someone. Each of us needs to make sense of these experiences and feelings in the way that is right for us.

This chapter gives you an opportunity to think about what being a carer means for you - how you cope with the changes in your life that looking after someone brings, how you feel about the changes, how they affect your feelings and relationships - with the person you care for and with family, friends, neighbours and people at work. It also give you a chance to look at where you are now, where you are going, and where you would like to go.

LOOKING AFTER YOURSELF

You are your most important resource - conserve it!

When you are caring for someone else, it is easy to lose sight of the fact that you are your most important resource. You need to find ways of conserving and recharging your emotional and physical energy whenever you can. Whether you have just begun to care for someone or have been caring for some time, it can help to stand back and take stock of your situation.

That's what the questions below are about. Some of them are to do with how you look after yourself. Others are about the way you organise your role as a carer. There are no right or wrong answers, but at the end there are some comments and suggestions, and details of where you'll find more information and ideas on a particular question later in this book.

1. How often do you get a break from caring?

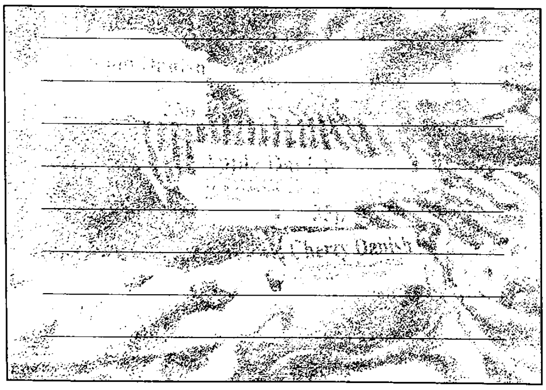
☐ twice a week or more?

☐ about once a week?

☐ less than once a week?

2. Are you eating a healthy diet?

Write down what you ate yesterday.



3. How often do you take some form of exercise ? (swimming, running, walking, yoga, keep fit, etc)

☐ twice a week or more?

☐ about once a week?

☐ less than once a week?

4. Stress can affect us both emotionally and physically. Can you recognise the warning signs?

Do you ever feel	**Often**	**Sometimes**	**Rarely**	**Never**
irritable for no particular reason?	☐	☐	☐	☐
overwhelmed by simple tasks?	☐	☐	☐	☐
panicky or breathless?	☐	☐	☐	☐
over anxious or tearful?	☐	☐	☐	☐
moody?	☐	☐	☐	☐
violent towards the person you care for, or towards other people or things?	☐	☐	☐	☐

Do you suffer from:

☐ indigestion or an upset stomach or bowels ?

☐ sleeplessness?

☐ rashes or allergies?

☐ aches, pains, shakes or nausea?

☐ forgetfulness?

☐ difficulty in concentrating?

☐ restlessness?

☐ nightmares?

5. How do you feel about asking other people for help?

☐ *I could do with some help, but the person I care for won't accept it from anyone else.*

☐ *I don't really feel that other people can give the same quality of care - I prefer to manage on my own.*

☐ *I don't like to talk about the problems to other people; it makes me feel I'm letting down the person I care for.*

☐ *I find it easy to ask for help.*

☐ *If people really wanted to help they'd do something - I shouldn't have to ask.*

6. How did you become a carer?

Here are some carers' experiences. Are any similar to your own?

☐ *It happened gradually - slowly our son turned from a healthy teenager into a stranger.*

☐ *I thought at the time it was the right choice to move my mother in with us - though now I'm not so sure.*

☐ *I was reluctant to take on looking after my father - I still am.*

☐ *I've never thought about it - I do it because she's my wife and I love her.*

☐ *I couldn't put her in a home, so there wasn't really any alternative.*

☐ *I didn't and still don't see myself as a carer. I see myself as a parent of a child who has special needs, but a parent first and foremost.*

☐ *There was no one else so I felt it was my duty.*

7. Do you share the care, or does one person have all the responsibility? What about other members of the family? Are any of these experiences similar to your own?

☐ *We both think it's important not to burden the children with responsibility for caring.*

☐ *I don't like to ask the family for help - I feel it should be offered with love, not demanded.*

☐ *We get together regularly and talk about how things are going. I get things off my chest and it clears the air. The rest of the family are reluctant sometimes but they accept that they've got a responsibility too.*

☐ *We've never really talked about problems - I wouldn't know where to start and I don't think they'd want to know.*

☐ *There aren't any other close relatives, so it's all up to me.*

8. How much of your life is taken up by caring?

Here's what some carers say:

☐ *I sometimes feel that I'm no longer a person in my own right.*

☐ *I try to make as much time as I can for the rest of the family.*

☐ *I feel that most of my time is controlled by other people.*

☐ *I kept on working because I knew I couldn't cope with looking after my mother without some other outlet.*

☐ *I got involved with a local community group - I really enjoy the social contact, and the feeling that I'm doing something valuable in my own right.*

☐ *I go out two nights a week and forget about things for a few hours.*

☐ *The person I look after sulks if I go out, so it's easier not to.*

Feedback

If you've worked through the questions, you may find it helpful to read through the comments and suggestions and decide whether you agree with them.

1. If you are getting a break less than once a week, it probably isn't enough. For your own emotional and physical wellbeing you need time to yourself. Have you found out about schemes in your area to help carers have time off?

See page 26 for where to find out more about taking a break.

2. Eating a balanced diet can help you keep fit and healthy, especially if your sleep is disturbed and you are often tired. Cooking can be tedious, but eating a healthy diet doesn't mean you have to spend hours in the kitchen:

- organise ways to give yourself a break from cooking by having salad for your main meal now and then, getting a takeaway or a precooked supermarket meal once a week, or asking someone else to cook perhaps once a week, or however often they'll agree to!
- there are lots of recipe books on cooking quick and healthy meals
- a microwave cuts down cooking, defrosting and reheating times
- a pressure cooker cuts cooking times for stews and casseroles from two hours to 20 minutes
- with a freezer you can cook large quantities of things like soup, stew and mince and freeze them in portions.

3. Finding a form of exercise you enjoy can make a big difference to tiredness and tension. Running up and down stairs, mopping up or doing the laundry are physically tiring, but they're not refreshing or relaxing. It doesn't have to be daily or strenuous to do you good - gentle regular exercise, such as a brisk 20-minute walk, swimming or yoga twice a week is enough.

4. Many carers suffer symptoms of stress. If you experience several of these signs often or always, you may be trying to do too much. If you are unwell and your GP suggests that your symptoms are caused by stress, ask her or him to suggest or arrange practical help to reduce the pressures on you. If you have persistent symptoms they should be investigated and treated, whatever the doctor's opinion about the cause. If necessary, go back to your doctor and ask to be referred to a specialist.

5. Most of us find it difficult at times to ask for help, but if you're not careful you may reach breaking point. Crisis or emergency arrangements are never as satisfactory as ones you have planned and organised. See page 12 for some suggestions about asking for help from family, friends and neighbours. The charts on pages 33-46 suggest where to go to get practical and financial help.

6. Do you feel that caring is something you have chosen to do? If you do, it may not have been an easy choice. For most people caring is not an easy task but gives the satisfaction of being able to provide something that makes a very real difference to the life of the person they look after. What most carers need is help and support to lighten the load, so that they can organise care in a way that is right for them and for the person they look after, and can get the emotional support they need. That is what most of this book is about.

For a few carers it may not seem like a choice at all. They may feel as if they are the unwilling victims of circumstances. Or sometimes the decision to care, which seemed the right one at the time, turns out to have been a mistake. If looking after someone is making you or the person you care for, or both of you, deeply unhappy, you may need to reconsider the arrangement: certainly you should try to find someone you can talk to about it. It may be possible to get professional help, either to enable you resolve some of the painful feelings or to re-arrange care in a way that causes less unhappiness.

It got to the point where I often felt like slapping my mother. Occasionally I did. I burst into tears on the phone to the social worker one day and told her that I was afraid I was going to hurt my mother. They arranged respite care almost on the spot. Since then it's been better. I thought seriously about a home at that point but now we get regular respite care - a fortnight every three months - it's a lot better.

Some carers find counselling helpful. Talking things over with a trained counsellor can help to sort out feelings and to see problems and possible solutions more clearly.

7. Caring for someone may make family life more difficult. Coping with the pressure of caring can in some ways bring together and strengthen family ties, but it may also create conflict and disagreement. It may mean sacrifices for everyone in the family. Acknowledging these pressures and talking about them can help. It's never too late to begin talking, even if your family finds it hard to discuss feelings and relationships. A regular family meeting can make a big difference.

8. Being a carer is likely to put limits on what else you can do. Most carers feel they are unable to lead a 'normal' life. Though we each have our own idea of what 'normal' is, coming to terms with the loss of a 'normal' life can be one of the hardest parts of being a carer. Recognising these limits is helpful. Accepting them doesn't mean giving up control of your life; rather it means you can think realistically about what choices you have within the limits.

To some extent, we become what we do. Caring changes you. But you can make choices about how you care, about how you think and feel about caring, and about how you organise emotional and practical support.

This isn't easy if you feel your life is out of control, or if you're continually exhausted and depressed. If you find yourself in this situation you should talk to someone about it - perhaps someone else in the family, another carer, or a sympathetic professional. Your GP, health visitor or social worker may be able to put you in touch with other professionals or services that can help.

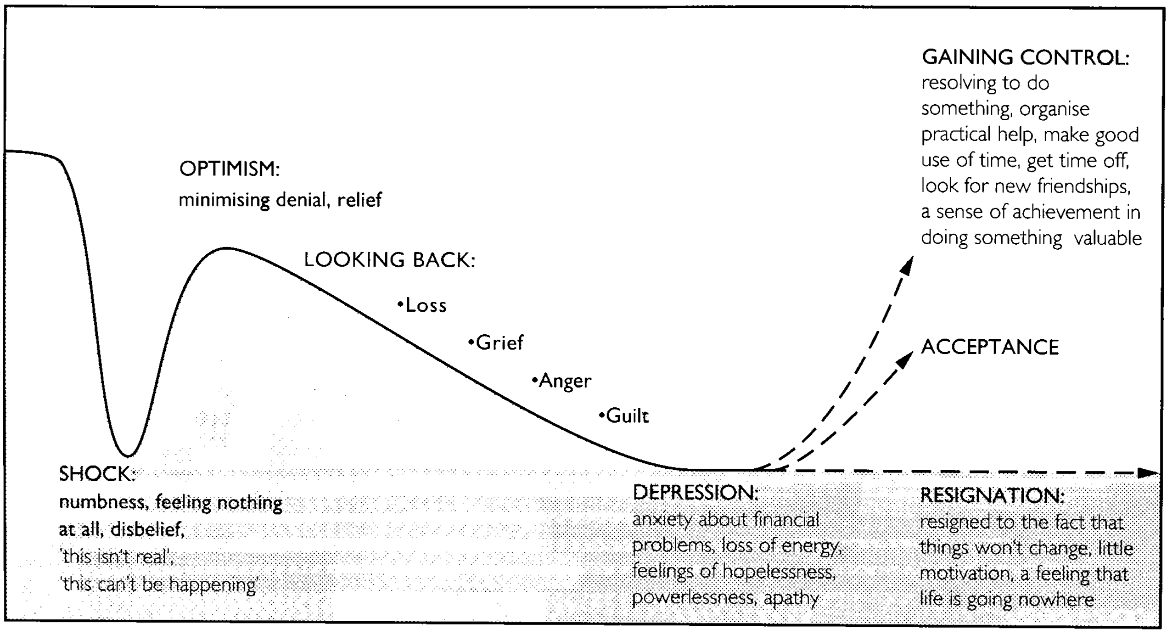
Carers who manage to keep at least some time for enjoying other roles and activities - doing a job, looking after a family, being an active member of a social group or community organisation - seem to find it easier to manage the pressures of caring.

LIFE CHANGES: BIRTH, MARRIAGE, DEATH AND CARING

The birth of a child, marriage, the death of someone we love - these are major upheavals in our life. If our ideals and expectations of the new situation are very different from the reality, the adjustment may take longer and be more difficult. Having responsibility for looking after someone is also likely to mean a major change in your life and in the life of the person you care for. Although we each deal with change in our own unique way, psychologists have found that there are common patterns in the way we do so, and in how we feel about and make sense of it. This is true whether the change is sudden, or gradual, chosen or unwanted. Understanding these patterns can help us to make sense of our own sometimes bewildering feelings and reactions.

Feelings about becoming a carer

The diagram on the following page shows how we tend to experience and react to changes. Some people go through these stages very quickly, some people take months or years. Some people experience all these emotions and more; others may experience only some of them. Each stage may last a longer or shorter time for different individuals. All these reactions are normal: there is no right or wrong way to react to change.



How we react to life changes

Shock

The first reaction may be shock, especially if the change is sudden. People may also feel like this when they finally get an accurate diagnosis of a problem that has been worrying them for some time. The sense of shock and disbelief may continue for a while.

When my husband had a stroke it was like a nightmare - I kept hoping I would wake up and find I'd dreamed it. It took a long time to really sink in.

Optimism - making the best of it

This often follows the initial shock. We tend to try and reassure ourselves, seeing the positive side of things, trying to minimise what has happened, perhaps hoping it is a temporary situation or that things are not as bad as they seem. Sometimes there is a sense of relief; for example, getting a diagnosis, even though it may bring new anxieties, may mean an end to disturbing worry and fear of the unknown.

Looking back, loss, grief and other emotions

It is natural to look back to things that seem to be missing or lost from your present life - the loss of freedom, friends or even perhaps the loss of a job, if you have given up work to care. If the feelings, personality or behaviour of the person you care for have been changed by their illness, you may also feel you have in some ways lost them, too. People who care for sufferers of Alzheimer's disease, for example, sometimes say the illness is like a 'living bereavement' as they see the person they know and love gradually become a stranger.

It helps to acknowledge feelings of loss, and to recognise that powerful feelings like guilt, anger, bitterness and despair are a part of coming to terms with the pain of loss. We need to grieve, not only after death, but after any painful loss. It's healthier to express these feelings than to deny them or keep them to ourselves. Finding constructive ways of expressing them can help, perhaps through drawing or painting, writing poetry, letters or articles, organising a campaign for carers - or simply by talking about them with someone you trust.

Anger

It is common and quite natural to feel angry - at the loss of freedom, the difficulties of caring for someone, the person needing care, other people who don't understand or who can't or won't help. It's important to find an outlet for strong feelings like this. Going out of the room, counting up to 20 or doing physical activity - even vigorous hoovering - can help to diffuse angry feelings. It can help to talk to other carers, who are likely to have been through similar feelings, or to anyone whom you feel you can confide in. Anger can be used positively - some people find it motivates them to do things like campaigning for better services. But it needs to find some form of expression or it can be destructive.

Guilt

Guilt is a common feeling following a major change or loss. Most carers experience feelings of guilt at one time or another about a whole range of things, from large to small.

I always feel that I'm not doing enough, that I ought to be able to do more to try and make up for what's happened to him.

I do push myself, I can't relax if the place is untidy because if someone comes I feel awful, because I know they won't understand. I feel like I'm letting myself down.

Although guilt is an understandable feeling it is often not helpful. Feeling guilty can prevent us from thinking clearly and making logical decisions.

When they tell you your child has Down's syndrome they keep reassuring you that it's nothing you've done or not done during pregnancy, but you still wonder if it's somehow your fault. It took me a long time to get over wanting to blame myself - I just wanted to hide.

Carers often set themselves high standards and judge themselves quite harshly. It may not be possible to stop feeling guilty altogether, but we need to be able to recognise guilt and accept that it doesn't really help. It's important not to let feelings of guilt cloud your judgement, and to accept that there are limits to what you can try to do and be.

Depression

Depression can sometimes set in when the dust has settled after a major change - it may seem as if life is going nowhere, and things will never get better. Depression may be part of grief, worry or anger. Denying or bottling up these feelings can make it worse.

Overwhelming feelings

Sometimes feelings can become so strong that they prevent us from functioning properly. Again, finding the right person to talk to about how you're feeling is important. This might be someone in your family or a friend, or perhaps your GP or a trained counsellor. Sleeping pills or tranquillisers may help in the short term but can be habit-forming, so talk over with your GP other things that might help before you consider taking medication.

Acceptance

I've got used to it now. I still get frustrated, and feel angry sometimes, but we just take each day as it comes. Some days he's much better than others. It's a funny kind of life, but there's nothing else to do but get on with it.

The first year was the hardest. Then we gradually got things organised - I joined the carers' group, and we got the house organised properly. I would say to anyone else the best thing you can possibly do is find good day care. That's made such a difference - you need to have time to be your own person.

Gaining control

Depression and resignation don't have to happen. There are almost bound to be days where you feel angry, frustrated, guilty, or depressed - but you can organise things in a way that helps you feel in control, and lets you make choices about what happens. Every major change brings new opportunities - for friendships, for learning, or for new aims and achievements.

Here are some ideas that may help you to feel more in control:

- **Get information** about the condition of the person you care for, and about the practical help available in your area (see Chapter 4). Once you have information you know what to expect and can make realistic choices.
- **Organise your own support.** Draw on the resources around you - ask for help if you need it, accept help when it is offered, and use your networks of friends, relatives, and people at work to find and organise emotional and practical support for yourself as well as the person you look after.
- **Find ways of living a full life in the present.** Look for the new opportunities that caring can offer you - not back to lost opportunities in the past. Set yourself new goals, to replace the ones you're missing. Look after yourself. And try to get regular breaks from caring.

RELATIONSHIPS

Becoming responsible for someone who depends on you is likely to change your relationship with them, with other members of the family, and with friends and neighbours. Sometimes these changes are difficult and painful. Being prepared for them can help. Sometimes new relationships and friendships develop - perhaps with professionals or with other carers - that bring new strength and support.

Your relationship with the person you look after and the feelings you have for each other may be changed by their illness or condition. Like you, the person you care for is likely to feel at times angry, frustrated, resentful, and depressed; if their condition or illness has brought about a great change in their life, they may suffer intense feelings of loss and grief. They may feel bewildered or frightened and they may feel angry or frustrated at having to depend on someone else.

If their condition affects their ability to communicate, it may be difficult for them to tell you or for you to know exactly what they are feeling, or why. Touch, tone of voice and body language may be the only way you can 'speak' to each other.

Are you and the person you care for able to talk to each other about your feelings? If you are, do you talk to each other? Do you listen to each other? If the person you care for cannot communicate easily, can you tell how they feel from their body language, or tone of voice? Can they tell how you feel?

If it is difficult to talk to the person you look after, for whatever reason, you may find it helpful now and then to imagine yourself in their place. What would you want to say to the person who looks after you if you could talk freely about how you see things?

Changing roles

The condition or illness of the person you care for may mean that your roles within your relationship - and within your family - are radically changed.

Caring for a parent may mean that your roles and responsibilities are reversed. A parent may try to treat an adult son or daughter like a child, or wish them to behave like one, while adult children can find it painful to accept child-like behaviour or dependence in a frail elderly parent.

Caring for a spouse or a partner may mean taking over some of their roles. This can sometimes be painful or difficult not simply because of the actual tasks involved but because they embody in a tangible way the changes happening to the person you love. Some

conditions may change the love and closeness that two people feel for each other, and can also affect their sexual relationship. It helps to talk with each other about these changes if you can, and to try and find other ways of expressing love and sexual feelings.

My husband completely lost interest in sex. Counselling helped me to stop feeling guilty about my sexual feelings - I realised all these urges were normal and healthy, and I could start to talk about it to him.

It might be a good idea to find a counsellor trained to help with marital and sexual relationships. Counselling can help you and your partner work out your own and each other's needs and feelings. For some carers, counselling is a valuable part of their support (see page 14).

RELATE (formerly the Marriage Guidance Council) and **SPOD** (the Association for Sexual and Personal Relationships for People with a Disability) can put you in touch with suitable counsellors. If you are caring for someone with AIDS the **Terrence Higgins Trust** can introduce you to counselling help or a local support group.

Many carers find conditions such as incontinence difficult and upsetting. People with incontinence may deny or feel ashamed or afraid of what is happening to their body. It may be hard to talk to a parent or partner about very personal things like body functions. Incontinence can always be helped, and can sometimes be cured completely. **The Continence Advisory Service** at the **Disabled Living Foundation** gives confidential counselling, information and advice about coping with incontinence.

Difficulties in the relationship

A relationship in which there has been a lot of conflict, tension or other negative feeling may become worse when one person is dependent on the other for care. Though it is important to let go of the past, becoming a carer doesn't wipe it out. Be honest with yourself about your feelings towards the person you care for, and about theirs towards you. For example a domineering parent or partner may become more demanding through illness, not less.

I wanted to look after Dad because I thought it was the right thing to do. But he became even more irritable and bad-tempered when he was ill. I suppose I didn't really like him much, but I'd never admitted it to myself before. Then I felt guilty, because he was so pathetic. Then I felt angry at him for making me feel guilty.

Who depends on whom?

The relationship between the carer and the person needing care may in fact be one of mutual dependence: there may be lots of ways in which the carer depends on the person they look after.

Everyone thinks Dorothy depends on me, because she can't see and can't walk far. In fact, she's the boss. She gets things organised, and gives me jobs to do. I'm hopeless at organising. We both need each other - I couldn't cope without her.

I do get a sense of fulfilment from being needed and valued, and from seeing him happy and well cared for.

Needing to feel valued is positive, but sometimes it is possible to become dependent on the caring relationship in a negative way. It may be difficult to recognise what is happening.

After Mum died I actually thought about suicide. I had no one. I was terrified of going out. I had nothing left to live for. My world had been these four walls for so long.

My daughter made me realise that I was blaming Frank's illness for not having had a life of my own. She wanted me to go on holiday with her and the family. She said, 'Are you going to spend the rest of your life blaming Dad, or are you going to enjoy yourself when you're given the chance?'

Relationships with family and friends

Some carers get a lot of support from family and friends, but others don't. Some members of the family may live too far away or simply not want to get involved in sharing the care. Giving up work or not being able to go out may mean that both of you lose touch with friends you used to see regularly.

Some people may be frightened or embarrassed by the condition of the person needing care, especially if it has changed their personality or behaviour. It may help to talk to family, friends and neighbours about what to expect from the person you care for, and to explain the illness or condition and what its effects are. Lending someone a booklet or leaflet about the condition can make a difference.

Caring for someone may change the way you are able to spend time with the rest of the family. It may change your relationship with your spouse or children, who may have to take on new roles and responsibilities. Here is how some carers feel about the changes in their relationships with other people:

We're thankful that we have a strong marriage and have been able to support each other in caring for our son.

I feel bitter that our friends have deserted us.

I'm determined not to put my children through what I've been through with my mother; I want them to put me in a home when I get decrepit.

I feel sad that the family won't help, and trapped.

Has caring changed your relationships with family and friends? If so here are some things that may help:

- **Recognise that some friends and relatives may drift away** - unless you make the effort to keep in touch.
- **Accept that some relatives and friends will not want to be involved in sharing the care on a regular basis** - although they may be willing to take on a specific task if you ask them.
- **Realise that people who offer to help often don't know what you need** - don't feel awkward about accepting help, but remember it's up to you to turn the offer into something concrete or practical.
- **Find ways of meeting or making contact with new friends who are willing to be involved** - perhaps a volunteer sitter or other carers.

Accept that these changes in relationships are not unusual. A family which feels the pressures of caring is a normal family. Friends do become more distant through lack of contact - this is normal too. What you need now from relationships with other people is likely to be different from before, and so you may need to look to different people for what you need.

What do you need or want from relationships with other people?

This isn't a selfish question. You are not being disloyal to the person you care for by giving time to your own emotional needs. If you neglect yourself,you may find that you become so drained that your emotional and physical ability to care are permanently damaged.

ACTION PLAN

1. Read through the suggestions below about what you might need. Do any strike a chord? Put a tick beside the things you feel you need at the moment.

2. What else would you add to your list of needs? Write your other needs in the space at the end.

3. Who can help? Under each point that you've ticked, try to write in the name of someone you could talk to or ask for help.

I need:

☐ to feel valued

☐ to talk without inhibitions about how I'm feeling

☐ help with practical tasks

☐ someone to listen

☐ someone who really understands what I'm going through

☐ acceptance of the person I care for, for what they are

☐ company for the person I look after, apart from me

☐ someone I can feel close to

☐ someone to help with the daily routine

☐ someone to do odd jobs

☐ social contact that will take me right away from caring for a few hours

What else would you add to your list of needs?

Now you've finished going through the list, have you got any new ideas about people you would like to get in touch with or see soon? Why not decide to make contact with one or two people in the next week? Start with someone about whom you feel confident. Work out what you'd like to say to them, and decide when you'll do it by. See how you feel after you've made contact with them.

Who I will contact:

What I will say:

When I'll do it by:

Using your network of relationships

If you tried the activity above, you began to think about how you could use your network of relationships with other people to organise support for yourself. You can build on this by making a list of all the people you know. Make three lists:

1. **family and friends**
2. **local groups** (for example, community organisations, church groups,voluntary groups)
3. **professional workers** you have seen in the past six months.

Go through each list person by person and think about what kind of help or support they might be able to offer. Do they have time to spend with the person you care for? Can they give you information, or tell you where to get it? Do they know someone else who could help? Could you talk over a problem with them? Asking yourself these questions may give you some more ideas for people you would like to see or contact.

Counselling

Talking to someone about a problem can help a lot, but it needs to be the right person. Family and friends aren't always helpful. A counsellor is someone trained to listen sympathetically and without criticism, in absolute confidence, who will encourage you to talk freely about things that are troubling you and help you find solutions or ways of resolving problems that are right for you.

For me the best thing about counselling was being able to put into words all these murky feelings about looking after Joe that had been lurking under the surface - things that I felt rather ashamed of. When you find that the person listening doesn't react with shock or disapproval you sort of stop feeling ashamed. Just by talking about them somehow the murky thoughts lose their awfulness and become easier to deal with.

Counselling is not widely available on the NHS or as a social work service. Most counsellors are independent practitioners. Charges vary widely, from about £10 to £25 a session. It's important to find a counsellor who suits you - someone you feel you can trust and get on with, and who is qualified and experienced. Personal recommendations are often best. Counsellors tend to specialise in different areas, so always check whether the person you contact has experience in dealing with the kind of problems that you want to discuss. Your GP, health visitor, social worker, or a local carers' group or voluntary organisation may be able to recommend someone. **The British Association for Counselling** or **Counselling Information Scotland** can provide a list of counsellors in your area who are registered with them, with details of their qualifications, the type of problems they counsel, and likely costs.

In a crisis some telephone helplines offer counselling help. **The Samaritans** are one of the best known, and also have details of other local counsellors and the type of problems they counsel. Look in the **Yellow Pages** under 'Counselling and Advice' or 'Social Services and Welfare Organisations' for other helplines and counselling services.

MANAGING STRESS

Stress (or tension) can be caused by any event which seems to you to need a quick reaction. This is sometimes called the fight-or-flight reaction because of its role in our evolutionary history. The heart beats faster, muscles contract, breathing becomes shallower and quicker, and adrenalin and fats are released into the bloodstream to heighten energy and alertness. The situations that produce these reactions today don't usually need a quick physical response, and stress becomes harmful if there is no opportunity to relax and recuperate in between situations that make you tense, or if the situation you find stressful is not temporary but continual.

Stress affects everyone differently. The important thing is to be able to recognise it and do something about it. If you are looking after someone, many aspects of day-to-day living can be stressful. Rather like tiredness, you may become so used to stress that you're not aware it is affecting you. Constant stress can produce the kinds of symptoms and behaviour listed on page 8. There is increasing evidence that stress can affect the efficiency of our immune system, and can make us more susceptible to illness.

There are various ways of tackling stress. You can try to reduce or remove the external causes, if possible. Or you can try to tackle the internal causes - feelings or attitudes that contribute to feelings of stress. Or you can tackle the physical symptoms. A combination of these approaches is likely to be most helpful.

For each of us, the causes of stress are likely to be different. The most obvious causes are external, and it may not be possible to do anything about some of them. Sometimes our own feelings and attitudes - towards other people, situations, relationships - can contribute to our feelings of stress. It may be possible to do something about these.

What for you are the main causes of stress? Is there anything you can do to reduce or remove any of the things that cause you stress?

- **Do you find some relationships particularly stressful?**

- **Do you recognise and accept that there are limits to what you can do,** or do you tend to push yourself too hard and be too self-critical?

- **Do you respect tiredness and reduce what you expect of yourself accordingly?**
- **Do you get a regular break from the things that you find most stressful?**

Things that can help to reduce stress

What suits one person won't necessarily suit another - you may find that none of the ideas below are useful. Each of us has to work out ways of tackling stress that suit our individual needs and personality. It's well worth looking at some of the excellent books available on dealing with stress, where you'll find more comprehensive information. Put a tick beside the suggestions below that you think might help you.

- **Accept your limits and set yourself realistic targets.** Lower your sights when you're tired. Measure yourself against your own targets - don't compare yourself to other people.
- **Try to avoid thinking negatively.** Try to turn negative feelings into positive ones - not 'I'll never get everything done' but 'I will get three things done today'.
- **Try to do something about the things that cause you stress if you can,** but if you find that you can't, accept that fact. Don't waste valuable emotional energy struggling against something that you can't change.
- **Keep a private journal or notebook.** Write about things that make you sad or angry or happy. Write poetry, draw, sketch or do cartoons. Write about your dreams, write an imaginary letter to or a conversation with someone. Write about the people or situations that make you feel stressed - try to put into words why they affect you, and how you would like things to be different.
- **Be assertive in your relationships with other people.** This doesn't mean being aggressive, it means finding ways of being honest, open and direct. Most of us find this hard in at least some relationships, especially where we feel the other person is not honest, or is unreasonable or manipulative.
- **Get regular breaks from the things that you find stressful.** Find out about different types of respite care (see page 41) if you need more regular breaks from caring.
- **Learn techniques to help your mind and body relax deeply, so that you can switch off from stress.**
- **Treat yourself sometimes** - buy yourself a present, go to a film or play or concert, give yourself time now and then to do something special that you really enjoy doing. Make yourself stop thinking about everything else except enjoying yourself.
- **Learn to cultivate your own 'natural' ways of releasing tension.** For some people this might be a walk, or a good cry, or a pint of beer or a favourite piece of music. Do whatever you find most relaxing, and try to do it often enough.

Relaxation techniques

Some techniques concentrate more on relaxing the body, some more on the mind, and some combine both. There are lots of other variants of the techniques described here, so try a range of them to find the ones that suit you.

Relaxation exercises

A simple relaxation exercise can help to get rid of physical and mental tension. Lie flat on your back on the floor or bed and, starting from your toes, work up your body slowly, first tensing and then relaxing the muscles in your feet, ankles, calves, knees, thighs, and so on until you have been through all the muscles in your body, ending with your neck, scalp and face muscles. Do this for a few minutes each day, and whenever you feel particularly tense.

Breathing

Slow, deep breathing helps you relax. Sit or lie down, close your eyes and concentrate on breathing deeply. Concentrate on breathing out slowly - try to empty your lungs. You will find that breathing in will happen by itself. Breathe deeply six times. Breathe only as deeply as you find comfortable - don't push or strain. Practise this every day, so that you find your own comfortable rhythm for deep breathing, gradually increasing the number of breaths you take. Work up to about five minutes every day.

When you feel tense, you'll notice that your breathing is quick and shallow. Switching to deep breathing will calm you and help release tension.

Visualisation

With practice you can learn to use your imagination to take a break and relax by visualising yourself in a situation where you feel calm and peaceful. Here is an example. Close your eyes and imagine yourself walking slowly into a perfect garden on a warm sunny day. As you walk along notice the sounds, the smells, the warmth of the sun on your skin and the rich colours of the garden. Imagine yourself sitting quite still in the sunshine, absorbing the garden through all your senses. Do this for five or ten minutes, until you feel completely rested. Then imagine yourself getting up and slowly leaving the garden, until you are ready to come back to the real world and open your eyes.

Yoga, meditation, and autosuggestion are other techniques that can help both mind and body to become relaxed and calm. Some exponents of these techniques believe that with regular practice they also lead to a deeper spiritual awareness.

ACTION PLAN

Read back over the section on managing stress. Have you found any of the ideas or suggestions useful? Write down one or two things you would like to start doing to reduce stress. (They don't have to be ideas from this book - write in your own ideas if you prefer.) Then decide when and how often you will do them. Don't be too ambitious at first. Set yourself an easy target to achieve - perhaps a twenty-minute walk once a week, or a five-minute relaxation routine each evening!

IDEAS TO REDUCE STRESS	When will I start	How often will I do it?

CHAPTER TWO

ORGANISING YOUR TIME

How do you plan your time? If you feel you don't have enough time to plan, you probably aren't getting enough time to wind down and relax either. A recent survey by the Crossroads scheme found that a third of carers have less than five hours a week to themselves.

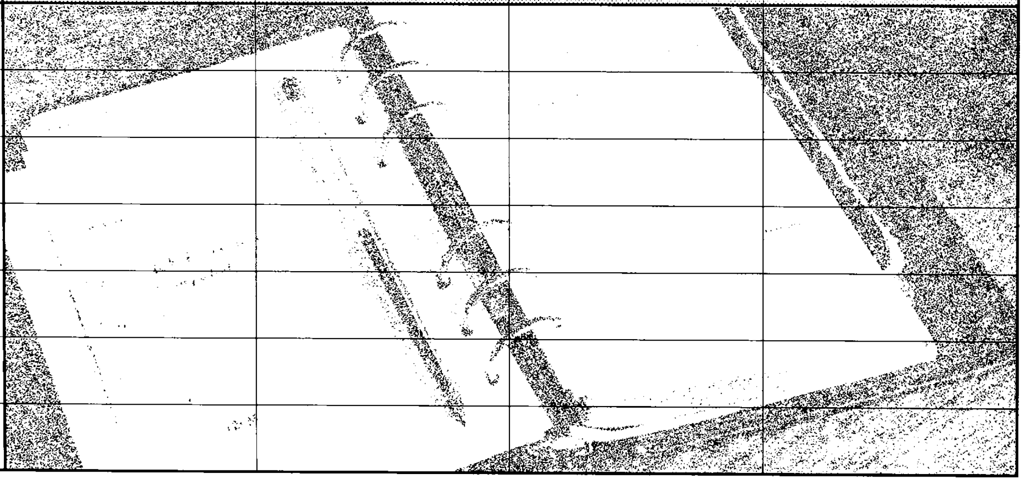
Some days I'm so tired I can think only one step ahead. I run out of milk, go to the corner shop, come back to make the tea and remember we've run out of tea as well.

NO TIME FOR ANYTHING

To care for someone else, you need to be well yourself. A good idea is to start by analysing how you spend your time now. One way is to keep a diary or record over several days. If you can, fill in the chart below at the end of each day for a week - it need take you only a few minutes. By the end of the week you should aim to have a detailed record of how much time you spend on, for example, relaxation, exercise, social activities, caring tasks, housework, cooking, shopping, paid work (if you have a job) and any other activities that are a part of your daily or weekly routine.

Discuss the chart and how you fill it in with the person you care for, if possible. The purpose of keeping the log is to help you become more aware of how you spend your time. The next step will be to look at whether there are changes you could make, however small, to organise your time more effectively.

Record the day, the time, what you did, how long it took, and any comments you want to add. Use the time-chart here to keep your own diary, or draw up your own version. Start the diary on whatever day of the week you like. Keep your record somewhere where you will remember to fill it in at the end of each day.



DAY	MORNING	AFTERNOON	EVENING	NIGHT
MONDAY				
TUESDAY				
WEDNESDAY				
THURSDAY				
FRIDAY				
SATURDAY				
SUNDAY				

Once you have filled in your diary, you can look more clearly at how you use your time. You may find it helpful to use the time chart on the next page to work out how much time you spend on different types of activity.

Add up the total number of hours you spend on each type of activity in the week. Divide by seven to get a daily average, and mark this on the chart.

When you've finished look the chart over carefully. Was this a typical week? Does anything surprise you about how you spent your time? What do you most need or want to change about the way you use your time at the moment?

If you can, discuss your chart with another carer or group of carers. Everyone's chart is different, of course, and for some carers no two days are the same. But a lot can be learnt by comparing experiences and exchanging ideas about how to juggle your time within the limits that you have.

TYPE OF ACTIVITY HOURS:	1 HR	2 HRS	3 HRS	4 HRS	5 HRS	6 HRS	7 HRS	8 HRS
Housework, cooking, cleaning, shopping								
Caring and nursing (the person I care for) extra cooking, if necessary, bathing, help with going to the toilet, dealing with professionals, filling in forms								
Personal care (of myself)								
Care of other family members feeding children, playing with children								
Paid work								
Sport or active leisure, walking, swimming								
Social activities (on my own)								
Social activities (with the person I care for)								
Relaxation								
Community activities going to social/political meetings, church/voluntary activities								

Who decides how you use your time?

The needs of the person you are caring for are likely to play a large part in how you use your time. There may be other people whose needs fill up your time. Go over your diary and, for each activity, ask yourself:

- **Who decided how you spent that aspect of your time?**
- **Is it fixed or can it be changed?**

You may be caring for someone who is only partly dependent on you, and you may not be caring for them all day long. But many carers, whatever their circumstances, feel that their time is controlled by other people - by the person they care for, by other family members, or by professionals, who often seem to find the most awkward times to visit.

I look after my father 24 hours a day. I almost never go out because he won't have anyone else in the house.

Caring for someone can be a full-time job and, because you look after someone, there are limits on what you can do. But even within these limits there are choices. If you choose to build your routine around the needs of the person you care for, and it works for you both, that's fine. But if you feel that your time is always controlled by someone else, and that you cannot make choices, you may be storing up future problems for both of you.

The right time for you

Each of us has a personal time clock that affects how well we function at different times of the day or week. If you discuss these questions with the person you care for.

- **What time of day do you feel at your best?**
- **What do you do at the moment during your best time of day?**
- **When is the best time of day for the person you care for?**
- **What does he or she do at the moment during the best time?**

Are you both using your best times in the most effective way? Write down two things you like to use your best time of day for and then write down two things the person you care for would like to use their best time for. Discuss this together if you can.

What is your worst time of day?

What is the worst time of day for the person you care for?

What could you change to make the difficult times of day as easy as possible? Again, discuss this together if you can. (You don't have to be ambitious - it's better to start with small changes which are easy to achieve.) Write down two suggestions. Here are three ways other carers have chosen to organise their time to make some space for their own needs.

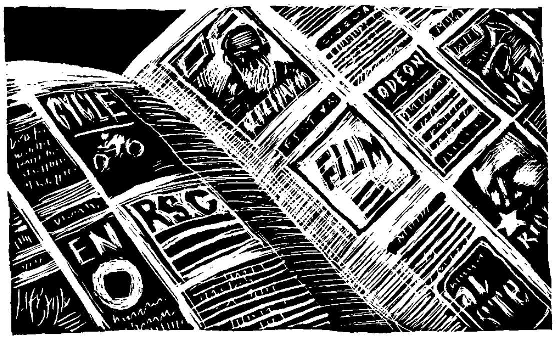
1. Adapting to the other person's routine to make more time for yourself.

I fit my routine in round my husband now because I found as his condition (Alzheimer's disease) got worse neither of us were getting enough sleep when we tried to stick to a normal day. He's very restless in the evenings and doesn't go to bed till about one. But then he sleeps late in the mornings, so if I get up by nine I have two or three hours to myself. I have a long bath in peace, and do jobs that I can't do when he's up.

2. Spending time on your appearance in order to look and feel more confident.

The first half-hour of the day I spend on myself. I do my hair and put on my make-up and then I feel I'm ready to face things. It may seem silly but, if I know I look good, it gives me more confidence to face things. Then I start seeing to my husband.

3. Building in a social routine to get out of the house and relax.



My parents-in-law both live with me and my mother lives ten minutes away. My father-in-law's disabled and my mother-in-law's getting quite confused. My mother's very arthritic but she copes on her own. I cook her a dinner and take it up every evening. In fact it's a relief to go and see her. I have a sitter so I can go out three nights a week with friends, and I go to a carers' group once a fortnight. Sometimes I'm so tired I really have to force myself to go out, but I couldn't do it if I didn't - I wouldn't give up my nights out for anything.

SETTING REALISTIC TARGETS

When you care for someone you want to do your best for them. You may have other members of the family to think of as well. You may worry about giving them enough time.

Many carers set themselves very high standards, feeling that if they don't do this and don't struggle to achieve them, they are somehow failing the person they care for or are failing in their responsibility to care:

We were given exercises to do with our Down's syndrome daughter. At first we struggled to get her to do them every day, even though she didn't like it - if we missed a day we'd feel guilty that we were somehow failing her - not giving her the best opportunity, and worrying that we weren't doing as much as other parents would. It took some time before we learnt to relax and not feel guilty about whether she was achieving the maximum - we began to learn to enjoy her for what she was, and to let her enjoy herself and just be herself.

The goals that you set for yourself and the person you care for have to depend on what is right for both of you. Everyone needs to feel a sense of achievement and satisfaction, but this comes from working out what is right for your situation. This means being flexible, knowing yourself and your own capabilities, and being forgiving towards yourself.

Learning to say 'NO'

We all find it difficult to say 'no' - to ourselves and to other people: family, and friends, neighbours - staying up until midnight to finish the ironing rather than getting an extra hour's desperately needed sleep, or agreeing to a long and tiring hospital trip for hearing tests when you know the person you care for will refuse point-blank to wear a hearing aid. Saying 'no' means acknowledging that you are overstretched and pushing yourself beyond your limits. It may also mean asking someone else for practical help, the other side of saying 'no'. If you find it difficult to say 'no' or to ask for help, you are likely to end up exhausting yourself, and the people around you may not realise the strain you are under.

Sometimes other people may not want to see the strain you're under. This is true of some professionals as well as family, friends and neighbours. Unless you tell people clearly, they may choose not to hear what you are saying. If you believe you are important to the person you care for, you need to be able to say 'no' sometimes, for their sake as much as your own.

Here's an exercise to help you think about the things that make you feel overstretched. Ask yourself:

- **When was the last time you felt you were overstretching yourself?**
- **What are the things you would like to say 'no' to?**
- **Who would you like to say 'no' to?**

Do you find these questions difficult? Do you feel it's more important not to upset someone or to avoid hurting their feelings? We all feel like this sometimes, but for a minute just think about what it means. You are putting another person's feelings before your own, but what if you always do this? Do you really believe your feelings are always less important than someone else's? Why? There are two common reasons why people feel like this. They may be trying to prove they are superhuman or they may not value themselves and their own well-being very highly.

Saying 'no' doesn't mean that you're being selfish, or disloyal to the person you care for. It means being realistic about your limitations, so that you can maintain the energy and resilience you will need to be able to provide long-term care. Nor do you have to ride roughshod over other people's feelings. Often there is a middle course or compromise which in the long term is better for both of you.

Here is a carer who said 'no' to a domestic arrangement that was making life unbearable for the whole family.

When she first came to live with us, we thought Ken's mother would just be part of the family. I don't think we anticipated the problems. She doesn't mean to interfere, but the first six months were dreadful for all of us, including the children. So we took a decision to ask her to stay in her room on weekday evenings and all day Saturday, and we take her meals up to her. That means we have time together as a family in the evenings after work and one day at the weekend, without her. It probably sounds very hard, but I think she realised that it was impossible to carry on as we were.

When you are a caring for someone you may sometimes even need to say 'no' to the professionals who are trying to help. One carer found her own way of saying 'no' to professionals who couldn't or wouldn't respect her carefully worked out routine.

Sometimes it seemed like an endless trail of professionals - GP, district nurse, social worker, occupational therapist and so on and so on - who all seemed to come at the worst possible moment. My father always slept after lunch, and I'd try to get a nap as well, but invariably the door bell went. I couldn't get them to agree not to come at that time of day, so in the end I used to take the battery out of the doorbell and ignored the knocking. So in the end they had to come back at a different time.

ACTION PLAN

Think of something that you need to say 'no' to. (Don't choose something that is so difficult that it makes you feel panicky just to think about it - start with something that you feel you can manage.)

- **Work out what you are going to say.**
- **Who are you going to say it to?**
- **Decide when you are going to say it.**

If you don't manage to do it on the first occasion, don't give up. Go through your plan again, and if you can, practise what you will say with a friend beforehand. Once you have made up your mind to do it, you will find that a time will present itself when you and the circumstances feel right for saying it.

Asking for help

Many of us feel awkward asking other people for help. Yet being able to say when you're feeling overloaded, and to plan and ask for the help you need before you reach a crisis point is perhaps one of the most important things you can do for yourself when you are looking after someone. The things that are often most helpful may be quite simple - perhaps someone to collect shopping, or to keep the person you care for company while you go out for a couple of hours.

What you ask

People who offer to help usually genuinely want to, but may need you to tell them what kind of help you need. Work out what you could ask different people to do. Try to make your request specific, rather than vague or general.

For example, you could ask someone to:

- read to, chat to, or do something with the person you look after for an hour each week, or do some of your grocery shopping, perhaps weekly or fortnightly
- do occasional odd jobs around the house
- cook a meal from time to time
- change library books or videos for you or the person you care for
- find out some information for you, or phone or write to you on a regular basis.

If you have the opportunity, discuss these questions with other carers and compare your ideas.

How you ask

It is sometimes most difficult to ask help from the people to whom you are closest. Asking family members for help may be going against established habits, routines and expectations.

Shirley comes home from work half an hour late because of heavy traffic. The automatic timer has cooked the casserole she put in the oven before work, but the table is not laid and is covered with books, dirty cups, newspapers and children's toys. The rest of the family are watching television. When he hears her come in, Shirley's husband Mike shouts, **'Hello,love. How long's tea going to be? I'm starving.'** Shirley feels fed up that everyone waits for her to do the work. She would like someone else to clear and lay the table, while she gets the food ready.

If you were Shirley, what would you do?

- Get angry and shout at either Mike or one of the children to lay the table?
- Hint - say something like 'I wonder why the table isn't laid?'
- Sigh, slam doors, and sulk to make it clear you're upset about something - but leave it to the others to guess what it is?
- Use sarcasm - say something like 'I suppose you've all had such a hard day that you're too exhausted to lay the table for me'?
- Ask someone directly - say something like 'I know you probably don't feel like doing it, but it would really be a big help if you would clear the table?'
- Say nothing but determine to discuss it later with Mike?

You may feel that your reaction would depend on what had gone before - how many times you had already come home to find the table unlaid and the family oblivious. We all do all of these things sometimes, but there is often a pattern in the way we respond to this kind of situation.

How do you usually ask for help? Do you recognise yourself in any of these responses? Do you tend to get angry, hint, moan or sulk? Do you use sarcasm? Do you say in a direct way what you would like to happen? Be honest with yourself.

It is possible to ask for help in a direct way, without getting angry, aggressive, apologetic or embarrassed:

- **be specific - say what you would like to happen**
- **let the other person know how you feel in a neutral way**
- **listen to and acknowledge their feelings too.**

Here's an example of how this can work:

Mike: 'What time's tea going to be? I'm starving.'

Shirley: 'Well, that depends. Can you help me by clearing the table? It'll be ready a lot quicker.'

She says exactly what she would like to happen. She doesn't say 'If you help me...' a sort of bartering that can sometimes be antagonising.

Mike: 'Oh no, I've only just sat down, love. I've had a really hard day. Get one of the kids to help you.'

Children: 'Oh, no, Mum.'

Shirley: 'Look, I know you're all tired, but I really do need some help. I feel tired, too, and I think it would be fair if we shared the job of getting tea ready.'

She acknowledges their feelings, and lets them know how she is feeling in a neutral way and without anger or pleading. Mike and one of the children reluctantly concede and clear the table.

Of course, it isn't always possible to deal with difficult situations calmly and reasonably. You may be thinking that Shirley is too good to be true, or that the whole scenario wouldn't work in your family or if you needed help with something really important. Before you make up your mind, try it out. Choose a 'safe' situation, where it doesn't matter too much what happens. See if it makes a difference.

Learning assertiveness

Some of the ideas suggested here - including learning to say 'no' and asking for help - are sometimes called 'assertiveness skills'. In *A Woman in Your Own Right* , Anne Dickson, a recognised expert on the subject, describes assertiveness as 'the art of clear, honest, and direct communication'. In some parts of the country professionals or carers groups have organised courses on assertiveness. Many carers have found the skills they learnt very helpful in all sorts of ways, increasing their self confidence in handling family relationships and in dealing with professionals and officials.

There may be an assertiveness course for carers in your area. If not, many adult education centres run assertiveness courses that are open to everyone and some run special courses for women.

Finding an intermediary

In some cases the person needing care is reluctant to accept help from other people, making it difficult for the carer to have time off or to go out. If the person needing care will accept advice or suggestions more readily from someone else - a family member, a friend, or a professional such as a GP or community nurse - it may help to ask another person to act as an intermediary.

Here's another way of looking at how you spend your time. Make a list of six things that take up a lot of time and that you would cut down if you could. Think about all the activities that are part of your daily routine. Try to be specific - for example, don't just write 'housework'. There will be caring tasks you enjoy doing, or that bring a sense of closeness to the person you care for, but what are the caring tasks that you find time-consuming and would prefer to cut down on? Think about your whole range of caring activities including things like dealing with professionals and filling in forms.

1 ____________________

2 ____________________

3 ____________________

4 ____________________

5 ____________________

6 ____________________

Once you've made your list, look it over. What three things would you most like to spend less time on? Take a couple of minute to think about this, and then underline the three. Now choose one of them and write down at least five things, large or small, that would make this task easier or quicker to do. At this point, put down any ideas that occur to you, however fantastic.

ACTION PLAN

The first thing is to discuss your ideas with someone else - the person you care for, another family member, another carer, or a professional such as a community nurse or social worker. They may come up with ideas you hadn't thought of, or be able to see ways of turning into reality an idea that you think is impractical.

When you've explored all the possibilities with someone else, make a decision to act on at least one or two of the ideas which are practical. Set yourself a target date for acting on your decisions.

Winston's wife, Irene, is in her late 60s, is physically disabled and has had kidney problems for the last 20 years; she's also had bouts of incontinence and these were getting worse. Winston found he needed to do a load of washing every day. They used an old twin-tub machine. Winston had a bad back and found it very painful to use. So he hated doing washing, and also hated the house being covered in wet sheets. These were his ideas:

- obtain automatic washing machine with built-in tumble dryer
- ceiling airer
- quicker drying sheets
- ask home help to do a load on the day she comes

Winston discounted the automatic washing machine, though at first he did think seriously about looking for a cheap secondhand automatic washer or tumble dryer. He thought polyester and cotton sheets or nylon sheets would dry more quickly than the brushed-cotton sheets they were using. He goes regularly to a carers' group at the local African.Caribbean community centre, and so asked them for their ideas. This is what they came up with:

- check whether the DSS will give financial help for an automatic washing machine
- ask the district nurse, continence adviser or chemist if there are better-fitting or more absorbent pads for night-time
- ask the district nurse or continence adviser if there is anything else that can be done to help Irene's incontinence, and if there is a laundry service for incontinence sufferers.

Winston didn't know about the continence adviser and hadn't realised they might be able to get financial help to buy a washing machine. Through his GP he was able to arrange a full assessment of Irene's condition by the continence adviser and, because he is on income support, he also got financial help in the form of a social fund loan from the DSS to buy a new washing machine.

Time-saving gadgets and equipment

Below several carers describe what household gadgets and equipment they have found most useful for saving time. Of course, what suits one person may not suit another, but read through the list and tick the items you think might be worth considering.

ITEM	CARERS' COMMENTS
ELECTRIC TIN OPENER / JAR OPENER	My very arthritic father can get his own simple meals like soup or beans on toast without having to depend on someone else being there to open things for him.
SMALL IRONING PRESS	Makes the ironing quicker and Mum helps. She's too uncoordinated to use the iron, but she likes using this and feels she's being useful.
MICROWAVE / BLENDER	Manjid, aged 8, still has to have his food pureed. I can make him a dinner from scratch using fresh ingredients in about ten minutes.
DISHWASHER	I hate washing dishes and it always seems to take me ages in the evening. Although it was a big expense for us, I reckon this gives me an extra hour and a half a day to do other things.
VIDEO RECORDER	My husband likes watching TV but he's very restless, so you can't see anything right through. This gadget means I can relax watching something I really want to at a time that suits me.
CAMP BED	Mother has bouts of sleeplessness. If she's having a bad night I put the camp bed up next to her, and she seems to sleep better with someone there. I don't want to sleep in her room all the time, but it means we both sleep a bit better on bad nights.
WHAT OTHER ITEMS WOULD HELP?	

What other items would help?

Time-saving gadgets and equipment aren't just expensive luxuries. A couple of hundred pounds spent on reducing tedious chores by an hour a day may be an excellent investment for your long-term well-being. Of course, you may not be able to afford this sort of expenditure because there simply isn't enough money coming in each week to save for a large item. However, there is also a wide range of aids and equipment designed specially for people with disabilities - often to give the disabled person greater independence or to make caring tasks such as lifting easier to manage - and some of these may be available locally either free, or on loan. It may also be possible to get a grant or loan towards the cost of large items you need (see page 42).

To find out more, contact your **local social services** or **social work department**. Your local **council for voluntary service** can tell you about local voluntary schemes which hire out or lend equipment. Your nearest **disabled living centre** (see page 38 for details) will have a range of aids and equipment on display and be able to offer information and advice.

Other ideas

Build planning and thinking time into your day. Accept that things take longer and become more complicated if you are planning for someone else as well. Calculate the time you think a job will take - and then double it!
Accept that some things are less important when you are caring for someone. Ten minutes spent relaxing and doing something you enjoy is more precious than ten minutes spent hoovering or hanging out washing. It doesn't really matter if the house isn't spotless - but it does matter if you're too tired to cope. Let the less important things go a bit. Write down three things you could do less often - that don't really matter- and pin them up somewhere to remind yourself.

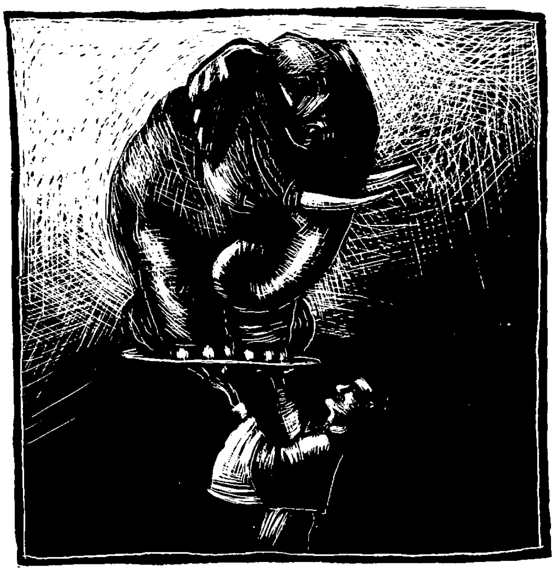
Do the unpleasant things first: get the jobs you dislike out of the way early on in the day if you can, so that they're not hanging over you. Do the trickiest and most complicated tasks when at your best: It's not a good idea to fill in a complicated form or make a difficult phone call when you're very tired.

Make allowances for tiredness: tiredness makes you slow-witted, confused and forgetful -even though, after nights of broken sleep you may come to forget what not being tired is like, learn to recognise tiredness and cut down the amount you're trying to do accordingly.

Get worry under control. It may not be easy to stop worrying, but if you find it hard to switch off, try one of these ideas to help keep it under control:

- **A worry timetable:** plan a specific time to think over a problem. For example: I can't actually do anything about this tonight, so I'll worry about it after breakfast tomorrow.
- **A worry peg:** many people find it helps to imagine hanging up their worries for a set time - perhaps on a peg in the kitchen at the start of the evening or, if you go out, on the garden gate until you get back.
- **A worry book:** often things seem worse because they just go round and round in your head, so try writing down what it is you're worrying about. Writing down a problem as it occurs to you can help you see more clearly what it is that's worrying you.

Q: How do you eat an elephant? A: Bit by bit



Try using the elephant technique if you find yourself putting a job off because you feel overwhelmed by its size or complexity - in other words, do it bit by bit. Break it down into small steps, and write these out as a list. When you've done the first small task, tick it off. Often getting started is the most difficult thing, and this is a good way to work yourself into a job. It makes difficult jobs more manageable, and gives you a sense of progress right from the start.

Time for yourself

In order to keep up your energy levels, you need to give yourself enough good quality time to recharge your batteries. Ideally this doesn't mean sinking passively in front of the TV and falling asleep but doing something that you actively enjoy. This could be something that you enjoy doing on your own, with other people, or with or for the person you care for.

- Write down at least five things you would like to do if you had the time. Avoid saying to yourself, *'Yes but I can't.....'*

1 ____________________
2 ____________________
3 ____________________
4 ____________________
5 ____________________

- Is there anything you used to really enjoy doing in the past which you've stopped doing now?
- Is there anything you've always wanted to do but never got round to?
- Write down up to 10 things that lift your spirits or help you relax.

1 ____________________
2 ____________________
3 ____________________
4 ____________________
5 ____________________
6 ____________________
7 ____________________
8 ____________________
9 ____________________
10 ____________________

- When was the last time you did one of these things?

Many carers find that they begin to get out of the habit of enjoying themselves. If this is true for you, it is important to re-invent the habit. You will need to think about arrangements for getting out of the house (see page 41) as well as ideas for doing things at home and for keeping in touch with other people.

You owe it to yourself to go out now and then. I got out of the habit of going out because it was so difficult to arrange and because Jack really disliked strangers coming in. I was in quite a bad state, though it happened gradually so I didn't realise. We had a visit from the new social worker, and she kept on at me to go to the carers' group. I was physically sick just with nerves the morning she was coming to take me to the meeting. Now I come every week - you can't keep me away.

Here are some other carers' suggestions for doing things at home and keeping in contact with other people:

- *Find a hairdresser who'll visit the house.*
- *I bought a knitting machine.*

- *I used to enjoy going to concerts so my son got me a Sony Walkman and some of my favourite music; now I can potter about oblivious with my headphones on while my husband watches the TV at full volume.*
- *Our carers' group has alternate meetings at my house because my wife gets really distressed if I'm away for more than half an hour or so.*
- *Work at keeping your friends, or they drift away - make it a routine to phone two or three once a week, and ask them round once a fortnight; you have to work at it, because it's a one-sided thing if you can't go round to them or out with them.*
- *There's a mobile video library, which I now use regularly and I've got a good neighbour who'll pick up and take back my library books when she does hers.*
- *Use the phone - I make it a rule to phone my sister, my daughter and my best friend every week: I get them to talk to my husband if he's in the right mood so they don't forget about him!*

ACTION PLAN

Start making a little more time to enjoy yourself straight away. Look back over the ideas in this section - your own and the suggestions from other carers. Spend a couple of minutes thinking before you fill in the box below. Start with small steps you can easily achieve - for example, promise yourself to phone a friend or relative once a week, or to spend an hour a week doing something you enjoy but don't do enough - knitting, or reading, or listening to music (or all three at once!):

One thing I enjoy that I will start doing once a week:

One thing I enjoy that I would like to do within the next month:

CHAPTER THREE

WORKING OUT WHAT YOU BOTH NEED

Every carer is different, and every caring situation has different needs. To get the most out of the services available in your area, the first step is to say:
'What is it we really need?'

This chapter presents an opportunity to look at your own needs and those of the person you care for in an organised way.

If you've been caring for someone for some time, you may have mixed feelings about all this. Do any of these comments match your own experience?

I know what it is we need - the problem is constantly that the services just don't match up with what you want.

How can you work out what you need when it's so difficult to get information about what's available?

I've got nowhere with the professionals - they've offered us nothing so far, and I've had enough of them.

If any of these experiences are similar to your own, here are some practical suggestions. They're not instant solutions, but they may help improve things:

- If services don't match up with what you need, it's vital to tell someone (your GP, social worker, local councillor, even your MP), because the more carers who tell the services what is wrong, the more likely that changes will be made. There's an example of how to write this sort of letter on page 57.
- If it's difficult to get hold of information, you just have to keep asking. Ask a range of different professionals - one person won't know everything, so you have to be persistent. There's a list of all the people who might help on page 33.
- Carers who have had one or several bad experiences in trying to get help understandably feel like giving up. Coping entirely on your own may work for a short time, but in the long term every carer needs help and support. Things do change - even the bureaucratic structures of the local services - so it is never too late to try again. The sections on pages 38 and 42 may give you some practical ideas for trying again in a different way.

Use the checklist on the next page to help you and the person you care for organise your ideas. On page 33 you'll find a chart listing the different types of help and support you might want to consider. Not all of these may be available, but the list will help focus your own ambitions.

You may each have different views about some of your needs - for example, about time off, or help in the home. So use the checklist as an opportunity to talk through some of these.

If, for whatever reason, you can't go through the checklist with the person you care for, talk about it instead with another person who knows you both - perhaps a friend or a family member.

Checklist

What the two of you need may be a combination of things - your joint needs and your individual needs.

Under each heading in the list write down exactly what sort of help you would like - be as specific as possible. Add your own ideas to the list as well. Do you and the person you care for need:

☐ more information about what's available?

☐ information, advice or treatment from a doctor?

☐ practical help with medication?

☐ help with bathing, dressing, feeding, lifting or going to the toilet?

☐ financial help?

☐ advice about the benefits system?

☐ help in meeting community charge/council tax payments?

☐ regular time off each week?

☐ respite care (from a few days to a couple of weeks)?

☐ help with finding somewhere more suitable to live?

☐ help with adapting your home?

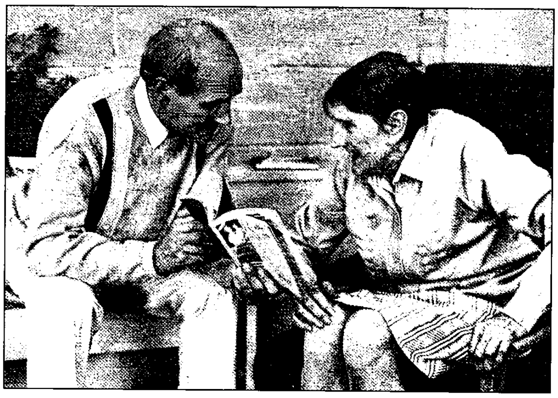
☐ help in the home?

☐ an aid or piece of equipment?

☐ help with transport?

☐ someone to talk to about how you're feeling?

☐ someone to talk to who can give practical advice and support?



Where next?

You may find it useful to show your list of needs to a sympathetic professional - your GP, district nurse or social worker. Discussing it together will help them gain a better understanding of your needs. From their knowledge of the services they may be able to add to or build on your own ideas.

Under the 1990 **Community Care Act**, social services departments have a responsibility to make a detailed assessment of a person's need for services if they are frail or have an illness or disability and are being cared for at home. If the social services decides that care services are needed, they have a duty to arrange a 'package of care' which also takes account of the needs of the carer.

Work out your own 'community care' plan

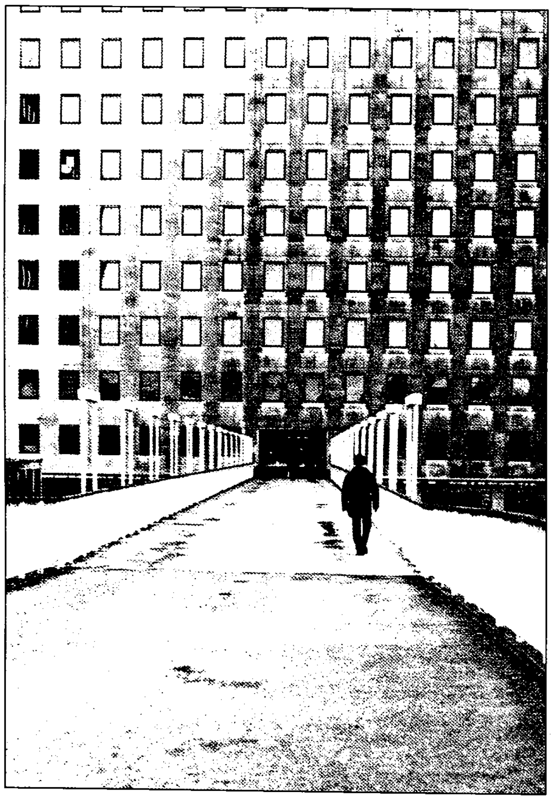
It doesn't mean it will be plain sailing, but use the checklist to work out your own plan of needs and services that would help, and discuss with anyone involved the services you will get. Some social services departments already encourage people caring and needing care to be involved in this way, but others do not. Working out what you both need means you can be specific in what you ask for. You may not always get what you need, but you are in a much stronger position if you are clear about what you want.

CHAPTER FOUR

COPING WITH THE 'SYSTEM'

This chapter is called *Coping with the 'system'* but many carers find that the 'system' isn't an organised system at all. The range of services to help people cared for and caring at home varies from area to area.

Most financial benefits are the same in every area, though some grants and loans are made at the discretion of local officers, so can vary. Each part of the 'system' is run independently. The services should work closely together but in fact fit together differently from one place to another. People who provide one type of service often don't know much about services outside their own department or organisation, making it difficult for you to find out what is available, whether you are eligible, and how to get access to what you need.



WHAT CARERS SAY ABOUT THE 'SYSTEM'

Here are some carers' comments about coping with the system and using the services. Tick the ones closest to your own feelings and experiences:

1. *It shouldn't take so long to get help when you ask. They don't seem to appreciate how much it takes to ask for help in the first place.* ☐

2. *Unless they can see you're at your wits' end there's very little help forthcoming.* ☐

3. *If you can find the right person - in our case it was the social worker - they can open a lot of doors for you.* ☐

4. *I suppose I've learnt that you just have to be persistent. You have to keep on asking.* ☐

5. *You have to be prepared for the fact that what you need may not be available, and that what's on offer isn't exactly what you need.* ☐

6. *I would prefer to go on caring for my wife for as long as possible. A social worker has been to see us and offered help but I'm worried that once they get involved they'll end u p trying to take over.* ☐

7. *I feel that we are entitled to some outside help. After all, if I couldn't look after my son it would cost the government a lot more to look after him.* ☐

Which comments did you tick?

2 or **5** You may like many carers have had frustrating or disappointing experiences in dealing with the 'system'; you may perhaps feel it's pointless to keep trying. You're not alone in feeling like this. But, for your own sake, don't give up. You may find some helpful ideas and suggestions in this and the next chapter.

1 and **6** People caring for someone they love sometimes feel uncertain about whether they are doing the right thing in asking for help at all, for many different reasons. Some people, for example, feel guilty that they need to ask for help, some fear that 'the system' will take over and prevent them from continuing to care in the way that they want to. It's worth remembering that the services exist to help people who need them and that many of them are paid for out of your money. If you are caring for someone partly or completely dependent on you, you have a right - if they are not offered - to ask for practical help and support from your local services, and the earlier you do this the better you'll be able to cope. There is no danger of being taken over by the services; the greater danger is that you'll be overlooked by the 'system' if you don't ask. And if a service proves to be unsuitable, you can always refuse it.

3,**4** and **7** The carers who get the best out of the system seem to be those who:

- feel confident in their right to ask for help
- are prepared to persist
- manage to find a sympathetic professional to give good advice and put them in contact with other services.

Finding a helpful professional is partly a question of luck, but your own confidence and persistence can take you a long way.

HOW DOES THE 'SYSTEM' FIT TOGETHER?

The table shows the general range of services which may provide help for the person needing care or for the carer. If you are lucky you may deal with a 'care manager', 'case manager' or 'key worker' (usually from the council social services department) who is well informed about the whole range of services and who puts you in touch with the ones you need. But in some areas the services are poorly coordinated, or there are gaps, or the professionals don't know about services outside their area of responsibility.

Some carers find their first contact with a particular service is an unexpected visit from a professional; others find they have to a lot of detective work to make contact with the help they need.

In the first week after my wife came home after her stroke I think we had at least one visit a day from different people. They came and went and apart from the health visitor and the GP, I couldn't really tell you who the others were or where they came from. Some introduced themselves but some didn't bother.

The consultant said he would write to my GP when my father was diagnosed but we didn't see or hear from anyone in those first three months.

ORGANISATION	SERVICES THEY PROVIDE
NATIONAL HEALTH SERVICE **most local health services are provided by two bodies:** 1. DISTRICT HEALTH AUTHORITY	**Hospital Services** eg. Hospital specialists, outpatient clinics, day hospitals, short or lingewr term care in hospital, councilling for patients and carers **Community Health Services** eg. community nursing services, health services, community dietitions and physiotherapists, councilling for patients and carers
2. FAMILY HEALTH SERVICE AUTHORITY (used to be called Family Practioner Committee)	**GP's, Opticians, Dentists, Pharmacists**
LOCAL AUTHORITY ie. your borough, district, city or county council. Refered to as Local Eduaction Authority for education purposes	**Social Services** eg. social workers, home helps, equipment and adaptions for the home, occupational therapist, day centres, residential homes, someone to talk to

ORGANISATION	SERVICES THEY PROVIDE
LOCAL AUTHORITY (Continued) Referred to as **Local Education Authority** for education purposes	**Education Services** eg. special schools, further education services for people with disabilites, educational assessment of children with special needs **Housing Services** eg council housing, housing benefit
DEPARTMENT OF SOCIAL SECURITY Central Government Department which provides services through local offices	**Financial Benefits and Allowances** eg. income support, attendance allowance, invalid care allowance, mobility allowance
VOLUNTARY ORGANISATIONS These and the type of service they offer vary from area to area. May fill gaps in services provided by NHS and lacal authority - specific services for balck and ethnic people in some areas.	**Pracitical help, services, facilities** eg. loan of equipment, sitters or care attendants, community centre, social club, day care **Advice and information** eg. about a particular condition or illness **Support** eg. local self help or support group, counselling services
Council for Voluntary Service	Central information point about local voluntary orginisations and services
ADVICE CENTRES May be independant voluntary orginisatons or part of the local authority - centres vary from area to area	
Citizens Advice Bureau	advice on any problem
Law Centre	advice on legal matters
Housing Aid Centre	advice on housing
PRIVATE SERVICES	eg. nursing and residential homes, nursing agencies, domestic help or home care assistant services.

One way to help piece together the jigsaw of services is to keep a diary or notebook and write down the date and details of any contact that you have with professionals. They should always introduce themselves, and explain who they are. Ask if they have a calling card. Here are some useful questions to ask any professional you meet:

- **Who are you?**
- **Which part of the services do you work for?**
- **Where are you based?**
- **What do you do?**
- **(If someone visits unexpectedly) who arranged for you to visit?**

- **Can I contact you directly if I need to?**
- **How do I contact you?**
- **Is there a best time of day to get hold of you?**
- **What do I do if I need help out of office hours?**

YOUR RIGHTS

Your circumstances or the condition or illness of the person you care for may mean that you are entitled to certain services or financial benefits. Some you may be entitled to by law. Other services, may be offered only to those people with the greatest needs. Services and benefits may not be automatically offered: the professionals who provide the services are often working under a lot of pressure, may not be fully aware of your situation, and may not volunteer information about what you can get unless asked. So you may have to be persistent to find out about your rights and ask for services.

Health and social services are becoming more aware of the needs of carers. Recent legislation has increased support for carers, and some local authorities have produced a **'Carers Policy'** or **'Carers Charter'** along the lines of that on page 65. Although there is still a long way to go, carers as well as those they care for have a right to talk to any professional worker in confidence if they need to, and to choose where they want to hold that conversation.

Sometimes your need for help and support may conflict with what the person you care for wants, and the services you are offered should take account of this. It helps if you can talk about these differences with each other but, if this is difficult, it is important to let your GP or social worker know what you feel your needs are.

ACTION PLAN

What services or support do you need for yourself?

Write down two priorities:

1 ______________________________

2 ______________________________

- Have you investigated what services are available that might help?
- How far do the services you have been offered meet these needs?
- Is there a sympathetic professional person to whom you could talk to about your own needs?

Legal rights

Note that there may be variations in the legislation in Scotland and Northern Ireland.

The NHS and Community Care Act 1990 aims to improve services and give additional rights to all people being cared for at home and to carers. Local authorities should:

- draw up plans for community care services jointly with health authorities and voluntary organisations – anyone can ask to see the plans
- consult carers about their plans – carers' organisations should be represented on consultative and planning bodies
- set up inspection units to monitor standards in residential homes and publish annual reports which anyone can ask to see
- assess the needs of individuals whom they consider to need care services, as well as designing a 'package' of services, that takes into account the needs of the carer
- set up a procedure to look into complaints by people who need or use the social services about how the services operate
- provide information about their services and about how to make a complaint.

The Carers National Association leaflet *NHS and Community Care Act: The carer's view* is a useful short guide for carers.

The Children Act 1989, which came into force in October 1991, aims to improve services and give additional rights to 'children in need', including children with special needs (for example, those with a physical or mental disability), and to their families. Local authorities should:

- publish information about services
- assess the needs of individual children
- provide services for children in need cared for at home, as they consider appropriate, including advice, guidance and counselling, activities, home help, help with travel to use a service provided under the Act, and help to enable children in need and their families to have a holiday.

Contact one of the local or national organisations concerned with children with special needs, such as Contact a Family or MENCAP, for up-to-date information about how the changes introduced by the Act are working in practice, as this varies from area to area. If you belong to a parents' group, let your social services department know what your needs are and what services would be most useful.

The Disabled Persons Act 1986 aims to improve rights and services for disabled people and carers. It gives local authorities additional responsibilities towards disabled people. The Carers National Association leaflet *Disabled Persons Act 1986: How to use it to get services* is a useful short guide.

The Mental Health Act 1983 outlines the grounds on which people can be compulsorily detained in hospital as 'formal' patients. It requires hospitals to give 'formal' patients and families information about their legal rights, and gives relatives certain rights to be involved in decisions about compulsory detention. For general information, *The Mental Health Act 1983* from MIND, is a short helpful leaflet for patients, families and carers. If you need specific legal advice about your rights, contact your citizens' advice bureau or the legal advice department at MIND.

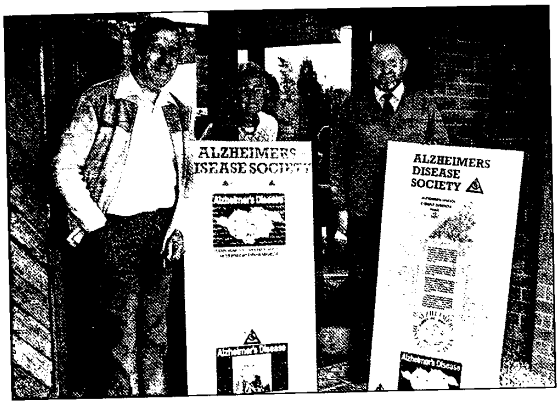
It will take time for all these changes in legislation to be implemented. The way changes are made will vary widely from place to place, so it's vital to get up-to-date local information about whether and how they apply to you. Local advice workers may be able to tell you how and when the changes will be implemented by the services in your area.

Getting advice

If you are having difficulty obtaining a service or benefit, or if a service is refused, reduced or withdrawn, find out what your legal rights are.You can contact:

- **your community health council** - for advice about your rights to help from the health services
- **your nearest citizens' advice bureau** - for advice about your rights to local services and to social security benefits
- **the advisory centre for education** for problems to do with education (eg. for children with special needs)
- **the welfare rights unit** (if there is one) of your local council

- **the national or local office of one the voluntary organisations** concerned with carers - Carers National Association, Contact a Family, MIND or MENCAP - or your local council for voluntary services
- **Disability Alliance Rights Service**, a national telephone advice service on welfare rights for people with disabilities and for carers
- **or you could read the *Disability Rights Handbook*** (in your public library), an annually updated guide which contains detailed information about rights, services and benefits.



Putting your views

If you want to put your views about what services are needed, you could write to the director of social services for your area, or to the councillor who is chair of the social services committee.

You may find it easier to make your voice heard if you join a carers group, or local voluntary organisation involved with carers. One of the organisations listed above or your local council for voluntary service, or equivalent, should be able to tell you whether there are any local organisations actively campaigning to improve services for people with disabilities or for carers.

ACTION PLAN

Look back over the questions in this section on 'Your rights'. Are there any ideas you want to follow up? Write down what action you will take, and set yourself a date to do-it by. Do you need:

DO YOU NEED:	WHAT ACTION COULD YOU TAKE?	WHEN WILL YOU DO IT BY?
any information or advice?		
information about coming changes in the way services are provided?		
more information or advice about your legal rights?		
more support to help you care or take a break from caring?		

WHAT HELP IS AVAILABLE?

The table describes the range of services that might help if you are looking after someone at home.

As you work through the list, make a note in the box beside each service:

I already use this ☐ This is not relevant, or not available ☐

This sounds useful and is worth getting more information about ☐

Remember this is only a general guide. Most financial benefits are the same wherever you live, but the availability of other services, and the way they are organised, varies widely from area to area.

SERVICE:	WHO PROVIDES IT:	WHO TO CONTACT:
PRACTICAL HELP AT HOME	Details of organisations printed in **bold** are available at the back of the book.	
Help with housework and personal care	Home helps (community care, home care or domiciliary care aides/or assistants)	Home help organiser, **social services** **Crossroads scheme coordinator**
Midday meals delivered for people unable to cook.	Meals on wheels service	**Social services** or GP
Help with bathing or going to the toilet	District nurse or auxiliary nurse	GP

SERVICE:	WHO PROVIDES IT:	WHO TO CONTACT:
PRACTICAL HELP AT HOME Free laundry service for people with incontinence or unable to do their own laundry	**District health authority** or **local authority**	District nurse or **social services**
Advice on: lifting, moving and turning the person you care for	Physiotherapist, district nurse or occupational therapist	**Social services** or GP
dressing, washing, and other daily task	Occupational therapist	**Social services**
incontinence	District nurse or continence adviser	**Association of Continence Advisors** or GP
	Continence Advisory Service	**Disabled Living Foundation**
EQUIPMENT, AIDS & SUPPLIES		
Equiment for toilet and bathroom (eg. raised toilet seats, commodes, hoist or rails for the bath)	**District health authority** or **social services**	District nurse (through GP) or **social services**
Equiment for the bedroom (eg. raised or special bed, hoist or rails)	**District health authority**	District nurse (through GP) or **social services**
Aids for washing, dressing eating, going to the toilet	Occupational therapist	**Social services**
Walking sticks, walking frames, wheelchairs	**District health authority**	GP or physiotherapist or hospital specialist
Exhibitions to see and try equipment	Your nearest disabled living centre	**Disabled Living Centres Council**
Advice about special equipment and where to buy or hire it	Occupational therapist	**Social services**
	District nurse, physiotherapist (for mobility aids)	GP
	Disabled Living Foundation	

SERVICE:	WHO PROVIDES IT:	WHO TO CONTACT:
EQUIPMENT & AIDS (cont.)		
Short term hire of equipment	Your nearest branch of the **British Red Cross**	**British Red Cross**
	Other voluntary organisations	Your nearest branch **council for voluntary service**
Free pads, pants and other incontinence aids	**District health authority**	District nurse (through GP) or in some areas the health visitor
ADAPTING YOUR HOME		
Adaptions such as ramps, door widening, adding toilet	**Local authority**	Occupational therapist or social worker at **social services**
Advice on adapting or extending your home	Occupational therapist	**Social services** **Centre for Accessible Environments**
GETTING ABOUT		
Door to door transport for people unable to use public transport	**Dial-a-ride** or local equivalent	**Dial-a-ride London Users Association,** or **social services** or **council for voluntary service** for details or local equivalent
Reduced or free travel on local transport for people with disabilities	**Local transport authority** or **local authority**	Person who deals with concessionary fares
Information and practical help with train travel for people with a disability, including disabled person's railcard	British Rail	Full information about services in Disabled Persons Railcard leaflet from railway stations
Taxis - reduced fare schemes / adapted for access for people with disabilities (in some areas only)	**Local transport authority**	Person who deals with transport schemes or fare concessions for people with disabilities
Advice on adapting your car (eg. for wheelchair access)	**Disabled Living Foundation, Mobility Advice Vehicle Information Service (MAVIS)**	
Using Mobility Allowance to buy or lease a car or electric wheelchair	**Motability**	**Motability** or local **Dept. of Social Security office**, mobility allowance dept. or **RADAR**

SERVICE:	WHO PROVIDES IT:	WHO TO CONTACT:
GETTING ABOUT (cont.) Buying a special car or arranging hire purchase	**Assistance and Independence for Disabled People**	
Orange parking badge for people with a disability	**Local authority**	**Social services**
Guide to local buildings with wheelchair access	**Local authority**	**Social services** or public library
Addresses and key for disabled toilets around the country	National Key Scheme	**RADAR** or **Council for Voluntary Service** for details of local key holding organisations
MEDICAL HELP (in addition to help from your GP or hospital specialist)		
Nursing care at home (eg. help with changing dressings, giving injections etc.)	District nurse	GP
Advice for people with mental health problems and for their family/carer	Community psychiatric nurse, mental health centre, mental health team	GP, or contact directly in some areas
Help with speech problems	Speech therapist	GP, hospital specialist, teacher or health visitor
Help with incontinence	District nurse Continence adviser	GP, District nurse or **Association of Continence Advisors**
Footcare, including home visits	Chiropodist	GP or **district health authority** chiropody dept.
Dentist, including home visits	Dentist	See Yellow Pages or ask **family health service authority** for details of which practitioners will make home visits
Optician, including home visits	Optician	
INFORMATION & ADVICE:		
On any problem	**Citizens' Advice Bureau**	In your phone book, or ask your public library or **Citizens' Advice Bureau**
On legal matters	Local law centre	
On housing	Local housing aid centre	
On anything to do with the health services	**Community health council**	
On education	**Advisory Centre for Education**	
On benefits and allowances you may be entitled to	see below	
About the illness or condition of the person you care fo, and on practical ways of coping	National organisations and local groups for people with particular illness or disabilities	Your local **Council for Voluntary Service** or **community health council**

SERVICE:	WHO PROVIDES IT:	WHO TO CONTACT:
INFORMATION & ADVICE: (cont.) About personal and emotional issues and relationships	see suggestions in the section of the book on 'Counselling'	
A BREAK FROM CARING		
General information and advice	**Taking a break** by Maggie Jee describes the full range of schemes and options that may be available for short-term, regular and longer-term breaks from caring	
Someone to look after the person you care for a few hours	Sitter or care attendant	**Social services, voluntary organisations,** private organisations
Someone to help the person needing care with getting up or going to bed	'Tucking in' or 'twilight' service	**Social services, voluntary organisations,** private organisations
Day care away from home for children and young people	Depends on age and needs (eg. nursery, nursery school, play group, clubs, workshops)	**Social services, local education authority, district health authority, voluntary organisations**
Day care away from home for adults and older people	Depends on age and needs (eg. lunch and social clubs, day centres, day hospitals, education and training centres, sheltered workshops)	**Social services, local education authority, district health authority, voluntary organisations**
Residential break for the person needing care	Respite care from a few days up to a few weeks (eg. in a home, hospital, hospice or with another family)	**Social services, voluntary organisations,** private organisations. For hospices, **Hospice Information Service**
Holidays for the person needing care, with or without the carer	Special centres or adapted accommodation	**Social services, voluntary organisations, Holiday Care Service, RADAR**
HELP IN A CRISIS OR EMERGENCY **(apart from 999 services)**		
Out of office hours services, immediate practical help, urgent temporary care (residential or at home etc.)	GPs have 24 hour cover. Some social services departments have 24 hour duty teams to help in a crisis. Police and Samaritans may also help or put you in contact with the appropriate person or service. Some areas have a carers telephone helpline.	
BENEFITS		
Information and queries	Department of Social Security leaflet FB2 **Which Benefit?** describes all social security benefits. This information is also available in Chinese, Turkish, Hindi, Urdu, Bengali, Punjabi and Gujerati. Ask for leaflet FB22 in the language you want. Or phone Freeline Social Security 0800 666555. Contact citizens' advice bureau for independent advice. You can get most leaflets mentioned here from your Social Security office or from the **Leaflets Unit, PO Box 21, Stanmore, Middlesex HA71AY.** Some are available in post offices.	

BENEFIT:	WHAT IT IS / WHO IS IT FOR:	MORE INFORMATION:
Income support	To bring income up to a minimum level. Means-tested, may be taxable.	DSS leaflet IS20, **A Guide to Income Support**
	People on income support may qualify for help with NHS costs, housing benefit, community charge benefit, help from the social fund and additional premiums (cash supplements - eg. see Carer Premium below)	
Social fund	Grants or loans to help with exceptional expenses for people on a low income. Discretionary.	DSS leaflet SF300, **Grants and Loans from the Social Fund**
Mobility allowance	Help with transport costs for people unable or virtually unable to walk, aged 5 to 80. You must claim before you are 66.	DSS leaflet N1211, **Mobility Advice**
Attendance allowance	For disabled people who need a lot of looking after either by day or by night (lower rate), or both (higher rate)	DSS leaflet N1205, **Attendance Allowance**
	Note: In 1992 mobility allowance and attendance allowance is to be replaced by a new disability allowance. Get up-to-date about who is eligible and how to claim.	
Invalid care allowance	For carers of working age who spend at least 35 hours a week caring for someone who gets attendance allowance. Taxable.	DSS leaflet N1212, **Invalid Care Allowance**
Carer premium	For carers on a low income who qualify for invalid care allowance	DSS leaflet IS7, **The Carer Premium**
OTHER FINANCIAL HELP:	WHAT IT IS / WHO IS IT FOR:	MORE INFORMATION:
Independent living fund	Regular payments to help with cost of housework or care for people who receive income support and qualify for higher rate attendance allowance	**Independent Living Fund**
Grants from charities	Financial help for individuals from voluntary organisations, professional associations, community organisations, armed forces benevolent funds, etc.	See **Directory of Grants for Individuals in Need** in your public library or contact **Association of Charity Officers** for advice

Making sense of the benefit system

The benefit system is complicated. Some benefits are dependent on others - for example, someone who qualifies for income support or attendance allowance may automatically qualify for further benefits. Some benefits cancel each other out - for example, widow's benefit or unemployment benefit cancels out invalid care allowance, so you can't get both. Some benefits depend on your income and savings, others do not. Some are taxable, others are not. If you find it confusing, you're not alone! It's well worth getting independent advice from your citizens' advice bureau, or from a relevant disability organisation.

If you think you may qualify for a benefit, claim it straight away, as benefits cannot usually be backdated. If you are already receiving a different benefit, get advice first about how the new one would affect it. If you have been refused a benefit in the past, get advice about appealing or asking for a review. If you can, keep a note of dates and copies of letters or documents supporting your claim.

Local welfare advice centres know their way round the system and can save you a lot of time, as this advice worker explains:

Some allowances are very difficult to get, even on appeal, and it helps to know this if you're trying to weigh up whether it's worth the time, effort and stress. It helps to know what sort of things are easy or difficult to get a grant or loan for from the social fund. These decisions are made by local officers, and we have a good idea of what they'll accept or refuse. You won't find this sort of information and experience in advice books. Sometimes just being able to say you've been to citizens' advice makes a difference to the way social security staff treat you.

Here are some questions an advice worker can help answer if you care claiming a benefit:

- is it taxable?
- is it means-tested (dependent on income and savings)?
- does it overlap with and cancel out other benefits I receive?
- is it a benefit which qualifies me to receive other benefits as well?
- is it discretionary?
- can I get a review or an appeal if it's refused the first time?
- how long do I have to wait?
- how often are reviews or appeals for this benefit successful?
- if there is a delay in awarding my claim, can I get payment backdated to the date of the original claim?

Further reading

Your Rights from Age Concern is a useful guide to benefits for older people, and is updated every year. *Finding Your Way Round Benefits, Invalid Care Allowance - The rules explained* and *Community Charge/Poll Tax - Cushioning the blow* are useful leaflets from the Carers National Association. Some of the voluntary organisations listed on pages 68 - 71 produce their own guides to benefits.

GETTING MORE INFORMATION

First decide the services you want to find out more about. You will need to ask in different places for information about different parts of the system.

The service you want may not be on offer in your area, but don't give up until you are sure you have accurate information: the first person you ask may not have heard of a particular service, but that doesn't mean it doesn't exist. Ask if there is someone else you could contact for more definite information.

Sue had phoned her local social services office three times to find out whether she could get any help in the home as her husband's condition was getting worse and she was finding it difficult to cope on her own. Each time she was told the person she needed to speak to was not available but would phone her back. After three weeks she had heard nothing. She found out by chance that there was a medical social worker based at her local health centre. Sue contacted her and explained the situation. The social worker gave her a great deal of useful information about the home-help service and Crossroads care attendant scheme , as well as details of other help available from social services and local voluntary organisations, and who to contact.

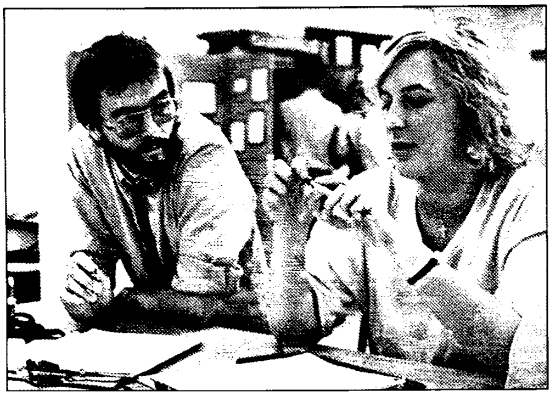
Keep on asking for information - from a wide variety of sources. The more information you have, the better your chances of finding the kind of help that you need. Get into the habit of thinking sideways if you draw a blank. Ask yourself, *'Who else do I know who might know someone who might know?'* Other carers or a carers group might be a good starting point.

If you think you have been unfairly treated, you'll find some suggestions for action on page 59.

SOURCES OF INFORMATION

WHO TO ASK...	FOR INFORMATION ABOUT...
- your GP - another doctor if you belong to a group practice - district nurse or health visitor - community psychiatric nurse if you care for someone with a mental illness - practice nurse (if there is one)	what services you can get from the NHS at home and in hospital
- hospital specialist - other hospital doctor - ward sister or outpatient clinic sister or charge nurse	- hospital services and hospital links with community health services
- community health council - your local social services or social work dept. - medical social worker (if there is one) - at your doctor's surgery or health centre - hospital social worker	- anything to do with the health services, including what to do about problems or complaints - help and support available from social services
- your child's teacher or the head teacher - your local education authority	- education services
- housing department of your local authority	- housing service
- local social security office (Freephone Social Security)	- benefits and financial help you may be able to get
- Citizens' Advice Bureau or other local advice centres - your local community organisation (if you are from a minority community)	- local services, legal rights, welfare benefits, etc.
- community relations council - equal opportunities unit of your local council - your local community organisation	- local services for black and ethnic minoritiy people
- council for voluntary services / voluntary action - rural community council - volunteer bureau	- voluntary services and support, and details of local carers' groups
- local carers group (if there is one) - Carers National Association	- services and support for carers
- local gay or lesbian support group	- services and support for gay carers or needing care

ACTION PLAN



You may find it useful to note down any services or benefits you would like to find out more about under these headings:

1. Services

2. What I need to know

3. Who to contact

Work out exactly what it is that you want to know, and in the second column write down the questions you would like to ask. Here are some examples, but your own queries may be quite different:

- Is this service available?
- Who is it for?
- How do I/we go about obtaining it?
- Is there someone else I can contact for further information?
- Where can I get advice if I/we have difficulty obtaining a service?
- Who should I write to if I want to suggest that a service should be made available?
- Is there a charge? If so are the charges means 'tested?

Write down in the third column at least two people you could contact for each item you've noted.

Which item on your list do you feel most confident to tackle? Investigate this one first, and work up to the ones you think may be more difficult.

Getting support

It helps if you can find someone who knows about the services and who will give you advice and support and generally be an ally. You might want someone to help you work out a course of action, or to come with you and support you in meetings with professional workers.

There's a Turkish-speaking worker at the advice centre who helped my father get compensation for his accident. He interpreted for my Dad at the hearings and sorted out legal help. He also told us about the occupational therapist and about getting help for a downstairs toilet.

Some carers find this kind of support in a carers group, where there is usually a wealth of knowledge about and experience of dealing with local services. But not everyone needs or wants to be part of a carers group and there are many different people who may be able to offer support or advice, according to your other particular circumstances and needs - a friend, a sympathetic professional, a voluntary worker, another carer, an advice worker or advocate.

Even if the services in your area are far from ideal, there is almost always something they can offer you, however. And there is almost always someone who can give you advice and support. But it may take persistence.

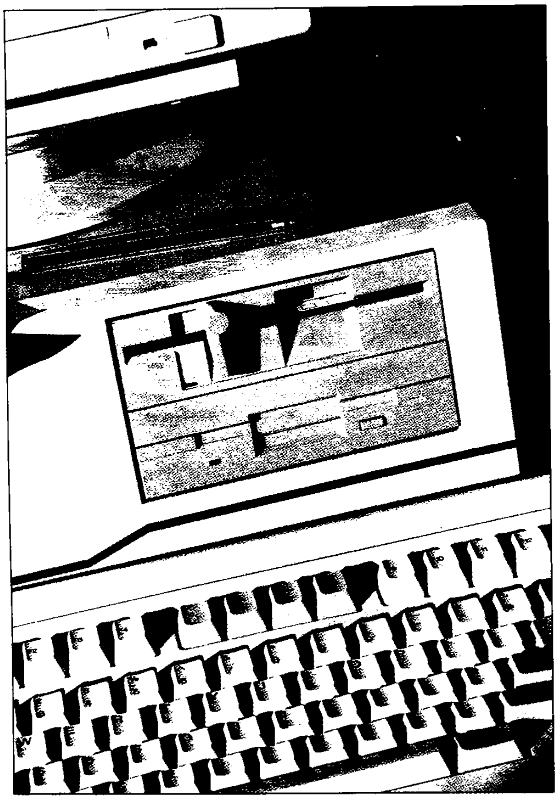
The first time I tried to speak to someone in the health authority about getting incontinence sheets it was a joke. We went round and round in circles on the phone. So I rang the Community Health Council just to get the frustration off my chest, really - I didn't expect they could do anything. A week later I got 100 sheets delivered. I'd only wanted half a dozen!

CHAPTER FIVE

DEALING WITH PROFESSIONALS

People sometimes find it difficult to get the help they need from professionals. Some are very approachable, but others can be intimidating. Contact with professionals can sometimes be frustrating and even distressing.

Often a professional may know only their own field, and be unable to give you much information about other services. Occasionally you may come across someone who seems to be deliberately unhelpful: this may be because the person does not really have the power to help, or is embarrassed about being unable to help. Sometimes it may be difficult to get through to the right person.



What are your own experiences of dealing with professionals? Can you think of one positive and one negative experience you've had? If you have the opportunity, discuss your experiences with other carers.

BUILDING UP YOUR CONFIDENCE

Many people find that talking to professionals such as doctors and social workers can be a bit intimidating. It helps if you can feel confident in yourself and are clear about what you need. There is no instant way to build up confidence, but below are some techniques that can help. Different ideas work for different people so, while some of these techniques may appeal to you, others may not. Always remember, though, that confidence increases with experience.

Draw on your own experience

One of the most difficult things I ever did was learning to ride a bike as a child. I can clearly remember how impossible it seemed before I did it. Whenever I have something difficult to face I say to myself: If I could learn to ride a bike I can get through this.

Think back over some of the difficult things you've done successfully. Think of a past experience when contact with a professional had a successful outcome. If you find yourself feeling despondent or overwhelmed, encourage yourself by recalling those positive experiences.

Draw on other people's experiences

Is there anyone you know who has more experience than you of dealing with the professional service you need? If there is ask them how they would deal with the situation. Or, if you have the chance, ask other carers.

Imagine yourself being successful

If you have a difficult appointment or interview with a professional coming up, go through the forthcoming situation in your mind, and imagine yourself having a successful meeting where things go well. This can help you go into a situation in a positive frame of mind, looking for success rather than failure.

Think of someone you admire – what would they do?

I worked for a woman who was very, very good at dealing with people. Sometimes if I'm not sure how to approach someone I ask myself: What would Jill have done? and it helps me work out what to do. Stepping outside the situation and imagining you are someone else can help you see things more clearly and be more objective. Of course, it's really your own inner voice that's finding the solution, but this can be a good way of tuning in to it.

Develop a positive attitude

Many carers find that looking after someone else's needs for a large part of the day can erode their self-confidence and their sense of their own worth. This can affect how you feel about dealing with professionals as well. If you feel confident and believe in yourself and in the value of what you're doing, the people you come in contact with will value and respect you in return. Conversely, if you feel uncertain about asking for professional advice or help, people may respond to your lack of confidence, intentionally or unintentionally, by putting you off.

Try making a list of all the things that you do to care for the person you look after. Make a rough estimate of the time you spend on each of these things. Work out how much it would cost if the person were in residential care instead, or if someone had to be paid to come into your home to look after them. If you can, make the list with someone else, perhaps the person you care for or another carer. Any time you feel your confidence faltering look at the list to remind yourself what a valuable job you're doing. And use it to discuss what support you need with the professionals with whom you come in contact with - it will help them to help you.

Try not to take things personally

The chances are that, if you find someone difficult to deal with, others do too. Remind yourself that it's not you that's the problem. Sometimes it can help to get together with other people and compare notes, as this Bengali carer did.

One receptionist at our doctors' surgery was always rude to Asian people. Some of my friends wouldn't go to the surgery when she was on duty. A new Asian woman doctor started at the practice, so I told her about it. Since then the woman has moved - she doesn't do reception work any more.

If someone is difficult or off-hand, it's helpful to acknowledge it to yourself rather than try to pretend it isn't happening. This gives you more control over the situation. You can then choose for yourself whether to tackle it or ignore it.

Sometimes it may be better to ignore difficult behaviour: if you can concentrate on what you want, in a calm and reasonable way, you may be more successful than if you try to tackle or confront it. If this makes no difference, and you feel you really are getting nowhere with a particular individual, it may be worth trying to see someone else. Tell the person concerned or their manager or supervisor the reason why. You may even want to consider making a complaint. See page 58 for what to do when things go wrong.

Act 'as if'

It can be important to let a professional person know how you are feeling, but at times you may want to keep certain feelings to yourself. For example, even though you're feeling nervous, angry or frustrated, you may feel it is important to keep these feelings under control during a discussion.

One way of doing this is to tell yourself to act 'as if'. For example, if you feel angry, try to act as if you feel calm and reasonable. If you feel nervous, try to act as if you feel confident. Imagine yourself in a familiar situation where you do feel completely confident, or where you do feel completely calm.

NEGOTIATING

Though you may not realise it, negotiating is perhaps one of the most important things you do as a carer. Each person who comes into contact with the person you care for sees them differently. Professionals see the person you care for as a patient or client. Different professionals are trained to identify different kinds of needs and to offer different kinds of solutions, and so it's not unusual to be offered different or even conflicting advice about the same problem. But you, the carer, probably have the most complete picture of the whole person. You may often have to negotiate between what's on offer from the professionals and what you and the person you care for really need or want. This is especially so if the person cannot communicate their own wishes to the professional. Even when someone can communicate themselves, they may need or want the carer to act as an intermediary.

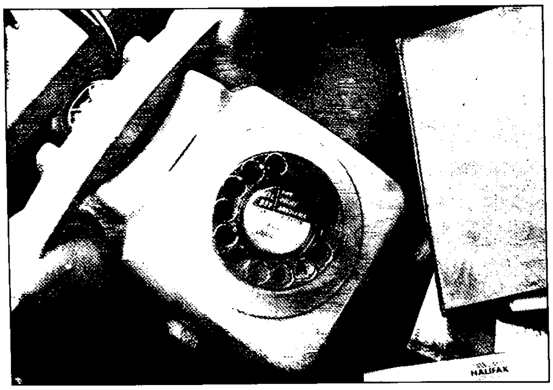
I get so het up when they start talking about doing this or that to me at the hospital. Jack sticks up for me - he knows how I feel and he can keep much calmer than me. He talked to the doctor about stopping the chemotherapy. I just didn't know how to say it.

Negotiating is not easy, especially if you feel very emotionally involved in what you are negotiating about. In the next few pages you'll find some ideas and suggestions about how to negotiate. Of course, these suggestions cannot offer instant solutions or successes, and not all these ideas will be appropriate for everyone. Adopt or adapt the ones that you think may work for you.

Be clear about what you want

This may seem obvious, but it does make a big difference if you have the necessary information to hand and have thought about or talked it through beforehand so that you can explain clearly what the problem is or what you need.

- **Be specific** - think about the important facts that the person to whom you're speaking needs to know.
- **Say what you want directly** - you don't need to be apologetic about saying what you need.
- **Stick to what you want to say** and don't be sidetracked.



Here are two phone calls to a Social Services office.
(Calls are usually answered by a duty officer who is a trained social worker.)

Man's voice: 'Hello, duty officer.'

Woman's voice: 'Hello, I'm sorry to bother you, but I wanted to get some information about home-helps, because I would quite like to get one if it's possible.' Rather vague, she doesn't say what her circumstances are or why she needs a home help.

Man's voice: 'Actually, the home-help organiser is at lunch at the moment. But I can tell you that we're very short of home-helps at the moment - there's quite a waiting list I think.' Intentionally or not, the duty officer is blocking off this enquiry.

Woman's voice: 'Oh, I see. Oh, all right, thank you. Goodbye.'

Man's voice: 'Duty officer.'

Woman's voice: 'Hello, I'd like to know if it would be possible to arrange a home-help. My husband is disabled and I really feel in need of some help.' She is specific. She explains her circumstances and why she needs help.

Man's voice: 'I see. You really need to speak to the home-help organiser - she's at lunch at the moment.'

Woman's voice: 'Could I please leave a message for the organiser to ring me? It's Mrs Maureen Bayley, phone number 464844. Could you please mention that my husband is disabled and I am desperate for help.' She sticks to what she wants to say, and gets one step nearer by leaving a message for the home-help organiser. If the organiser doesn't contact her she can phone back again, but the message may help to speed things up.

If there is something you need to discuss with a professional, work out in advance exactly what you want to say. What are the facts that will help the professional help you? What specifically is it you want from the professional? Write down the words you will use, or practise the conversation with someone else.

Solving problems

Carers face complex problems every day. When you're in the middle of a problem, it can be very hard to think clearly about possibilities or solutions. Some problems are genuinely intractable - there are no solutions. At at the other extreme there are those problems that seem much bigger than they really are. This section cannot offer solutions, but it does suggest several different ways to approach problems.

Five steps for solving problems

The problem-solving steps suggested in the table provide a way of organising your thoughts to enable you to work through the difficulties. They can help you to

- stand back and see things more objectively
- consider a range of different possibilities rather than seeing only all-or-nothing options
- feel more in control by working out what steps you can take to get nearer a solution.

STEPS FOR PROBLEM SOLVING	WITH THE PROFESSIONAL
1. Describe the problem. Make a summary of all the facts of the situation.	Ask if they see the problem in the same way. If not you will need to reach agreement before you go in.
2. Make a list of possible solutions, however unlikely some of them may seem.	Offer your own suggestions. Ask for theirs.
3. List any obstacles to each solution you have suggested.	Ask them to explain any obstacles you are not aware of. Tell them what obstacles you can see.
4. Decide which solution seems most feasible.	Try to reach agreement about the most feasible solution.
5. Decide what concrete steps you can take to make progress towards the solution.	Discuss what steps you can both take to move towards the solution.

These steps can be used to help with any problem; go through them on your own or with someone else. It may be important to get information, advice or help from a professional, or the solution may involve some form of professional help or support. But don't be intimidated by professional views. Professionals tend to follow set procedures and rules. You may be able to think more creatively and flexibly precisely because you are not trained to think in a fixed way.

More ideas

- The very process of putting a problem into words to describe it to someone else can often help to clarify it and its possible solutions. Talk it through with several different people if you can. Someone else may be able to help you see things from a different angle.
- Check your assumptions about the problem: Are you looking at it in the right way? Is the problem as big as you think it is? Have you identified the real problem or is it a symptom of something else?
- Imagine the problem from someone else's point of view - perhaps that of the person you care for, the professional concerned, or an independent observer. Does this shed any light or help you to see things more clearly?
- Sometimes you just 'know' that a solution is the right one or, conversely, that it won't work. It isn't always possible to explain why in logical terms. Intuition is valuable in solving problems, but don't rely on it exclusively: talk the problem through with someone else to try and get clear in your own mind what the source of your feeling is.
- Sleeping on it, or at least forgetting it for a while, is a good idea. If you can stop worrying about a problem and switch off from it - even just for a couple of days - you can often see things much more clearly when you go back to it.
- Making notes, or a list, or drawing a diagram can sometimes help you see things more clearly. Putting something on a sheet of paper can also help you distance yourself from the problem, because now it's out there rather than going round and round in your head.
- Have you got all the facts you need? Ask professionals, other carers, voluntary organisations or anyone who might know about useful books and leaflets.

ACTION PLAN

Are you facing any problem at the moment that would benefit from the involvement of a professional? If you are, can you describe the problem here?

Would any of the ideas suggested in this section help you to tackle the problem with the professional? Tick the suggestions that you think may be useful.

Use the five steps for problem solving

☐ **Approach the problem from a different angle**

☐ **Trust your intuition**

☐ **Put it on paper**

☐ **Incubate the problem**

☐ **Talk it through**

☐ **Arm yourself with information**

Giving and asking for feedback

It's important for you and for the person you care for to give doctors, social workers and other professionals plenty of feedback about how things are going. It's just as important to ask them for feedback, too.

Giving feedback

Some professionals are good at telling you what's happening from their end and at drawing you out about what you're doing, thinking and feeling. They encourage you by making you feel involved and appreciated. Some are good at asking if you have any problems or worries, and at checking what you and the person you care for want and that what they are doing is really helping. However, if someone doesn't ask you, it is important for you to tell them.

If you're pleased with the help you're getting, tell the person concerned and say why. If you're not happy about something, explain what is wrong and what you would like to happen. If you don't give feedback to professionals, they can't change things:

- don't assume that the professional knows the full picture
- don't assume professional help will be offered automatically
- don't assume that, because help isn't offered, someone has judged you don't need it.

How good are you at giving feedback?

How often do you:

Tell the professionals you come into contact with what effect you think their help is having on the person you care for and on yourself ?

OFTEN ☐ SOMETIMES ☐ RARELY ☐ NEVER ☐

Tell them how you both feel about what they are doing, for example; if you have doubts or worries explain what they are. If something is upsetting you or the person you are for, say so and try to explain why?

OFTEN ☐ SOMETIMES ☐ RARELY ☐ NEVER ☐

Say what you'd like to see happenning in the future?

OFTEN ☐ SOMETIMES ☐ RARELY ☐ NEVER ☐

Tell a proffessional honestly how you're feeling in yourself?

OFTEN ☐ SOMETIMES ☐ RARELY ☐ NEVER ☐

Asking for feedback

No one would be straight with me when my mother's cancer was diagnosed. The consultant just kept saying things like 'your mother is doing fine'. One day I cornered the senior registrar, who seemed more approachable, and said I was unhappy about not being told anything. I almost begged her to tell me the truth. She sat me down and told me exactly what the possibilities were and what to expect as the illness progressed. Afterwards I felt shattered, but she prepared me for the months to come and for that I was very grateful.

You also need feedback from professionals about how they see things. Don't be reluctant to ask questions if you are not offered the information or advice you feel you need. Some people find it helps to keep a notebook so they can write down questions as they think of them.

How easy do you find it to ask for feedback?

How often do you:

Ask what's happening, or what's going to happen, or what possibilities to expect?

OFTEN ☐ SOMETIMES ☐ RARELY ☐ NEVER ☐

Ask what someone is doing, or going to do, or why they're doing it?

OFTEN ☐ SOMETIMES ☐ RARELY ☐ NEVER ☐

Ask a professional how they think you're doing?

OFTEN ☐ SOMETIMES ☐ RARELY ☐ NEVER ☐

Ask how they think the person you care for is doing?

OFTEN ☐ SOMETIMES ☐ RARELY ☐ NEVER ☐

ACTION PLAN

Giving feedback

Is there a professional who would benefit from getting feedback from you? Work out what you would like to say and how you will say it.

Asking for feedback

Is there a professional who you would like to ask for more feedback? What would you like to ask? Work out when to do it.

Decision-making

Decision-making is an important part of dealing with professionals. As with problem-solving, there may be no quick or easy answers, but there are some practical things you can do to help you reach a decision:

- give yourself plenty of time to think
- talk it over with someone else - get several people's opinions if you can
- work out carefully the pros and cons of the choice you're faced with.

Writing down the advantages and disadvantages of making a particular decision can be a very useful way of clarifying your own ideas. At the top of a piece of paper, write down the decision itself. Below this, draw a vertical line, dividing the paper into left and right-hand columns. On the left-hand side write down all the advantages - the pros - of making this particular choice. In the right-hand column write down all the disadvantages - the cons.

Take your time thinking about the pros and cons because, just by concentrating on the decision, your thoughts will become clearer and new ideas will occur to you.

When you've completed your list of pros and cons, give each point a score of between 1 and 10, scoring 10 for something that is very important down to 1 for something least important. Add the scores on each side. If the score on one side is much higher than that on the other, you may have reached a clear decision - for example, if the cons far outweigh the pros, you've probably decided against the choice. Bear in mind that this technique is a means to an end, not an end in itself. Anne looks after her father who is very arthritic. He has increasing difficulty getting up the stairs, so they have begun to think about getting a stairlift.

Whether to get a stairlift

PROS		CONS	
Bedrooms can stay upstairs.	10	Cost.	10
Dad can be more independent, I don't have to be there to help him.	10	Ugly, gets in the way.	5
I can stop worrying about him falling.	10	Might not be able to use it - controls too fiddly?	not sure
		Mess and chaos when it's put in - can I stand it?	not sure
		How long does it take to install?	not sure
		Will it be reliable and safe?	not sure

When she did this chart, Anne realised that she was very keen in principle on the advantages of a stairlift, but that she needed to get more information about the practical questions before she could realistically decide. It helped to clarify the steps she needed to take before making the final decision.

Sometimes you may find that your intuition contradicts what seems to be the logical result; this is important because it means there are probably other considerations that are difficult to put into words. Even if the most important things are in your head and not on the paper, the exercise can help you sort out your feelings about the decision. You may find that, as you think about the decision, you begin to see it in a different way, or it loses its worrying importance.

If you can, compile your list of advantages and disadvantages with someone you trust, who can help you honestly list the pros and cons - not what you think they ought to be, but what they actually are. To some extent anyone can get better at making decisions just by making them. The most important thing about less important decisions is to get on with them, and to avoid using up your energy on them. Even big decisions can sometimes be changed if they turn out to be wrong.

Don't get sidetracked

It's very difficult to get anything out of our doctor. He's always a bit vague if you ask him anything.

Professional people are only human, and some are better at communicating than others. Sometimes a doctor or nurse may avoid your questions because they don't know the answer or because they don't want to worry you or the person you care for unduly. But this can be frustrating. If you need to get a clear answer from someone, the broken-record technique can be helpful. Think of yourself as a broken record:

- **say what you want**
- **repeat it**
- **keep repeating it until you get a response**
- **don't be sidetracked into another point.**

Here's an example of how this technique can work. Mrs A cares for her husband who has Alzheimer's disease. He has recently developed problems with a leaking bladder.

GP: 'It could be his prostate gland. It's quite a common problem in men your husband's age.'

Mrs A: 'What does it mean if it is his prostate gland? Will he need an operation?'

GP: 'Well, it may not be that. Better wait until we get him assessed.' Blocking off Mrs A's question.

Mrs A: 'But if it is his prostate will he have to go into hospital?'

GP: 'Don't worry Mrs A, let's cross that bridge when we come to it. I'll arrange for an assessment by the continence adviser. All right?' Sidetracking Mrs A into a different point.

Mrs A: 'I'm not worried - I'd just prefer to know what to expect. I understand that you're not sure yet, but if it is his prostate gland, would he have to have an operation? Would he have to spend some time in hospital?'

GP: (weary sigh): 'Well, as you say, we don't know yet, but if it is, then yes, it would be a simple operation and he might have to stay in for anything up to about four weeks.'

Mrs A says the conversation was helpful because it made her realise that until then she hadn't really thought about what would happen if she had to leave her husband in someone else's care.

You can probably think of other situations where the broken-record technique might help. You can adapt it to suit different circumstances. There is no point in antagonising someone from whom you want advice or information, so be gently and politely insistent, but you can be firmly insistent if someone is reluctant to give you your money back!

DECIDING ON THE RIGHT APPROACH

How do you make contact with the different people who can provide services to support you and the person you look after? Sometimes the first contact is an unexpected visit from a professional. But what do you do when you need to approach a professional person for information, advice or help? Should you phone, write, call at the surgery, clinic, department or office, or ask for for a home visit? Each approach has its advantages and disadvantages.

ACTIVITY	GOOD FOR	NOT GOOD FOR
TELEPHONING	When you need information or action quickly. Simple or straightforward inquiries	Discussing things in detail, explaining complicated facts.
WRITING A LETTER	Making sure that there is a record of what you have said. Setting out details of your case, or explaining the facts in a complicated situation.	Getting something dealt with quickly.
VISITING A PROFESSIONAL	Discussing your case in detail. Building up a relationship with the professional. Getting information or action quickly. If you need to see the person alone, without the person you care for.	If you are short of time. If you are not certain who to see. You can spend a lot of time waiting, or being directed from one department to another.
RECEIVING A HOME VISIT	Helping the professional to appreciate your circumstances. Building up a relationship. Involving the person you care for. Essential if you need a face to face discussion but can't get out.	Talking over things that you don't want to discuss in front of the person you care for.

In the following pages we'll look at some ideas for getting results over the phone and for writing letters effectively.

Getting results over the phone

Sometimes it takes me a whole day to work up the confidence to pick up the phone to the social security office.

Most of us sometimes feel like this about a phone call we have to make, even people who earn their living using the phone. It takes confidence to make a phone call to someone you don't know, especially if you need to ask for information, advice or practical help.

Becoming confident in using the phone is perhaps one of the most important things you can do for yourself. Even if you can get out, you may still need to use the phone quite a lot to organise help for the person you care for - for example, to contact professionals, sort out services, or get advice about filling in forms or claiming financial benefits.

How can you get the best out of a phone call?

- Do you know who to speak to? Always give a name and extension number if you have it. If you don't know who to speak to ask the person on the switchboard, saying something like, *'Can you tell me who to speak to about . . ?'*
- Do you know what you want to ask? Try writing a short summary of what you want to know so that you don't have to keep repeating a long-winded explanation. For example, *'Can you tell me who can give me advice about adapting our home for my disabled husband?'*

- Check that the person you are put through to is the right person to help, Ask something like, *'Are you the right person to speak to about...?*

- Have a pen and paper ready if you need to note down important information or advice, or if you want to keep a record of what the person says.

- Don't be afraid to interrupt if something is not clear. If you lose the thread or if the information is complicated stop the person and ask them to repeat what they've said or to go more slowly so that you can take notes.

- At the end of a lengthy telephone conversation, briefly go back over the main points to check that you have both understood the same things.

- Ask for written confirmation of any important decisions made over the phone, or write and confirm the decision yourself, keeping a copy of your letter.

- If someone isn't available when you phone, leave a message and find out when the person will be available. It is quite easy to spend days trying to get hold of someone whose job takes them out and about a lot. If you leave a message every time you try to contact them, they at least know that you want to reach them. If the person still has not got back to you after three or four messages over several days, it is reasonable to insist on speaking to someone else. Ask for a colleague who can deal with your case, or for the person's supervisor or manager.

ACTION PLAN

Is there a difficult or important phone call that you need to make in the near future? Next time there is, try using these steps. Use the space here to make notes, if you'd find it helpful.

1. Decide when you're going to do it by.

2. Who do you need to speak to? When is the best time to get hold of them?

3. What is your call about? Try writing summary of between 10 and 20 words.

4. What specific questions or points do you want to raise?

5. Have you got a pen and paper to make notes of what is said if you need to?

6. Interrupt if you need to ask a question or clarify something.

7. Can you summarise what's been discussed or agreed?

Writing effective letters

Sometimes a letter may be better than a phone call - for example, if the facts of your case are complicated, and can be more clearly understood when written out on paper. Bear in mind that it often takes longer for a letter to be answered, so anything urgent is better dealt with by phone. Nevertheless, a letter may be better:

- if you find it helps you to organise what you want to say on paper rather than trying to say it off the top of your head on the phone

- if you are providing information in support of a claim for financial benefit - in some cases people have been successful in getting a claim back dated because they kept copies of letters and forms proving that social security officers had been given all the relevant information by a particular date

- if you want to make sure that what you say goes on record - for example, if you would like to speak to the hospital consultant in person about something at the next appointment, or if you want to query a decision about a service or benefit

- if you are making a formal request for information, advice or a particular service, having had no response to earlier telephone requests

- if you need to explain a problem or make a complaint, or to ask why a particular service isn't available.

Sometimes it is a good idea to write a letter and follow it up with a phone call. If your case is complicated, write first setting out all the facts, so the person concerned has the full written details. Then phone two or three days later, saying something like: *'I wonder if you've had time to digest my letter. Could we discuss it now or do you need any more information?'* Don't feel that you are pestering someone by phoning as well as writing. This is common practice among professionals, especially in complicated cases, and most people find it very helpful.

- Remember to keep a copy of any letters or forms that are important, or that you might want to refer back to later on.

What makes a good letter?

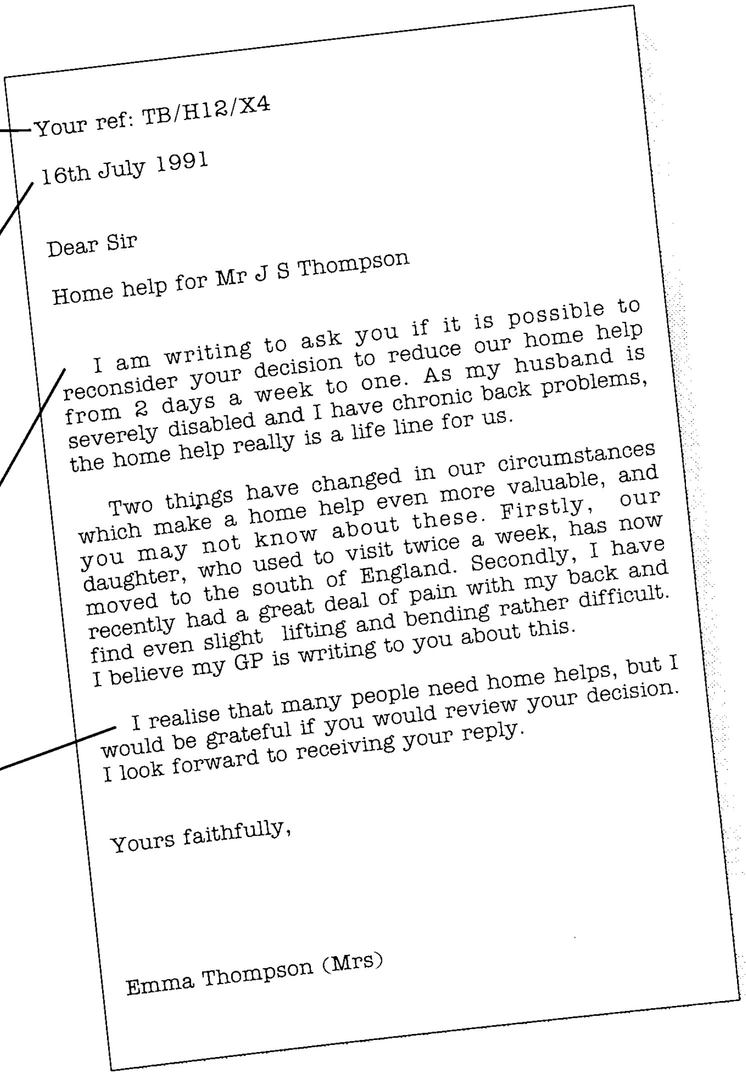
This depends on the circumstances, but there are some key things to remember to put into formal letters. Here is an example of a carer's letter asking about the decision to reduce the home-help service from two days to one day a week.

Remember to put the reference quoted on any letters you've received at the top of your letter. If there is no reference, put the name of the client, patient or claimant, etc. If the professional's records or case notes are in the name of the person you care for, it may be confusing if yours is the only name given.

Always put the date. The date of the letter may be important later- eg if you are claiming a benefit.

In the first paragraph, say briefly what the letter is about. Be concise. Include all the relevant facts but be brief. Try to keep the letter to a maximum of 2 - 3 sides. If you need to, make several rough drafts first.

Say what you would like to happen as a result of your letter. If you intend to follow up your letter with a phone call, say when you will be phoning. This may encourage the person who receives the letter to act on it more quickly. Ask for a reply.



Your ref: TB/H12/X4

16th July 1991

Dear Sir

Home help for Mr J S Thompson

I am writing to ask you if it is possible to reconsider your decision to reduce our home help from 2 days a week to one. As my husband is severely disabled and I have chronic back problems, the home help really is a life line for us.

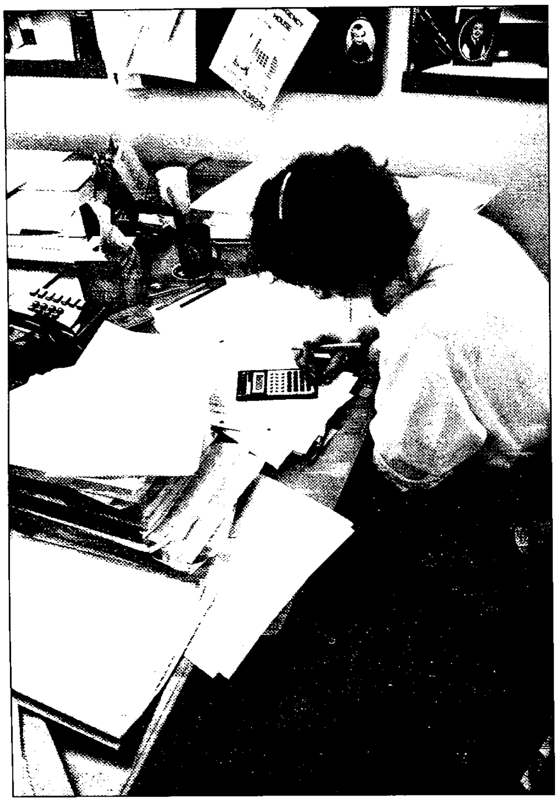
Two things have changed in our circumstances which make a home help even more valuable, and you may not know about these. Firstly, our daughter, who used to visit twice a week, has now moved to the south of England. Secondly, I have recently had a great deal of pain with my back and find even slight lifting and bending rather difficult. I believe my GP is writing to you about this.

I realise that many people need home helps, but I would be grateful if you would review your decision. I look forward to receiving your reply.

Yours faithfully,

Emma Thompson (Mrs)

GETTING NOWHERE



Sometimes, however patient and determined you are, nothing happens, or something goes wrong. This may be the point at which you feel like giving up - you may feel angry, bitter, desperate, even hopeless. These feelings are understandable, but they don't change things and they can be damaging to your own well-being and perhaps to future relationships with professional people. For your sake and that of the person you care for, it is worth trying to resolve things.

In some cases it may not be possible to fully resolve the difficulties, but things can't change if you don't tell someone about the problems you are experiencing. Whatever the outcome, it helps to share the problem rather than to keep it to yourself. Talking it over with someone (for example, another professional or an independent advice worker) or writing a letter, (for example, to the person in charge of the department you are dealing with or to your local councillor) can give you an outlet for your feelings and help you to clarify what further action is feasible.

Talking it through helps you to weigh up the chances of winning if you do decide to take further action. Sometimes the problem lies with 'the system' rather than an individual professional or your negotiating abilities. You may decide that you don't want to take a problem any further, preferring to save your energy for other things.

That said, here are some suggestions about action that you might take. Choose the ones that seem to you most feasible and talk them over with someone else, perhaps the person you care for, a friend, a sympathetic professional or another carer.

Get independent information, advice and support from an informed person

Various people can offer independent advice or support, according to the circumstances:

- **Another sympathetic professional**
- **An independent advice centre** such as your local **citizens' advice bureau.** If the person you're dealing with doesn't speak your language, and you would like advice and support from someone who does, you may be able to get help from your local **community relations council,** or your **district health authority** may employ interpreters or link workers who speak your language. Your local community centre or organisation may have a welfare rights adviser.
- **An advocacy scheme:** advocates are people experienced in representing and supporting those who need to use public services. They don't exist everywhere. Some schemes are specifically for certain groups. Volunteer 'citizen advocates' offer help to people needing representation or support in dealing with services. Your citizen's advice bureau, council for voluntary service or community health council should be able to tell you about schemes in your area.

Tell someone you're not happy with the service

Speak or write to the person you are dealing with about your concerns. Explain what you think is going wrong and what you would like to happen. If you feel you are getting nowhere with a particular individual, consider writing to the person in charge of the department. Explain the situation clearly but briefly. Try and make sure the tone of your letter is objective rather than accusatory. Tell the person you are writing to that you would appreciate their help in sorting out the difficulties, and make sure that you specifically ask them to reply to your letter. Always keep a copy of your letters in case you wish to take the matter further.

Change practitioner

Some professionals provide a better service than others. If you are fairly sure that you would get a better service from a different practitioner, it may be worth trying to change. Changing your GP should be straightforward; with other professionals it may be more difficult, but it is worth a try if you believe it is the right answer.

To change your GP, simply find a doctor you would like to move to and phone the surgery to ask if they will accept you. Sign the appropriate section of your NHS card, and take or send it to the new doctor, who should sign it and send it on to the family health service authority. If you don't have an NHS card, the new doctor can give you form FP1 to fill in.

Carers' organisations are concerned that NHS reforms may result in some GPs being reluctant to take on new patients who need a high level of medical care. If you have any difficulty in finding a doctor for someone with a long-term illness or disability, contact your local family health service authority immediately. The FHSA has a responsibility to provide GP care and will investigate any difficulties.

If you are not happy with your consultant, ask your GP to refer you to a different one. It may help if you can give the name of a preferred consultant - ask other carers or your community health council for suggestions. Explain your reasons to your GP.

It is unusual but not impossible to change your social worker. Phone or write to the principal social worker for your area team. (Phone your social services department to find out their name and check their job title) Explain in your letter why you would like to change. The principal social worker may try to help you and your social worker solve the problem together. If this doesn't work, you may be allocated someone else.

Make a complaint

Every social services department has a complaints procedure, a duty to give you information about how to make a complaint, and a responsibility to deal with complaints quickly and efficiently.

If you have a complaint about the health services, contact your community health council for help. If the CHC cannot resolve the problem, and you wish to take it further, they can tell you how to contact the health service ombudsman for your area.

Contact your local councillor if you are not satisfied with a service provided by a council department. As an elected representative, your councillor has a responsibility to investigate your problem and advise you about what can be done, if anything. If your councillor believes you have been unfairly treated, he or she may take action on your behalf to sort out the difficulty. You can make a complaint to the local ombudsman (in your phone book). You can do this directly yourself, or you can ask your local councillor to help.

You can write to your MP about any problem where you feel you have been unfairly treated. You can visit his or her local surgery, which is usually advertised in your local paper; alternatively, look up the local HQ of the relevant political party in the phone book, ring them and ask them for details of the surgery. If your MP believes you have a good case, he or she may be willing to take up the issue on your behalf. Even if not, it is well worth bringing your problem to his or her attention. The more letters MPs receive from carers, the greater their awareness of carers' needs, and the stronger the pressure on government to improve policies in support of carers.

Join forces

Don't forget there are others like you. Contact your local carers' group or a national organisation involved with carers, such as the **Carers National Association, RADAR or Contact a Family.** Carers' organisations have a lot of expertise. They can advise you about the best way to tackle your problem and they will also give you emotional support.

There are carers' groups and voluntary organisations around the country working to get changes and improvements in the services and support available to carers and the people they care for. Your local authority has to consult carers about their community care plans (see page 30). There may be a carers' forum, carers' project or carers' group in your area already actively involved in putting the views of carers to the people who make policies and provide services. Why not get involved?

CHAPTER SIX

GETTING TOGETHER

Carers can benefit enormously from getting together to do things- from social activities to campaigning.

This chapter looks at different ideas for getting together with other people and some examples of groups and activities in which you might want to get involved. We also look at working for change - ways in which carers together can influence decisions at national and local level.

IS A GROUP RIGHT FOR YOU?

Each area has its own network of voluntary and community organisations, social groups and classes and courses for adults, and all of these have something to offer carers. Different groups or schemes will suit different individuals. Some carers get a lot of support from joining a carers' group. Other people prefer to get involved in activities that take them right away from caring.

I don't relish the idea of a carers' group. But I do enjoy working as a volunteer in our local charity shop. I meet lots of people and I feel I'm doing something worthwhile.

I act as secretary to our residents' association committee. I can't go out much so it gives me something to do at home - keeps my brain from stagnating. We have a lot of our meetings here, but I try always to get to meetings when they're at someone else's house.

Many carers feel nervous or apprehensive about joining a group. People who have been caring for some time can become very isolated and perhaps afraid to go out.

I wanted to invent a reason not to come to the carers' group but I was in such a state I didn't have the bottle to phone the social worker and tell her not to pick me up. I was terrified the first time I came, but it's the best thing that's happened to me in the last four years, finding this group.

Some carers find it helps just to be able to talk with other people who understand their situation.

Three or four members of our group don't come to meetings, but they keep in touch by phone. As I'm the group organiser I phone them if I haven't heard from them for a while, just to make sure they're OK.

The interpreter introduced me to another Punjabi woman whose child has thalassaemia. There are three of us now who go to the same clinic. We don't live in the same area, but we keep in touch. We learn a lot just from talking to each other.

Carers' groups

Every group is different. Some carers' groups are open to anyone who is or has been, a carer; others are for people caring for someone with a particular illness or disability. In some areas there are groups for people from a particular community - perhaps a Chinese, Jewish or Bengali group.

Meetings may be monthly, fortnightly, or even weekly. But joining a group doesn't mean that you have to go to meetings. Most groups are informal and friendly, and it's entirely up to you how often you go. If you feel nervous the first time, ask if you can go along with another member.

What can a carers' group do?

Typically a group will give you:

- an opportunity to meet and make friends with people who understand your situation
- somewhere to let off steam, be listened to, and talk through problems
- information - about, for example, local doctors, other professionals, services and facilities, the condition of the person you care for
- social events and outings - a chance to have fun
- help in finding someone to sit with the person you care for so you can get to meetings
- training in practical nursing skills or other aspects of caring

Some groups have gone on to tackle larger projects, or to take on a campaigning role:

- producing a local carers' handbook and other helpful booklets
- drawing up recommendations, lobbying and campaigning for improvements in local services
- starting a telephone help line or a drop-in centre
- starting an interpreting service to help carers who speak little or no English
- representing carers' interests on local authority and health authority consultative bodies
- setting up befriending schemes, sitting services, or Crossroads care attendant schemes
- organising conferences, workshops, or carers' fairs

Starting and running a carers' group

Some groups are started by professionals, but some carers have started up their own groups. Many are run jointly by carers with the active help and support of professionals. If you are interested in starting up your own group, you may like to read Judy Wilson's handbook, *Caring Together.* Consider whether you would like help and support from a professional worker - perhaps a sympathetic social worker, health visitor, voluntary organisation worker or patient advocate. If you know someone who you think would be good, phone them up and talk to them about it. The right person may be able to help you get facilities such as a room to meet in, transport and even funding.

Other groups and schemes

There are likely to be a whole range of other groups and schemes in your area that may offer the kind of support and activities that would be right for you. Here are some examples:

- Groups for people coping with the same illness or disability are often open to families and carers as well and can be a valuable source of information, advice and support.
- Some GPs and consultants set up patient participation groups to give patients and their families a say in how services are organised.
- Women's centres and women's groups provide somewhere you can drop in for a chat, discuss a problem, or make friends with other women. Some groups and centres run courses in things like assertiveness training or in looking after yourself.
- You may simply want to get together with other people in a social group. Find out from neighbours, friends, professionals, local newspapers, your place of worship or your local community centre what local groups there are.
- Between them, voluntary organisations in your area are likely to offer a whole range of different kinds of support to carers.

- Black and minority organisations and groups can give valuable support to carers, providing an opportunity to meet and talk to others from your own community, even if they are not carers.
- Gay and lesbian support groups may be able to provide practical and emotional support for gay people caring or needing care. Many groups are knowledgeable about local services and support for gay people affected by HIV/AIDS.
- Many adult education centres offer classes on relaxation, managing stress, assertiveness skills and other subjects that are useful to carers.

Finding out more

Groups and schemes and the type of help they can offer differ widely from place to place. The best way to find out about local ones is to ask a range of people and organisations. Try to be specific about what you are looking for. If you have been able to identify two or three things you'd like to get out of a group, mention these when you ask. Start by trying the people and places listed here:

- **your council for voluntary service** or the local equivalent
- **professionals** with whom you come in contact. But don't rely on information from professionals alone: some are very knowledgeable, but some are not
- **your local community health council** for information about organisations concerned with health issues, including patient participation groups
- **other carers**
- **a carers' worker** - if there is one
- **the information or enquiries service** of your local authority or your public library
- **national voluntary organisations** - if they don't have a local branch or group in your area they'll suggest where to go for information
- **your local community organisation** or community relations council if you want to find out about sources of support for black or minority carers
- **your local adult education centre** or the education department of your local authority for information about daytime and evening classes
- **Yellow Pages** - look for 'Help and Advice' in the contents list or under headings such as 'Charitable Organisations', 'Disabled - Information and Services' and 'Social Service and Welfare Organisations'.

WORKING FOR CHANGE

Much of this book has been about working out small changes you might want to make yourself that could make a difference. We've also touched on many of the larger needs and issues which affect carers - which often can't be tackled by one person alone. Some carers get involved in campaigning, or other forms of political activity. Some groups get involved in trying to change or improve things - for themselves, for carers in general, or for people needing care. One of the best summaries of what carers need, and what changes would help, is the Carers' Charter.

The Carers' Charter

This plan, endorsed by the leading voluntary organisations concerned with carers, is designed to help bring attention to carers' needs, and to encourage carers to feel confident in asking for better services and support.

CARERS NEED:

1. Recognition of their contribution and of their own needs as individuals in their own right.

2. Services tailored to their individual circumstances, needs, and views, through discussions at the time help is being planned.

3. Services which reflect an awareness of differing racial, cultural and religious backgrounds and values, equally accessible to carers of every race and ethnic origin.

4. Opportunities for a break, both for short spells (an afternoon) and for longer periods (a week or more), to relax and have time to themselves.

5. Practical help to lighten the tasks of caring, including domestic help, home adaptations, incontinence services, help with transport.

6. Someone to talk to about their own emotional needs, at the outset of caring, while they are caring and when the caring task is over.

7. Information about available benefits and services as well as how to cope with the particular condition of the person cared for.

8. An income which covers the costs of caring and which does not preclude carers taking employment or sharing care with other people.

9. Opportunities to explore alternatives to family care, both for the immediate and long-term future

10. Services designed through consultation with carers, at all levels of policy and planning

This is of course a general list designed for all carers. What other important needs of your own would you like to add? Write them down.

Which points (from this list and your own) are the most important priorities for you personally?

If you have the chance to discuss the Charter and these questions with other carers, you might find it useful to discuss and agree a list of priorities for yourselves as a group. Could your group use the Charter to publicise carers' needs locally, perhaps by sending copies to key people in the health or social services?

What is the government doing for carers?

It has been estimated that if every carer stopped tomorrow it would cost the Treasury about £24 billion annually to take over the task.

Support for carers was the second objective of the **NHS** and **Community Care Act** which came into force in 1990, so the government recognises that carers do a valuable job.

In 1990 the government also introduced the **Carer Premium**, an addition to income support or invalid care allowance for people on a low income. While everyone welcomed the government's recognition of carers' financial needs, many carers say the amount is too little to make a real difference.

What can carers do to influence the government ?

Gradually carers all over the country are beginning to come together and find a voice through local self-help groups and through national organisations such as the **Carers National Association**. Some people are even talking about the 'carers movement'. Though it is early days, it is a very positive idea to think of carers becoming a force to be reckoned with by the people who make policies and plan services. The more we can do to raise awareness of carers' needs among politicians, planners and providers of services, the easier it will be to bring about the changes we so badly need.

National government

The Carers National Association and other national voluntary organisations involved with carers are continually lobbying all the political parties at national level to raise awareness of the needs of people cared for and caring at home.

As an individual or as a group of constituents you can write to your MP or visit his or her surgery about any problem (see page 59) to ask questions or say what you think about what the government is doing, or should do, for people being cared for at home or for carers. You can write to your MP at the House of Commons, Westminster, London SW1.

Local government

There are real opportunities at local level to influence political decisions about support and services for carers - from writing letters to the local newspaper, as an individual or as a group lobbying or campaigning through voluntary organisations, community groups, trade union branches, and political parties. Some carers' groups have successfully joined forces with voluntary or community groups to push for changes.

ACTION PLAN

If you are interested in finding out more about what the government and your local council and health authority are doing for carers, or in trying to influence what they do in the future, you need to know where to find the right people to talk to.

Do you know who your MP is? Your public library should be able to tell you and to give the address and time of his or her local 'surgery'.

Do you know what he or she knows about carers' needs?

Local councillors are there to represent the interests of their constituents, so why not write and tell your councillors what your needs are, or invite them to a meeting of your carers' group for a discussion?

Do you know who your local councillors are?

Your public library, or the information or the enquiries service of your local council, can give you details of your local councillors' names, addresses and phone numbers.

Do you know what they think about carers' needs?

Do you know which **local organisations** actively represent carers' interests to the health authority and local authority? Which local organisations campaign on issues affecting carers?

Local authorities have to consult carers in drawing up their community care plans. Consultation or planning committees may have places reserved for carers and users of services - you could contact the carers' representatives if there are issues or needs you would like to be raised.

Your council for voluntary service or community health council should be able to tell you which organisations represent carers' interests on consultative bodies and which are campaigning organisations. You might consider contacting one of these organisations and finding out how you can offer support. They will value your views and be glad of any help you would like to give.

USEFUL PUBLICATIONS

Some publications are only available by post. If the address of the publishing organisation is not given here, you will find it in **Organisations**

A Guide to Grants for Individuals in Need, Directory of Social Change (available in public libraries - lists thousands of trusts and benevolent funds)

Awaaz, Manchester Council for Community Relations, Elliot House, 3 Jackson's Row, Deansgate, Manchester M2 5WD, or in person from The King's Fund Centre Bookshop, 126 Albert Street, London NW1 7NF (video and booklet for Asian parents about help for children with special needs)

British Rail and Disabled Travellers, British Rail (free from local railway stations or SAE to RADAR)

Call for Care, King's Fund Carers Unit, 126 Albert Street, London NW1 7NF (a book for Asian carers of elderly people)

Carers National Association Leaflets & Factsheets:

Leaflet 3: Finding your Way Around Benefits

Leaflet 4: Community Charge/Poll Tax - Cushioning the blow

Leaflet 5: Invalid Care Allowance - The rules explained

Leaflet 6: Disabled Persons Act 1986 - How to use it to get services

Leaflet 7: NHS & Community Care Act - The carer's view

Factsheet 1: Gadgets & Aids to Daily Living

Factsheet 2: Getting Alternative Care at Home

Factsheet 3: Holidays

Factsheet 4A: Finding, Choosing and Paying for Residential Care

Factsheet 4B: Residential Care: Your legal position and your new role

Carers' Needs: A ten point plan for carers, Bournemouth English Book Centre (BEBC), 15 Albion Close, Parkstone, Poole, Dorset BH12 3LL.

Caring at Home, Nancy Kohner, National Extension College and King's Fund Centre, 1988, available from BEBC (see above)

Caring Together: Guidelines for Carers' Self-Help and Support Groups, Judy Wilson, National Extension College and King's Fund Centre, 1988, available from BEBC (see above)

Coping with Dementia : A handbook for carers, Health Education Board for Scotland, Woodburn House, Canaan Lane, Edinburgh EH10 4SG

Disability Rights Handbook, from Disability Alliance (published annually)

Door to Door: A guide to transport for disabled people, Department of Transport Door to Door Guide, Freepost, South Ruislip, Middlesex HA4 0N

Help at Hand : The home carers' survival guide, Jane Brotchie, Bedford Square Press, 1990, from bookshops

If Only I'd Known that a Year Ago..., RADAR, 25 Mortimer Street, London W1N 8AB (a guide to services, benefits and organisations which may be of use to newly disabled people, their family and friends)

It's My Duty Isn't It?, Jill Pitkeathley, Souvenir, 1989 (a personal view by the Director of the Carers National Association)

The Mental Health Act 1983: An outline guide, available from MIND

National Key Scheme (NKS) List and Key, from RADAR

Orange Badge Scheme, Department of Transport, 1987, 18p (postage) from RADAR

Stress and Relaxation, Jane Madders, MacDonald Optima, 1981, from bookshops

Teach Yourself Relaxation, James Hewett, Hodder & Stoughton, 1985 from bookshops

Taking a Break: A guide for people caring at home, Maggie Jee, King's Fund Centre, 1987, available from BEBC (see above)

The Support You Need, details from King's Fund Carers Unit, 1991 (a book for African Caribbean carers of elderly people)

The 36-hour Day: Caring at home for confused elderly people, Nancy L. Mace and Peter Rabins, Hodder & Stoughton with Age Concern, 1985, from bookshops

Who Cares Now? Caring for an older person, Nancy Kohner and Penny Mares, BBC Education, London W12 7RJ

Your Rights, from Age Concern, (a guide to benefits for older people published annually)

National organisations

ACTION FOR DYSPHASIC ADULTS

Canterbury House
1 Royal Street
London SE1 7LL
Tel: 071-261 9572
Information and advice for dysphasic people and carers. Small network of regional groups.

ADVISORY CENTRE FOR EDUCATION

16 Aberdeen Studios
22 Highbury Grove
London N5 2EA
Tel: 071-354 8321
Free information and advice to parents of all children in state maintained schools, including the rights of children with special needs and parents' rights.

AGE CONCERN ENGLAND

Astral House
1268 London Road
London SW16 4ER
Tel: 081-679 8000
Support for older people and their carers. Books, leaflets and factsheets. Local groups provide services in some areas.

ALZHEIMER'S DISEASE SOCIETY

158-160 Balham High Road
London SW12 9BN
Tel: 081-675 6557
Support for families of Alzheimer's disease sufferers. Literature. National network of support groups.

ARTHRITIS CARE

5 Grosvenor Crescent
London SW1X 7ER
Tel: 071-235 0902
Local branches. Mobility equipment. Welfare advice. Holiday centres. Leaflets and information.

ASSISTANCE AND INDEPENDENCE FOR DISABLED PEOPLE VEHICLE SUPPLIES

(AID VEHICLE SUPPLIES)
Hockley Industrial Centre
Hooley Lane
PO Box 26 Redhill
Surrey RH1 6JF
Tel: 0737 770030
Supplies cars with or without conversion for disabled people.

ASSOCIATION FOR ALL SPEECH IMPAIRED CHILDREN (AFASIC)

347 Central Markets
London EC1A 9NH
Tel: 071-236 3632
Information and support for families of children whose speech or language is impaired. Campaigns to raise awareness and improve services.

ASSOCIATION OF CHARITY OFFICERS

2nd Floor
Tavistock House North
Tavistock Square
London WC1H 9RJ
Tel: 071-387 0578
Can put people seeking financial help in touch with an appropriate charity.

ASSOCIATION OF CONTINENCE ADVISERS

Disabled Living Foundation
380-384 Harrow Road
London W9 2HU
Tel: 071-266 3704 or 071-289 6111
Advice and literature for people with continence problems.

ASSOCIATION OF CROSSROADS CARE ATTENDANT SCHEMES

10 Regent Place
Rugby
Warwickshire CV21 2PN
Tel: 0788 573653
Provides care attendants who come into the home to give the carer a break. 170 autonomous schemes throughout the UK.

BRITISH ASSOCIATION FOR COUNSELLING

37A Sheep Street
Rugby
Warwickshire CV21 3BX
Tel: 0788 578328/9
Can provide list of counsellors in your area, giving counsellor's qualifications, type of problems counselled and probable cost. Information sheet for people seeking counselling.

BRITISH RED CROSS

9 Grosvenor Crescent
London SW1X 7EJ
Tel: 071-235 5454
Some local branches lend or hire medical equipment to people needing care at home.

CANCERLINK

17 Britannia Street
London WC1X 9JN
Tel: 071-833 2451
For people with cancer and their carers.

CARERS NATIONAL ASSOCIATION

29 Chilworth Mews
London W2 3RG
Tel: 071-724 7776
Information, advice and support for carers, local branches in many areas

CENTRE FOR ACCESSIBLE ENVIRONMENTS

35 Great Smith Street
London SW1P 3BJ
Tel: 071-222 7980
Organisation concerned with the physical environment for disabled and elderly people.

CHEST, HEART AND STROKE ASSOCIATION
CHSA House
123-127 Whitecross Street
London EC1Y 8JJ
Tel: 071-490 7999
Advice, information, welfare and rehabilitation services. Large number of local groups.

CONTACT A FAMILY
16 Strutton Ground
London SW1P 2HP
Tel: 071-222 2695
Support for families who care for children with special needs.

COUNSEL AND CARE FOR THE ELDERLY
Lower Ground Floor
Twyman House
16 Bonny Street
London NW1 9PG
Tel: 071-485 1566
Advice service for old people, their relatives and professionals. Information leaflets. Grants to help people remain in or return to their homes

COUNSELLING INFORMATION SCOTLAND
Health Education Board for Scotland
Woodburn House
Canaan Lane
Edinburgh EH10 4SG
Tel: 031-452 8989
Can provide list of counsellors in your area, giving counsellor's qualifications and type of problems counselled.

CRUSE, BEREAVEMENT CARE
126 Sheen Road
Richmond
Surrey TW9 1UR
Tel: 081-940 4818
Bereavement counselling. Practical advice. Social contact. Publications.

DIAL UK
(DISABLEMENT INFORMATION AND ADVICE LINES)
Park Lodge
St Catherine's Hospital
Tickhill Road
Balby
Doncaster DN4 8QN
Tel: 0302 310123
Telephone information and advice on any aspect of disability. Can put you in touch with more than 80 autonomous organisations around the country.

DISABILITY ALLIANCE EDUCATION AND RESEARCH ASSOCIATION
1st Floor East
University House
88-94 Wentworth Street
London E1 7SA
Tel: 071-247 8776
(or 071-247 8763 for welfare rights enquiries)
Information for people with disabilities and their advisers about their entitlement to state benefits and services. Produces *Disability Rights Handbook* annually.

DISABLED DRIVERS' MOTOR CLUB
Cottingham Way
Thrapston
Northants NN1 4PL
Tel: 0801 24724
Membership available to drivers and passengers with a disability. Information and advice on motoring and mobility problems.

DISABLED LIVING CENTRES COUNCIL
380-384 Harrow Road
London W9 2HU
Tel: 071-266 2059
Provides list of disabled living centres around the country where aids are on display.

DISABLED LIVING FOUNDATION
380-385 Harrow Road
London W9 2HU
Tel: 071-289 6111
National resource for information on aids and equipment for people with a disability.

DOWN'S SYNDROME ASSOCIATION
155 Mitcham Road
London SW17 9PG
Tel: 081-682 4001
Information and support for parents, families and people who work with Down's syndrome sufferers.

FORCES HELP SOCIETY
122 Brompton Road
London SW3 1JE
Tel: 071-589 3243
Financial and welfare help for ex-service men and women. Residential homes. Can put you in touch with other welfare organisations for service people and their families.

HELP THE AGED
16-18 St James's Walk
London EC1R 0BE
Tel: 071-253 0253
Fund-raising charity for projects at home and abroad. Advice services for elderly people, their relatives, carers and friends.

HOLIDAY CARE SERVICE
2 Old Bank Chambers
Station Road
Horley
Surrey RH6 9HW
Tel: 0293 774535
Advice and information on holidays, holiday helpers and travel arrangements for people who are disabled or elderly.

HOSPICE INFORMATION SERVICE
St Christopher's Hospice
51-59 Lawrie Park Road
London SE26 6DZ
Tel: 081-778 9252
Publishes a directory and provides information about hospices.

INDEPENDENT LIVING FUND
PO Box 183
Nottingham NG8 3RD
Tel: 0602 290423
Money for people who are on income support and the higher rate attendance allowance to enable them to receive care at home.

LONDON DIAL-A-RIDE USERS' ASSOCIATION
St Margarets
25 Leighton Road
London NW5 2QD
Tel: 071-482 2325
Campaigns for improvements in transport for people with disabilities. Can put you in touch with local transport schemes in the London area.

MENCAP
(ROYAL SOCIETY FOR MENTALLY HANDICAPPED CHILDREN AND ADULTS)
123 Golden Lane
London EC1Y 0RT
Tel: 071-454 0454
Parent-based organisation which provides nationally a range of information and services for individuals and their families.

MIND
(NATIONAL ASSOCIATION FOR MENTAL HEALTH)
22 Harley Street
London W1N 2ED
Tel: 071-637 0741
For carers of people with any form of mental illness; local associations round the country. Publications from MIND Publications Mail Order Service, 4th Floor, 24-32 Stephenson Way, London NW1 2HD. Tel: 071-387 9126

MOBILITY ADVICE AND VEHICLE INFORMATION SERVICE (MAVIS)
Department of Transport
Transport and Road Research Laboratory
Crowthorpe
Berkshire RG11 6AU
Tel: 0344 770456
Practical advice on driving, car adaptations and car choice for disabled drivers and passengers.

MOTABILITY
2nd Floor
Gate House
Westgate
Harlow
Essex CM20 1HR
Tel: 0279 635666
Supplies cars and wheelchairs to people in receipt of mobility allowance.

NATIONAL ASSOCIATION OF BEREAVEMENT SERVICES
122 Whitechapel High Street
London E1 7PT
Tel: 071-247 1080
Can put you in touch with bereavement counselling services in your area and advice about the most appropriate service for you.

NATIONAL SCHIZOPHRENIA FELLOWSHIP
28 Castle Street
Kingston-upon-Thames
Surrey KT1 1SS
Tel: 081-547 3937
Information and advice for people with schizophrenia and their families.

PARKINSON'S DISEASE SOCIETY
22 Upper Woburn Place
London WC1H 0RA
Tel: 071-383 3513
Branches all over the country. Welfare department. Leaflets and newsletter.

PHYSICALLY HANDICAPPED AND ABLE BODIED (PHAB)
12-14 London Road
Croydon CR0 2TA
Tel: 081-667 9443
Seeks to further the integration of people with and without disabilities.

RADAR
(ROYAL ASSOCIATION FOR DISABILITY AND REHABILITATION)
25 Mortimer Street
London W1N 8AB
Tel: 071-637 5400
Information on aids and equipment, access, holidays, mobility, sport, leisure. Campaigns to improve rights and services.

RELATE
(NATIONAL MARRIAGE GUIDANCE)
Herbert Gray College
Little Church Street
Rugby
Warwickshire CV21 3AP
Tel: 0788 573241/560811
Local organisations throughout the country. Relationship counselling.

ROYAL NATIONAL INSTITUTE FOR THE BLIND (RNIB)
224 Great Portland Street
London W1N 6AA
Tel: 071-388 1266
Provides services, information and advice to visually impaired people, families and carers.

ROYAL NATIONAL INSTITUTE FOR THE DEAF (RNID)
105 Gower Street
London WC1E 6AH
Tel: 071-387 8033
Information and advice. Projects. Training. Interpreting service. Campaigns.

SPOD
(ASSOCIATION TO AID THE SEXUAL AND PERSONAL RELATIONSHIPS OF PEOPLE WITH A DISABILITY)
286 Camden Road
London N7 0BJ
Tel: 071-607 8851
Publications, advice and counselling. Telephone counselling service available Mon/Weds 1.30-4.30, Tues/Thurs 10.30-1.30.

STANDING CONFERENCE OF ETHNIC MINORITY SENIOR CITIZENS
5 Westminster Bridge Road
London SE1 7XW
Tel: 071-928 0095
An umbrella organisation for around 300 community groups for people over age 55.

TERRENCE HIGGINS TRUST
52-54 Gray's Inn Road
London WC1X 8LT
Tel: 071-831 0330
Provides information, counselling. Can put you in touch with local support groups for people with HIV/AIDS, families and carers.

VOCAL
(VOLUNTARY ORGANISATIONS COMMUNICATION AND LANGUAGE)
336 Brixton Road
London SW9 7AA
Tel: 071-274 4029
Umbrella organisation for voluntary organisations concerned with communication difficulties. Can put you in touch with local sources.

WOMEN'S THERAPY CENTRE (LONDON)
6 Manor Gardens
London N7 6LA
Tel: 071-263 6200

WOMEN'S COUNSELLING AND THERAPY SERVICE
(LEEDS)
Leeds Methodist Mission
Oxford Place
Leeds LS1
Tel: 0532 455725
These centres offer counselling and therapy services for women.

Local organisations - how to find them

CITIZENS' ADVICE BUREAU

Look in the phone book. Advice on any problem.

COMMUNITY HEALTH COUNCIL

(IN ENGLAND AND WALES)

LOCAL HEALTH COUNCIL

(IN SCOTLAND)

DISTRICT COMMITTEE FOR HEALTH AND PERSONAL SOCIAL SERVICES

(IN NORTHERN IRELAND)

Look in phone book or in Yellow Pages under 'Consumer and Trading Standards Organisations'. Information and advice on anything to do with the health services.

COMMUNITY RELATIONS COUNCIL

Look in the phone book or in Yellow Pages under 'Social Services and Welfare Organisations'. Names vary from place to place, so try also Racial Equality Council, Council for Community Relations. Information and advice on local support for black and minority people.

COUNCIL FOR VOLUNTARY SERVICE

Look in phone book or in Yellow Pages under 'Social Services and Welfare Organisations'. Names vary from place to place so look also under Voluntary Action, Rural Community Council, Volunteer Bureau. It may be listed under the name of your town, borough, district, etc. Information about anything to do with local voluntary organisations and services.

DEPARTMENT OF SOCIAL SECURITY

Local office provides information and deals with claims for benefit.

DISTRICT HEALTH AUTHORITY

(IN ENGLAND AND WALES)

HEALTH BOARD

(IN SCOTLAND)

HEALTH AND SOCIAL SERVICES BOARD

(IN NORTHERN IRELAND)

Look in phone book under the name of your borough, town, district, etc, or in Yellow Pages under 'Health Authorities and Services' The health authority is responsible for hospital and community health services.

FAMILY HEALTH SERVICE AUTHORITY

Look in the phone book under Family Health Service Authority or in Yellow Pages under 'Health Authorities and Services'. Responsible in England and Wales for NHS services provided by GPs, opticians, dentists, and pharmacists - can deal with any enquiries about or problems with these services.

LOCAL AUTHORITY (COUNCIL)

Your local authority is reponsible for a whole range of services including housing and social services. Look in the phone book under the name of the council for the department you want.

LOCAL TRANSPORT AUTHORITY

Look in the phone book under the name of your county. Information about concessionary fares and other local authority transport schemes for people with disabilities.

SOCIAL SERVICES

A department of your local council. There is usually a social services office for each area served by the council. Can provide information, advice, practical help and services for elderly and disabled people and carers.

VOLUNTEER BUREAU

Look in the phone book under Volunteer Bureau or under Council for Voluntary Service. May be able to arrange volunteer help or services, depending on what is needed.

YOU AND CARING

AN ACTION PLAN FOR CARING AT HOME

YOU AND CARING
is a self-help book designed to help carers feel more in control of their lives and empowered in their dealings with service providers.

Chapters include:

- Organising your time
- Coping with "The System"
- Dealing with professionals

This book can be used by both individual carers and groups. Throughout, carers are encouraged to analyse and practise solving real life problems; to develop and carry out action plans.

Price: £4.50