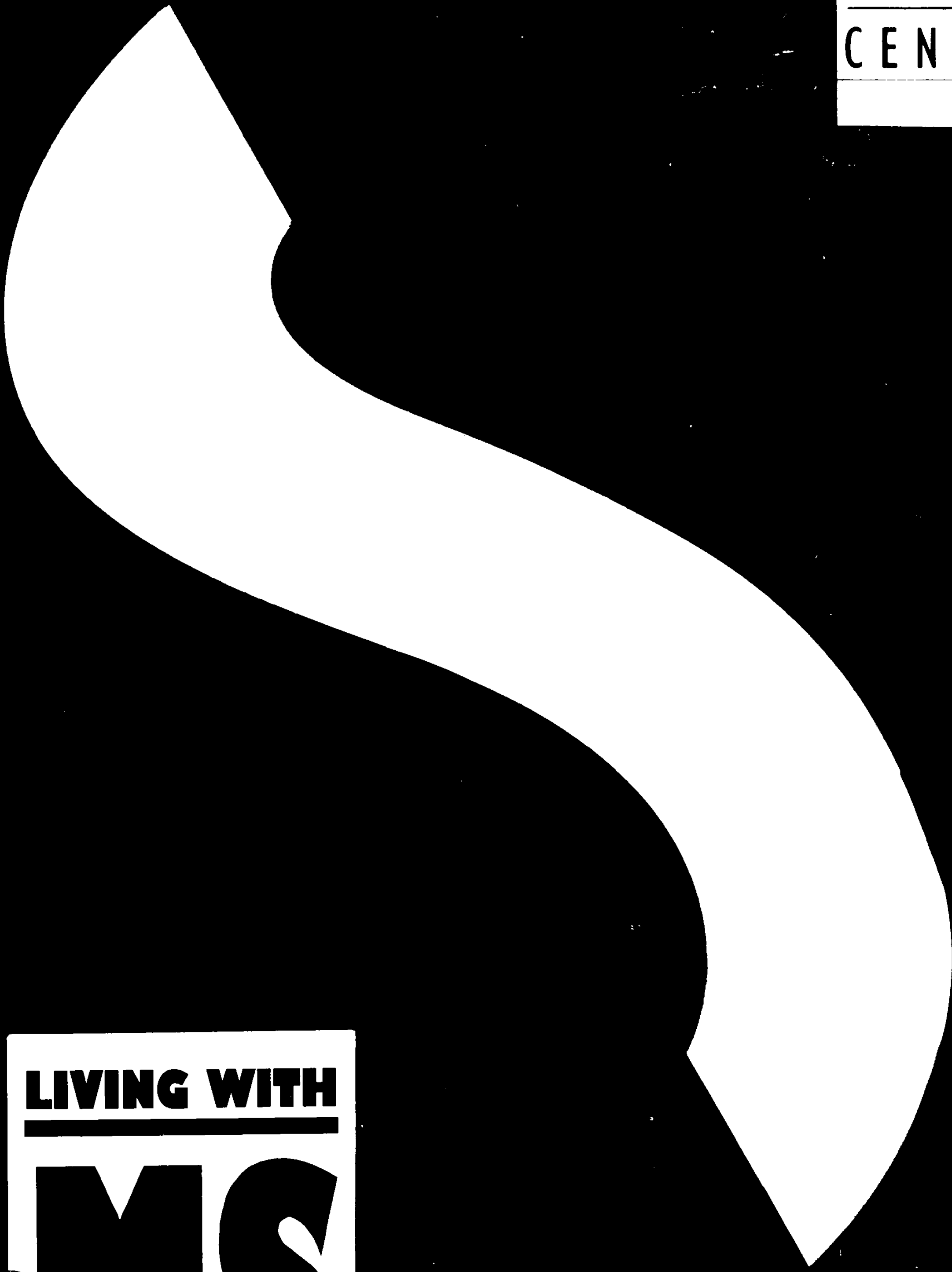
KING's
FUND
CENTRE



LIVING WITH MS

LIVING WITH MS

A guide for carers, families and friends

KING'S FUND CENTRE

ISBN I 8551 044 8

King's Fund Centre
126 Albert Street
Lonon NW1 7NF
01-267 6111

Text: Maggie Jee
Research: Julia Segal and Mary-Sue Moore
Project director: Ian Robinson

Design and cover by Corinne Pearlman
Typesetting by Windhorse 119 Roman Road London E2 0QN 01-981 1407

Printed by Adept Press 273 Abbeydale Road Wembley Middx HA0 1PZ
01-998 2247

CONTENTS

This booklet arose out of the work of the Brunel Arms (Action for Research into Multiple Sclerosis) Research Unit at Brunel University, and later the work of the Multiple Sclerosis Survey (funded by the MS Society) at Southampton University. Through this research the problems, concerns and needs of those living with people with MS became increasingly evident. Following an original proposal to the Kings Fund Carers Unit, the project received the generous financial support of the Baring Foundation, and later essential funding from the MS Society to ensure the publication of the booklet. Julia Segal, research counsellor at the ARMS Research Unit at the Central Middlesex Hospital; Angela Spackman, formerly Research Fellow with the MS Survey at Southampton University; Mary Sue Moore, psychotherapist and Fulbright Fellow formerly at the Tavistock Clinic, all made essential contributions to the project, as did Maggie Jee, writer and research consultant on health issues, who has acted as researcher, as well as writing the booklet. I am particularly grateful to Professor McClellan of the Rehabilitation Unit, Faculty of Medicine at Southampton University for his comments on an earlier draft of the booklet. Jenny Charteris, administrator of the Brunel ARMS Research Unit, has ensured that the complex coordination of the project was undertaken with care and efficiency. Janice Robinson, Programme Director, of the Kings Fund Carers Unit has throughout the duration of the project acted in a patient and facilitating role, and has made the successful completion of the project possible.

Above all I wish to acknowledge the enthusiastic cooperation of the Multiple Sclerosis Society and Action for Research into Multiple Sclerosis and their respective branches and members. The overwhelming support we received from all those whose help we sought has made the project even more worthwhile, as has the continuing and intensive interest of family members of people with MS who, over many months, first set the agenda for the project, and commented on and discussed earlier drafts of this publication. In a real sense it is their booklet.

Ian Robinson
Project Director
Department of Human Sciences
Brunel
The University of West London.

Introduction

This booklet is about living with MS. It is not a book which deals with the practical problems which may arise. It is about some of the feelings people have about MS, and some of the ways MS affects relationships.

All the issues raised in this booklet are based upon the experiences of people who have MS and their families and friends. Their words show a range of responses and ways of dealing with complex and sometimes worrying emotional and personal issues. It is not possible to offer solutions or options in the same way as for practical problems, so these feelings and relationships are discussed in an open-ended way without drawing conclusions or recommending best courses of action. It is hoped that the words of the many people who helped to put this book together speak for themselves, and will help others in similar circumstances.

Who this booklet is for

Living with MS has been written for anyone living with or helping someone who has MS. In many cases you will be the wife, husband or partner of the person with MS, and the booklet probably seems to reflect this. But it is meant for others too. You may be the son, daughter, parent or another relative of the person with MS. Neighbours and friends are often just as involved too, especially if the person with MS is single or lives alone.

This booklet refers to you as the 'carer'. Not everyone likes this word 'carer', but it is not easy to come up with a more acceptable term. Some people say it seems cold, or that it suggests that they 'take over' responsibility for the person with MS. Others feel it casts them in the role of a nurse, when they see themselves as giving emotional support rather than physical and practical care. In a way these objections show just how individual and rich the meaning of 'carer' can be – that it can mean caring *about* someone as well as caring *for* them. A woman who has been looking after her husband for many years sums up what she feels about the word, and her comment probably speaks for many others too:

> 'I think of myself primarily as my husband's wife. But I do 'care' for him, so I suppose we shouldn't place too much emphasis on a word. In the absence of a better one 'carer' is short and simple.'

It may seem odd to write a book for the person who doesn't have the disease. But you are affected just as much as the person you care for, although in diffeent ways. And sometimes your needs and concerns can be neglected. Of course, the booklet assumes that the person who has MS will read it as well. After all, most carers and people with MS consider they are 'in it together'. Ideally you will talk together about any sections of the booklet that are relevant.

Why it has been written

Living with MS has been written after talking to many carers, and reading what they have written about living with and helping someone with MS. A great deal has come out of this, far more than can actually be discussed here. Indeed, what comes across is the tremendous variety in people's experience – of the disease itself, and in their attitudes, circumstances, relationships and ways of coping.

But there are some common themes, too. On the whole, people seem to find it easier to cope with practical rather than emotional problems. Sometimes the strong feelings MS arouses can cause more problems than the physical effects of the disease. And it is not unusual for carers and people with MS to try to hide their feelings about MS. All this can put your relationship under emotional strain. Difficulties in relationships are often not easy to bring out into the open and tackle, and problems may be accepted in the belief that you must put on a brave face.

The aim of this booklet is to show that a lot of people share these same experiences and difficulties and that it is possible to deal with many of them. No one will be in quite the same position as you. Individual circumstances will, of course, be different for each person with MS, each carer and family. Even so, you will probably find that you have much in common with other people with MS and their families. Finding out about these shared things can sometimes help you to understand things in your own relationship. You may not agree with everything you read here, but it is hoped that at least some of it will be useful.

There are a lot of good reasons to base this sort of book on the experiences of real people. But there are also some problems. Experiences which were spread out over the life-time of many different people become condensed into a few pages. This can be misleading. It can seem as if all these things happened to one carer and one person with MS, all at the same time. Also, because this booklet describes a lot of difficult situations, it might seem as though the bad things are emphasised rather than the good. It could end up rather one-sided and negative. The booklet tries to avoid this by including a range of experiences and a balance of views both negative and positive. but it will be for individual readers to judge how far it succeeds. And, of course, your experiences, attitudes and feelings at the time you read it will colour your response. On the whole, people who have read the booklet during its preparation have found it reassuring rather than disturbing.

When to read this booklet

Living with MS is for you to read when it is *wanted* – which probably means at a different time for everyone. Many people need support early on when they are feeling shocked, afraid and rather uncertain. They want to know as much as possible, good or bad, from the start. Others need to wait until after the initial shock has subsided. It is for you to decide.

> 'We would have liked more information right at the beginning. We were lost...'

> 'A lot of people have to wait until their own means of dealing with it seems to break down.'

> 'The best time for information is after the initial shock has taken place. You need to *want* to know. For us it wouldn't have been any good when we came out from seeing the neurologist – for many people that's the end of years of knowing already... It's not at that point you need it but 6 months or a year later.'

Living with MS is written in five parts. Part One is about understanding some aspects of the disease. Part Two describes and discusses issues and problems that commonly arise between the main carer and the person with MS. Part Three is about families and children. Part Four discusses relationships with friends and other people outside the family. Finally, the booklet lists sources of further information and support.

1. Learning About Multiple Sclerosis

WHAT IS MS?

Multiple Sclerosis (MS for short) is thought to affect between 50,000 and 100,000 people in the UK. Most people first show signs of the disease between the ages of twenty and forty. It seems to affect more women than men.

MS is a strange disease. It is a puzzle both to the doctors who diagnose and try to treat it, and to the researchers seeking to find its cause and a cure. For people who have MS, the uncertainty it causes can be confusing and distressing.

What causes it? Is it hereditary? How will it affect people who have it? How can you treat it? These and many other questions, as yet, have no clear answers. However, it is possible to describe what happens even if we do not know why it happens.

Sclerosis means scarring or hardening. With MS, patches of sclerosis occur on the nerves in the brain and spinal cord. For some reason, as yet unknown, the protective covering (myelin) of the nerve fibres becomes inflamed. This swelling can die down, or permanent damage may be left in the form of a patch of sclerosis. These hard patches on the nerves scramble the nerve messages, or prevent the nerve signals getting through to different parts of the body.

The effects of this 'scrambling' vary considerably depending on which nerves are damaged. As the world 'multiple' suggests, many parts of the body can be affected. But there is no one pattern with MS, so some people will experience symptoms and others will not. This sometimes leads to difficulties and delays in diagnosing the disease.

It is impossible to be certain how a person with MS will be affected as the disease develops. Symptoms can alter from hour to hour, and day to day. Sometimes the symptoms may get better for weeks, months or even years – this is known as a remission. Sometimes they suddenly get worse again or new ones develop – a relapse or an 'attack'. These ups and downs cannot really be explained. A few people experience a slow decline over several years rather than periods of being better and worse. Even so, many of the people who have MS do not show any obvious signs of disability. Only a proportion will eventually be in a wheelchair. And although there is no cure for MS, there are treatments and therapies which many people find useful to control their symptoms.

With a disease as prolonged as MS it is almost inevitable that symptoms will appear which would have arisen anyway, as this comment shows:

> 'My wife was convinced that her deteriorating sight was due to MS until an optician tested her and told her that her sight was good for her age. In fact many of the frustrations which MS sufferers experience are familiar to old people – as I am now finding out.'

People often make comparisons with features of daily life to help them understand this puzzling disease:

> 'MS is rather like the electricity system in a house. You can't see it but you know it's there. Sometimes, with no apparent reason, a fuse might blow. This time the kettle might go, next time the cooker, or the whole house is out.'

AT THE BEGINNING

The diagnosis – to tell or not to tell

For most people, the discovery that they have a potentially crippling disease comes as a terrible shock. This sometimes means that doctors do not tell their patients what is wrong with them. They may tell you, the carer, instead. This can cause dreadful dilemmas. Should *you* tell? How? When? Or should you too 'protect' them from the truth?

If you keep it to yourself, you can feel guilty and dishonest. And the longer you keep the secret the harder it becomes to break. That can put an intolerable and lonely burden on you. It can drive a wedge between you. But if you tell, will it make things worse?

No one can say what is the right decision for you – it depends on so many things. But it may help to know that most people with MS find out in the end. Often the knowledge comes as a relief, and for many it confirms what they already suspected. Some people with MS are glad they didn't know at the beginning, others feel cheated if they find that someone close has known for some while and hasn't told them. Whatever the case, until you both know you can't start coming to terms with it together.

> 'After all the tests, nobody told my wife. They told me, and left it up to me to tell her... I told her several months later when I could pluck up the courage to do so.'

> 'My husband didn't have any severe onset. The GP said to me, 'I think it could be MS, but it is very mild.' I asked, 'Shall I discuss it with him?' The GP said, 'No, I'd wait.' And I did, I held back. I'm glad now. Why should I have worried him for all those years?'

> 'I knew that if our marriage was to succeed we had to continue to be truthful to each other. How would he react when he eventually found out that I had known and not told him? I feared he would never trust me again. I felt a completely numb loneliness which lasted the two months until I persuaded the family doctor that Ted should know he had MS. I needn't have worried. His reaction was, 'It's

> only MS'. It was a great relief to him that it wasn't cancer.'

The Age of Onset

MS usually hits young adults. This can make it hard to take in. Most people do not expect to be hampered by health problems when they are young. MS threatens to restrict your life just at the point when you expect it to 'take off'. Plans seem to be cut through, hopes and ambitions shattered. Ordinary things – working, falling in love, having children – may suddenly seem unattainable. It can throw everything about the future into question.

> 'It always seems unfair to me that it started when he was so young. We had only been married for a few months when my husband was diagnosed. It felt as if our life was in ruins. I felt a numb depression for many months. It was some while before we could start to think about how to rebuild the pieces and think that there might be some future.'

When MS strikes in older age, it may be easier to cope with, but the impact is different:

> 'It's difficult to put into words just what MS means to us. At our age it's pleasanter to dwell on the past when we had fun and a lot to laugh about. I feel angry and bitter at times that we can't enjoy our retirement years as we had planned. Yet I'm thankful for the good early years, as we wouldn't have been able to cope then.'

> 'It's been a dreadful shock to us. A healthy, active man, running a business for 30 years . . . and now reduced to this. It's very hard for us.'

These first feelings of shock and despair are a natural response at whatever age MS strikes, but they usually lessen with time. Many people have said that they felt more frightened and depressed early on. This is because at the beginning, although the symptoms are often mild and there are few practical problems, everything about the future seems so uncertain.

In fact most people with MS *do* achieve the 'normal' things in life. But of course some will be frustrated because they cannot achieve everything they had planned. It can be especially hard for young people to come to terms with living at a slower pace in a society that puts so much emphasis on personal achievement and social advance. It can be equally hard for older people to cope with the shattering of a career at its peak, or the prospect of a retirement very different from the one they had anticipated.

Denial

Sometimes people with MS, sometimes carers, and occasionally both, try to cope with the disease by pretending it does not exist. They avoid talking about it, and they don't tell anyone. This is probably more likely to happen at the beginning of the disease and when it is mild. Sometimes the person with MS continues to deny it even when it becomes obvious to others that there is something the matter.

This can be very difficult for the carer, who may feel bound to go along with the pretence no matter what their own views. One carer came to experience this as the:

> 'Total bloody-mindedness of the invalid determined to ignore the illness and every stage of the disability.'

Denial is, in fact, part of the normal process of coming to accept something unwelcome and painful. But if you, or the person with MS, gets stuck there it will make it more difficult for you to cope with the impact of the disease. The more you try to pretend MS is not there, the more it can be forced into your mind. A great deal of emotional energy may be used up in pretending nothing is wrong. Most people come to realise that this energy is better re-directed into more constructive ways of tackling the problems of MS.

Fighting

When they realise that the disease is not going away, many people feel angry. They constantly ask themselves why this happened to them. Eventually, most people channel their anger into finding ways to overcome or control the disease. Many do find treatments, or attitudes of mind, that seem to work for them. But for others the search is a disappointment. Even so, the majority of people with MS, and their carers, say it is important to be open-minded and optimistic. They find that their determination not to 'give in' helps them to cope better with MS.

But sometimes the search for a treatment to cure or control the symptoms can become a desperate and unrealistic fight, and the sole purpose in life. It can be very difficult for a carer to support the person with MS in this fight when they see it is a way of not accepting the disease, or when they realise that the search for a new and better treatment brings more disappointment that benefit. This may happen at any stage of the disease of course. But like denial, fighting can become an obsession which obstructs the development of better means of coping.

AS MS DEVELOPS

Coping with Uncertainty

In many cases the disease progresses slowly. The person with MS continues to lead a normal life, and needs very little 'care' at all. Many people find that they can make emotional and practical adjustments to cope with any relapses or gradual changes over the years.

> 'It's never really been a problem. He's slowly deteriorated over the years but he worked until retirement. We've gradually adapted our life style and house to cope with it all.'

Sudden and rapid decline, although unusual, can be especially devastating.

> 'It's been a total disaster for us. It happened very quickly. She

> really didn't know what was happening to her – neither did I. Now I can't leave her for more than two hours. I've had to stop work to look after her. It's all happened so suddenly, it's really too much for us to cope with. We haven't had time to catch our breath.'

On the other hand, many carers and people with MS are quick to point out that how well you cope with MS is not simply linked to how severe it is. They say that living with the uncertainty can be even more disturbing than putting up with the symptoms. Neither the person with MS nor the carer can ever be really sure what will happen – what symptoms will develop, how severe they will be, when they will have an attack, or what will happen 'in the end'. People are generally most confident, secure and stable when they feel in control of their lives. MS can make you both feel that you are not in charge. It can rob you of your self-confidence and make you feel trapped.

> 'People with MS just don't know what's going to happen next. They wonder how far it's going to go before they completely seize up. They get frightened. It makes them insecure. But what can you say? 'It won't happen to you'?... We don't know. We just do not know.'

> 'It's such an unpredictable disease. With other diseases you can predict what might actually happen; with MS, 'future' is a word it's difficult to use. You can't plan what to do next month, next year... That makes it hard for both of us.'

Not everyone feels as bad as this. And feelings and circumstances do change. Sometimes there is more certainty as the disease progresses. Although the future may not be predictable, this doesn't, in fact, prevent most people from making plans. They don't allow uncertainty to dominate their lives, they use it as a challenge instead. Some discover unforeseen benefits.

> 'It's unpredictability that makes it difficult. On the positive side it does make us re-evaluate life goals and values – in some ways to be more active in shaping our life rather than waiting for things to happen. We work to shorter-term plans and probably achieve more because of it.'

> 'You can't sit around waiting for the worst. We lead a full and active life as a family, and always have done, although my wife is now severely disabled. We put in a lot and it's worth it. We sometimes have to change our plans, but it doesn't stop us having them.'

Is it because of MS?

Many carers are puzzled as to whether MS actually changes someone's personality, and ask themselves 'Would he (or she) be like this anyway?' There is no clear-cut answer to this question. MS can cause mental symptoms in some people which may affect personality. But these symptoms can come and go in the same way as physical ones. In most cases people's basic personality remains much the same: if they were easy or difficult to live with, happy-go-lucky or anxious types, they are likely to remain so.

Of course, we all change throughout our lives. We have different sides which are more or less hidden and events and experiences bring them out. MS can emphasise one side of someone's personality so that it may seem that they have changed and are more difficult to relate to. MS tends to make people feel insecure, and this can evoke previous experiences of insecurity such as, for example, losing someone close or being unhappy or lonely in childhood.

Carers and people with MS may also ask this question:

> 'I have said to myself on many occasions, are these problems we have a result of the MS or would they have happened anyway? I don't really know the answer – it all seems muddled up.'

It becomes muddled for most people at times. Problems in relationships, as well as other day-to-day difficulties – an unsuitable job, housing problems, family troubles – may all appear to be caused by the MS. It can become all too easy to blame the MS for anything and everything that goes wrong in life, and to forget that these other sorts of problems can and do arise for everyone. This is not to deny, of course, that MS can make existing problems worse. But it is unlikely to be the only, or even the major, culprit. Indeed, people with MS and their carers do admit that MS can sometimes be used as an excuse for not sorting out other problems.

There are no easy solutions. But if this is a problem for you perhaps talking to someone outside the situation could help you to sort out what might be a result of the MS.

COMING TO TERMS WITH MS

How then do people who have MS and their carers come to terms with the disease? Naturally, it will be different for people who have the disease and those who don't. But, even so, most people find they go through similar stages.

Coming to terms with MS has been compared to mourning the death of a loved one. You may have to go through many similar emotions such as shock, denial, anger, sorrow and grief, as part of the process of coming eventually to accept MS. Many people are afraid to let their feelings take their course, perhaps fearing that the pain will stay with them and they will never be happy again. But you both need to be able to mourn the loss of what was in the past, and what might have been in the future, before you can come to terms with things as they are.

But, of course, there are differences. Unlike a bereavement, it is not final. With MS new symptoms can develop at any time. You can find you have accepted one sympton – that it may get better, stay the same or get worse – and then something new happens and throws you right back. You have to start all over again. Some people find that in this way each symptom, each fear, has to be coped with and mourned separately.

It would also be wrong to suggest that all these emotions follow on one after another, that you somehow 'grow out' of each one and progress to the next, until you finally come to terms with MS. It's not like that, of course. There is no once-and-for-all acceptance. Some of the feelings do go away, but some stay, and some are relived each time a new symptom develops or a relapse occurs.

Yet most people eventually do find a way of coping:

> 'Richard has had MS for 8 years now, but it is only in the last three months that I've come to terms with it myself. I didn't before – I had a terrible problem of inner-rage. I've had to accept that we live for each day and there's no point trying to push and push against it.'
>
> 'I'm not patient, and I can't live from day to day. But that's just my personality. Now I've stopped trying to be patient we're actually coping better and in fact we do get more out of each particular day. But we plan ahead as well, for small things... I'd go under if I didn't plan ahead. I've got to have something to aim at.'
>
> 'It's important to accept MS and to plan a life that takes account of it but does not let it rule.'
>
> 'I've just been through the two worst years of my life – but we've come through. We now have to think flat surfaces, flat world. There aren't any mountains we can climb physically, although mentally there are.'
>
> 'Can you come to terms with a situation which in some ways can't be come to terms with? I prefer to think about how you can positively harness these negative feelings. It is important not to suppress the anger, frustration and despair – even hatred on occasions – but to recognise these corrosive emotions as a very natural and human response to a desperate situation. One trick is to roll with the punches like a skilled Judo expert, and to convert these destructive forces into a positive source of new strength and determination.'
>
> 'We know she won't get much better physically, but emotionally we've both got a lot better in this last year or two. This has been quite a surprise to us – we suddenly realised we weren't depressed anymore and that our life did have some good sides!'

2. Understanding Each Other

RESPONDING TO EACH OTHER'S FEELINGS

Carers and people with MS have to cope with their own feelings. They also have to respond to each other's. Both can be hard to do. Feelings aroused by MS can be very powerful and painful. Few people find it easy to share such feelings, and it is often most difficult to do this with the person with whom we are most bound up. A lot of people end up hiding their real feelings. It can be especially hard to allow each other to express negative feelings and to share fears and anxieties.

There are, of course, a lot of good feelings too, but it's the negative ones that are hard to cope with, which is why they get so much attention here. The following comment, from a man who has been caring for his wife for several years, may help to put things in perspective:

> 'It's reassuring to realise that almost everyone goes through bad patches when common sense is overwhelmed by emotion.'

Coping with the Feelings and Moods of the Person with MS

A lot of people with MS have very changeable moods, and seem to express their emotions quite freely. You may be exposed to the full force of the other person's painful feelings – their anger, frustration, grief or depression.

> 'She gets very depressed and talks about suicide. When she's down like that my life is hell. Fortunately she comes out of it just as quickly as she goes in.'

> 'His depressions are unbelievable. I want to dig myself into a trench.'
> 'At the moment, he's feeling very lost and confused. He doesn't know where he's going and what he's doing.'

> 'Sometimes you can see the frustration and anger in him. He's struggling to get something right and he just can't do it. I want to cry for him.'

It can be difficult to know how to respond. Carers talk about feeling sympathy, compassion and sadness. Many are frustrated because they have to look on and feel they can do little to change things. Others keep out of the way and wait for the bad mood to pass. At times, trying to be cheerful and optimistic works. Even if it doesn't always pull the other person up, it seems better than if you are both pulled down. But you have feelings too, of course, and at times it's inevitable that your moods of depression or frustration will clash.

> 'The depression is dreadful. It's all right if it only gets one of you at a time, as the other can then help to overcome it. It's miserable if it gets you both at once.'

Sometimes carers think they must never let the person with MS know that they are depressed too, fearing that it will make them worse. They put on a cheerful front no matter what they really feel. But in the long term, this can add to the difficulties. It becomes a strain trying to keep up a calm and cheerful outward appearace when you feel dreadful inside. And you can lose touch with your real feelings.

Contrary to expectations, being over-cheerful may not help the person with MS either. They may become stuck with their miserable moods – the very opposite of what was intended. The person with MS can't buoy you up if you claim to be always cheerful. They can come to feel useless and even more depressed. You may start to lose touch with each other. Where there is more 'give and take' of emotions, including negative ones, you can support and care for each other. That is generally better for most people

On the other hand, some people with MS don't express their feelings easily. They may hold them in, refuse to talk about them, or seem withdrawn.

> 'I wish my wife would have a jolly good cry. I know it would do her good, but she bottles it all up.'

> 'He never really talks about it to me. He's a very outgoing personality but he doesn't talk about how he feels. I find out more when I overhear him talking to other people with MS, here at the ARMS centre.'

This can be equally hard for a carer to cope with. It can feel as if the person with MS is shutting you out and this can make you feel lonely. It can make you feel you can't show your feelings or talk about your worries.

Hiding Feelings

Many carers believe they cannot let out all sorts of emotions because they are afraid of the effect it will have.

> 'You try to cushion them, you daren't tell them your real feelings in case you bring on another attack. Perhaps it's silly to think that, but you can't help it.'

Hiding depression is common. But many carers also feel that they mustn't show normal anger over the day-to-day irritations that build up in all relationships. It is important to be clear about the cause of your anger, which is very often the disease, not the person who has it. It may help to spell this out:

> 'Sometimes what appears to be anger within the relationship disappears if it is recognised to be anger at the MS rather than the person. 'I hate MS!', is easier

> to cope with, and nearer the truth than, 'I hate you!"

Other sorts of feelings – guilt, anxiety and fear, for example – are also difficult to express. Guilt may arise from destructive emotions, such as hatred or jealousy which are hard to admit to, or from thoughts which seem 'disloyal'. And you may be reluctant to own up to such feelings in case it makes the person with MS feel insecure.

> 'I've often said to myself: Why should my life be tied down? I'm not ill.'
>
> 'I sometimes ask myself whether I can carry on. But I certainly wouldn't tell him that.'
>
> 'I feel resentful and then guilty that my life has had to change, although there is nothing wrong with me.'

You may often want to protect the person with MS from your fears and anxieties about their future.

> 'I'm afraid he's going to end up in a wheelchair. I don't know what we'll do then. But I can't let him know I worry about this too.'
>
> 'It goes through my mind all the time: What if I die first? Who will care for her then? But you can't just bring these things up.'
>
> 'My biggest fear is that he won't be able to read. He would be devastated.'

People with MS often have very similar feelings. They feel guilty for restricting the well person's life. They worry about how their carer will cope as the disease progresses. They too wonder if they will be left alone, and have a dread of 'something terrible' happening in the future. These are all normal and common responses. It is not surprising either that many people with MS feel they cannot be honest about their most anxious feelings in case it worries their carer.

Sharing Feelings

Although it is perfectly understandable why people in difficult circumstances come to conceal their feelings, on the whole it is not the best way of dealing with things. It can become a problem if you don't know what each other is feeling. You may end up guessing and getting it wrong. You may become lonely because you cannot comfort each other. Or you may bottle things up until you explode.

In fact, there is little to suggest that emotional 'outbursts' cause any long-term harm and make the MS worse, as many carers fear. It is likely to be more damaging to your relationship if things don't get discussed and are left to fester. Being calm all the time is not a good thing if it is really a cover up. It's a great effort to keep an even temper if you are angry or depressed underneath. And wanting to keep things calm can sometimes be a way of avoiding facing up to things. You may need to take a stand sometimes. If you can do it before everything builds up to an explosion, so much the better. But even rows can clear the air:

> 'We really get on each other's nerves at times, but we don't let it simmer, we have some real battles. I said to her, 'It's no good you sitting there moaning and groaning. I've got to live with it too, although I haven't got MS'. We have some real blunt talking and it clears the air.'

> 'I blow my top. I can't be the one who's got to take it all the time – but I have to live with it all the time. I know whatever I say I can't help her. So we just have a good chat. Words get a bit 'high' . . . and then she realises the strain I am under.'

'Blowing your top' doesn't suit everyone. It depends on your personalities. Some couples need to have rows. Others prefer to sort out their differences in other ways.

> 'You need to have a way of getting the feelings out – of clearing the air without feeling it will make the symptoms worse, as that leads to guilt. You have to try to find ways of communicating honestly and frankly. We think it's best if you constantly talk about how you feel, whatever you feel, and however painful.'

Of course, you have to find an opening to let those feelings out, and that may not be straightforward. Sometimes opportunities can be missed. Carers report that it's quite common for people with MS to complain, 'You never ask me how I am'. To which they retort, 'I don't need to, I see you every day.' It could be that the person is really saying that you need to talk to each other more.

Although it is a well-worn saying, it is still true that anxieties and fears shared are easier to cope with. For a lot of people it can greatly improve things to face problems together. It is a way of controlling them. You may find that you have both been worrying about the same things. And you can think about making practical plans to cope with eventualities. Some people find that the only way to achieve peace of mind is by sharing feelings and problems and trying to sort them out.

Some people need help to face their more difficult feelings before they can talk to each other. If your feelings are raw you may not be able to talk to each other in a constructive way. But these very painful feelings can often cause more problems than the MS itself if they are left to eat away at you. It can be more useful in these cases to discuss things with someone else, such as a social worker or counsellor who is trained and skilled in bringing these fears down to earth and keeping them in proportion. Both people with MS and carers may need this sort of help. It can often be a way of helping you to talk to each other.

MISUNDERSTANDING EACH OTHER

Clearly people with MS and their carers are going to have different ways of looking at things because one has the disease and the other one hasn't. For example, people with MS have to live from day to day with how the symptoms feel. What it feels like may not be the most significant or important aspect for the carer. They have to live with the effects of the symptoms and not the direct experience of them. This can sometimes lead to barriers being erected. Some people with MS believe that their families and friends can never understand what they are really going through, and this can cause disagreements and resentments.

> ‘I've tried to understand. But obviously I don't – and she tells me so. Whatever she's going through is obviously so devoid from what I feel that I ask myself ‘What the hell is she going through?’

> ‘I sometimes feel we're living in two separate camps. No matter how much honesty and openness there's a line.
> And it's like he's standing there going, ‘Ya, ya! I've got MS! You haven't!’ and I want to say, ‘But I'm living with you! So there!’.

> ‘I call it the baiting game: he says ‘You don't know what it's like because you don't have it’, or, ‘You'll never understand what I'm going through’. I reply, ‘But I have to live with you so I know what that's like!’ It's like a constant tug-of-war between us.’

It can come to seem like a game you are playing – a jostling for position between the one who has MS and the one who hasn't. You can feel tugged this way and that. You can end up trying to make each other feel bad or guilty.

> ‘I was running around trying to get ready for work. Dave wanted another cup of tea. I said to him, ‘The least you could do is put your cup on the table. I'm wearing this spot out between here and your chair’. And he said, ‘I wish I could run backwards and forwards like that’. I thought ‘Ooh!’ and I spent the rest of the day feeling guilty. When I came in I tried making appeasing gestures. Then I realised we were playing a game. I find that every once in a while I have to step back and think about it. We both do.’

Of course carers cannot *know* what it is like to have MS. But sometimes trying your best to understand what it is like is no consolation for the one who does know. Perhaps, occasionally, people with MS would like their carers not to try so hard but to accept that they cannot understand. Acknowledging this fact and talking about your different experiences of the disease may help you to see each other's point of view.

HELPING

In the early years of MS most people will not need much help. Tasks might take a bit longer to perform, but on the whole, most people mildly affected by MS are perfectly capable of carrying on their normal activities and looking after themselves.

As the disease progresses, however, most people with MS will find that there are some things they cannot do as easily as they once could. This, of course, has practical and emotional consequences for everyone involved.

Not being able to do as much, or becoming awkward and clumsy, can make the person with MS feel angry and frustrated. They can lose their self-confidence. It can be especially distressing and humiliating for people who need help to carry out basic personal tasks such as dressing, eating or going to the toilet, and difficult too for the person assisting them. It can feel like being a dependent child again.

Even so, it's only natural for you to want to help when you see the person with MS struggling to do something. You may also be under pressure to get things done quickly if there are children or other family members to think about as well. Things can't always be done at a slow pace to suit the person with MS, and you may feel that sometimes you have to step in.

But, of course, it is not simply a practical matter of how much physical assistance a person needs. It is an emotional matter too. It is not always the amount of help the person needs that is important, but how he or she feels about being helped. People with MS who need only slight help may feel more distressed and resentful than people who are quite severely disabled.

Some people with MS find it almost impossible to accept that they can not do things as easily as before. They will not admit to needing help and they resent being helped. On the other hand, many carers and people with MS are afraid either to offer or accept help. They fear that the person with MS may not be able to do that task again – that they might lose the physical skill or the emotional will. Yet other people with MS feel guilty about accepting help. They are aware that they could create extra work for relatives and friends who may already be very busy. They fear becoming a 'burden' and this leads them to turn down offers of help.

For all these reasons, and doubtless many others too, most people with MS reject offers of help at some time:

> 'I'll offer to help him down the stairs. 'No! No! I'll tell you when I want help'. Friends get embarrassed too. He wants to pretend everything is as it used to be and he refuses help.'

> 'We all try to help and we all get rejected. It's as though someone has cut your throat. You offer to do something and you get a snappy answer right back. It's devastating sometimes.'

> 'My wife is very resentful that I have to help her – she has a very independent nature.'

> 'My problem is different. My wife has improved so much she said she would take over the running of the house. I think it's marvellous that she has gained so much confidence and self assurance. But she thinks she's so much better than she is. Really she is so limited in what she can do. But I daren't offer to help. I have to wait until she's not around and then do it myself.'

Although carers may understand the reasons for such refusals, your feelings can be aroused too:

> 'I get angry because of his pride. He won't let anyone see he has to have his dinner cut up for him.'

> 'George will struggle with a knife and fork. He'd rather let it go all over him than have me help. I can understand his feelings but it still makes me annoyed.'

But it's not always refusing help that is a problem. Sometimes people with MS seem to expect too much help:

> 'I come home from work some days and there he is... We've had to spend all this money on adaptations so that he can make his own cup of tea, and do all these things, but there he is, waiting for me to do it!'

> 'I run round after him doing everything. I'm sure he could do more but he lets me cope single-handed. I know it's hard for them, but I think they can become a bit selfish.'

This sort of difficulty can arise for several reasons. Some carers admit that they are too eager to offer help, and that they tend to 'smother' the person with MS. They neither allow nor encourage the person to do as much as they could or should. And some people with MS, rather than getting angry, go along with this. They let their carers do more and more for them, and may come to feel that they can't be bothered to do anything for themselves. They 'give up'. On the other hand, one man felt that his wife 'giving up' was not laziness or being selfish at all, but the 'breaking of her spirit after years of struggling'.

With MS, it can be hard to tell whether someone really could do more. For a start, many people who have MS look 'all right' – they don't look ill or disabled and their tiredness and fatigue doesn't show. And as the symptoms can fluctuate greatly, even from hour to hour, they may sometimes need a lot of help and at other times can manage very well by themselves.

You may find yourself asking, 'Can she really not do more? Should he try harder? Should I push her further?'.

> 'How far do you push them? I'm sure my husband could do a lot more. But he won't push himself. He won't try for another job because he thinks no-one will accept him because of the MS. I know he feels insecure – he doesn't know what he'll be like in a few years time – but he has a lot more to offer...'

> 'It's hard to accept that she really can't do things. When she's sitting down she looks perfectly all right. I know she can be so physically tired she can't move. But sometimes I think could she make a bit more effort.'

This sort of problem can develop into a 'power struggle'. It can seem that neither of you ever gets it right. If you encourage them to do things, that's wrong. If you do things for them, that's wrong too. When they try to do things, they get it wrong. This is only to be expected, of course. But if it happens frequently a vicious circle can develop in which both of you feel resentful and exploited. When this happens it is not really about helping anymore but about something else. For the person with MS, trying to do too much and refusing help, or trying to do very little and expecting help, are often protests about needing to be helped at all. For all sorts of reasons most people dislike having to rely on someone else. It inhibits their freedom, and seems to take away emotional independence as well. It can be just as difficult for people who are depended on.

There's no easy solution to this. And it can be a problem for people who are mildly affected as well as those who are more obviously disabled. You both have to try to balance the need for physical or personal assistance against the need for independence. You may have to accept that it will be difficult to get it right and that you will both sometimes make mistakes. Learning when and how to offer help is hard. Coming to accept necessary help graciously is equally hard.

Some carers suggest you should wait until the person with MS asks for help. But clearly this would not work for everyone, since some people with MS would never ask for help. Others say you should be extremely patient and encourage the person to do as much as possible, and delay helping until the last possible moment. Again, this works for some people.

It can help to boost physical and emotional security as far as is possible. Using appropriate aids can improve physical confidence and increase independence for both of you, although many people fear the opposite effect – greater dependence. Whether this in fact happens may depend more on your attitude towards using an aid rather than on the aid itself. Most people with MS start to use a mobility aid with reluctance, and this is a completely normal response. After all, it is major step, and using a wheelchair, for example, represents for some people 'the beginning of the end'. It means having to accept the idea that you are 'disabled', and that you need help. But many people find that if they can cross this psychological barrier, using an aid does increase their freedom.

> 'Using the wheelchair has changed my husband completely. He fought it at first. But now he's so much more energetic and independent. It's helped us both.'

There are no easy ways to develop emotional confidence either. People with MS are likely to be emotionally insecure, and need constant reassurance in all sorts of ways. Many carers say that they develop skills in patience, and in encouraging the people they care for to do as much as they can. Of course, no matter what level of help they offer, all carers try to maintain the dignity and self-respect of the person they help, although this is not always straightforward in practice. When this works it makes things easier for both of you. It seems to be especially important to let the person with MS know that they can and do help you in various ways.

> 'I keep pushing my wife. Although I doubt whether she really can do some things, I'm often surprised by how much she can do. So is she!

> 'If there's something in the house he can do, I let him do it. I wait for him to ask me. I never do it for him. It's his way of showing me what he can do.'

> 'He can't do much for himself. He can't do much in the home. I know that makes him feel bad because I have to do it all. But he does help. I have to keep reassuring him – he's still better at dealing with the children's upsets than I am. They always go to him.'

> 'At first I drove her potty. . . 'What can I do? What do you want? Can I help you?. . .' I get it right more often now. And she's got better at asking – I wait now until she asks me. I don't fuss so much.'

COPING WITH CHANGES IN ROLE

Many people with MS and their carers find that as the disease develops they have to change some of the ways they organise their lives. Often the one with MS cannot continue to do everything that he or she once did, and the carer or other family members take over some of these activities. In some cases the carer may take on virtually all the former roles of the person with MS.

It can be very difficult for people to accept and adjust to such changes because it disturbs their ideas of who they are and how they should behave. If you both had clear and separate roles it can be confusing to blur the boundaries. For people who have traditional views about the roles of say, wife and husband, it can be especially difficult.

> 'My husband found it demoralising and 'unmanly' to have me as the major wage-earner. He is frustrated because he cannot provide for me. He also believes that as a woman I cannot understand how he feels about this.'

> 'My wife is worried that I won't love her for much longer. I'm continually reassuring her. . . : but her fears stem from a feeling of inadequacy – or not being properly a woman, a wife, a mother.'

If you have been used to working as a 'team', each making a fairly equal contribution, it can be hard for one partner to adjust to doing more and the other less.

> 'Since we were married we have always shared jobs, and as the years have gone by I have gradually taken more and more on. It used to get him down watching me. But he's had to get used to the idea.'

> 'My wife has had to accept a job she can cope with rather than one she is capable of. The fact that we can live comfortably on

> my salary makes her feel she can't make a real contribution.'

It can cause problems if the person with MS feels they are left without any useful role.

> 'Being able to do less about the home and garden makes him feel worthless and unable to help, share, or contribute.'

It can be just as difficult for the carer to take on a different role. Whether that means having to lose some part of the previous role or trying to combine several roles.

> 'Can I indefinitely be a nurse, manage the house and money, do the shopping, and be a husband and lover?'

> 'I do get overwhelmed with it all, being breadwinner, housewife, odd-jobber, gardener, bookkeeper, carer and general raiser of spirits.'

> 'I have to do things in the home which I never thought possible.'

It is not only husbands and wives who may have to adjust to unexpected roles. A child might look after their mother or father with MS, and parents might look after a child with MS. This can result in all sorts of role conflicts.

> 'My father has MS. I am often expected to take on 'male' tasks which he would like to do for my mother, like keeping the place up and mending the car.'

> 'It's difficult to help a parent of the opposite sex in personal things often associated with incontinence – an area which causes distress and humiliation to the sufferer.'

> 'We feel that our daughter should be more independent at her age (she's 25 now and has MS), but it's hard for her to 'grow up' and for us to let her because she still lives at home and we do so much for her – probably more than we need to.'

> 'My son has taken over his father's role in lots of ways. He was a DIY man, and he can't do it now. My son is only too willing to take over. But I know my husband feels his son has taken his place.'

The exact problems will vary for everyone. But carers say that there are things you can do to make it easier for all to adjust. Some carers find it helps to think themselves into the role of nurse, gardener and so on, and to treat these roles as jobs. In this way they can keep their feelings about these jobs separate from their feelings about being a wife, or a father. Others say that they can only do all the things they do because they *are* the wife, husband, son, mother or whatever of the person with MS.

For people with MS, it seems crucial to establish a role for them that is important and that they can do. You can't change people's ingrained views overnight, so you can't expect everyone to suddenly feel happy about doing something that doesn't fit with their idea of what a husband, wife or daughter *should* do. But most people in fact feel better if they can make some sort of contribution that is valued.

> 'Gerry compromises – he does the bits he can – he can't reach above waist level so he paints the skirting boards! He's the world's best organiser of everyone else. If he's got the diagram in front of him he can tell you what to do.'

> 'If she's involved she's alright. It doesn't really matter what it is as long as she's doing something and joining in.'

> 'Terry can still find ways of joining in. I'll play football with my boys. But we all go along, that's something Terry can take an interest in. He loves to watch Michael play football.'

> 'We find that although my wife is incapable of doing anything manual, the one thing we do together is to make all joint decisions. If the children ask for anything I never say 'Yes' or 'No'. I tell them to ask their mother, or else we discuss it together. That way she does not feel so left out of things.'

> 'My husband (who has MS) does all the running of the house. I work full-time. In a very real sense he is the carer. That suits us both. I have something to talk about and share – a life of my own that he is interested in. MS is not a noose around our necks. Rather it is a spur to me in my career... Someone has to mention that MS can have positive spin-offs.'

CARERS' NEEDS

It is important to look after yourself too. If your own needs are neglected caring becomes more difficult.

With an illness like MS, caring responsibilities can creep up over the years. Most people with MS need little or no assistance at the beginning. But as things change, the amount of care needed can increase gradually so that neither person really notices at the time. It may be several years before a carer looks back and realises how much caring they have come to do.

By that time, many carers are in the habit of putting the needs of the other person first. And what may have started as choice may now seem to be a necessity. Many feel that it is impossible to make demands on the person with MS in case it makes them worse. So carers tend to take on too much themselves:

> 'You feel you mustn't burden them with too much in case you bring on another attack. When you've got a house to run and young children, you find you're running round in small circles trying to do everything for everybody.'

The physical caring tasks involved in helping someone with MS can be exhausting. But there is also the emotional strain of watching in case the person falls or is injured, and worrying about old symptoms returning or new ones developing:

> 'She's very heavy. You try lifting 9½ stones several times a day. It gets too much for me. I get a lot of back trouble.'
>
> 'I can't leave her alone for more than a couple of hours because she needs to go to the toilet. Yes, I do feel tired and tied.'
>
> 'I get very tired running around working, watching and worrying.'

This all takes its toll. Many carers are young when they start and they may not know what will be involved in caring for someone long term. A lot make unreasonable demands on themselves to be 'super-carers' – they forget to say 'Wait' or 'No' occasionally. Their own needs somehow get lost. Some carers may even reach the point where they feel they cease to exist as a person in their own right:

> 'Because I've been caring for him for so long, and caring for the children, I've finally lost my identity... I'm walking around like a zombie, just doing what has to be done. I don't seem to have any feelings any more ... nothing.'

The result for many carers, though, is that they come to feel lonely and isolated. It can seem as if no-one cares about you.

> 'No-one asks how I am. They always say 'How is Mary?'.'
>
> 'I feel there is no-one to reach out to.'
>
> 'I cannot tell you how lonely I got ... after a long stretch of having to do just nothing but look after John and come in and out of the house. I had no social contacts, just the house, John, the day-to-day preparing for life, and nothing else ... it was tough! I was really isolated. It's hard to find an outlet.'

No matter how much or how little caring you do, you should think about your own life and your own needs. For many carers the issues are quite straightforward. They only want what most people would expect – interests and friends in a life outside of 'caring', a break, help in the home, someone to talk to who understands, perhaps more money.

> 'I must have a day out on my own every so often. I have to do this to keep feeling free and then I can cope cheerfully.'
>
> 'If I hadn't got my work I'd go absolutely spare.'
>
> 'I'm so lucky, I have a nurse come in every morning to get her up and wash her.'
>
> 'The greatest thing is sitting here with another person. You think Oh good, that's not so bad, someone else is going through that too.'

It can be difficult to arrange some of these things, and this may lead to increased frustration. It's not easy to renew friendships if you have lost touch, and it can be hard to make new friends. Help from family or friends may not be forthcoming. Increased finance often has to be struggled for through the state system of benefits. Relief care is not always available and it is sometimes very hard to allow someone else to care in your place, even for a short time.

For some carers the problem is how to balance their own needs against those of the person they support. Perhaps the person with MS resents you having a more independent life or getting in some extra help, and this can make you feel guilty.

> 'Every once in a while I'd like to go out for a drink or to a film and not worry that I'll come back and find him sitting in the dark with the curtains open – which he does, although he's perfectly capable of shutting the curtains and turning the lights on. He just has to make the point that he's been there on his own.'

But even so, you should not let this stop you from taking steps to look after yourself. It is important that carers accept that they have needs of their own, and that they try to find ways of satisfying them. If you always suppress your needs as an individual, caring becomes a strain and you become a worse carer. In the end, it can make you ill or force you to give up.

You may have to make others more aware of what you want. You will probably need to talk first with the person with MS, then the rest of your family and anyone else involved. You may have to persuade others to help out. If you need some confidence to get started it can help to talk to other carers. The need to talk with others and get a fresh view on things is, of course, common to both the person with MS and the carer. Sometimes this need can be fulfilled for both partners through the same outlet:

> 'It took us two years to go along to the local MS society. When we went to the first meeting I felt as if a big weight, which I didn't know I had, had been dropped from my shoulders. I was amongst people who understood and we could talk over problems which might arise.'

> 'This ARMS centre here is the best thing that ever happened to MS sufferers and their families. It keeps us all sane. It's absolutely fantastic. If you've got a problem we've got the right person to deal with it here – for the sufferer or the carer.'

Sharing your concerns about caring won't solve everything. But it can be an important step in helping you to accept that it is 'all right' to think about yourself and to identify your own needs. Drawing on others' experience may help you to work out ways to meet some of those needs.

COUPLES

Staying Together

Many people with MS fear that their partner will stop loving them and leave them. Carers sometimes do admit to such thoughts. But it would be odd if they did not have such feelings occasionally.

> 'There are times when you don't love them at all. But if I didn't really love my wife, I don't think I could go on with the daily round of looking after her.'

> 'In my moments of feeling down I sometimes regret the fact the Jack, my husband, and I got married. And yet we share such happiness and probably get more out of life because Jack nearly lost his.'

> 'Sometimes when we argue he throws at me, 'Put me in a home then!' I refuse to do that. I want him to have quality of life, and quite frankly he's given me quality of life. I don't know what I'd do without him. I'm better off here, doing what I'm doing, than I've ever been in my life.'

Of course, how you felt about each other to start with continues to affect your relationship. If you had a stable and caring relationship in the first place, illness and trouble can bring you even closer. Many couples find a new strength and fulfilment in rising to the challenge of MS.

> 'I think we have come much closer together because of the MS. We have a sense of facing it and beating it together. We feel more determined in our closeness.'

> 'When one partner has MS life can take on a new challenge, and your marriage a new direction. Instead of thinking about the things you can't do discuss the things you can do. You will be surprised just how many things there are.'

In some cases, MS holds together a relationship that might otherwise be shaky.

> 'If he hadn't developed MS, I doubt we would still be together. We never really had a lot in common. But I would never leave him now. He needs me, and in a funny sort of way his illness has given us something to share.'

It would be unrealistic to pretend that couples where one has MS do not separate. It may seem strange, but the crisis point for many marriages is early on in the disease – the uncertainty and fear about what might happen puts too much pressure on young, undeveloped relationships. Later on, it's not usually the MS on its own that causes separation. This tends to happen if the relationship is strained in other ways as well.

> 'My wife getting MS has been the last straw in our marriage which was never very good.'

Divorce under any circumstances causes guilt and pain, but where one partner has MS that guilt can greatly increase. Even so, separation is sometimes the most appropriate course of action.

Besides, break up is not the end. People do find new friends, marry again and even have children, unlikely as that may seem at the time. It can be a hard and long struggle, but one which can lead to maturity and newfound happiness.

> 'Bob's first wife divorced him. People tried to put me off marrying him, they said what a burden it would be as he can't do anything for himself. But he's

> no burden to me. It's what I wanted to do. We've been married for 13 very happy years.'

Sexual Relations

Sexual relations can be a problem for anyone, of course. But MS can lead to particular physical and emotional difficulties both for the people who have it and for their sexual partners. It can cause impotence in men and reduced responses in women. Incontinence or lack of mobility can make it physically difficult to make love. Fatigue can make it too much effort. These sorts of physical problems can easily lead to emotional ones. For the man with MS, impotence can be yet another blow to self-confidence and his sense of 'manhood'. Women with MS may fear they are unresponsive or 'frigid'. Both may fear that their bodies are no longer attractive.

It can be difficult for the partners of people with MS too. They may not know how to compensate for any physical difficulties, and may find it hard to cope with both their partner's and their own emotional reactions.

It is quite hard to find out how people feel about these sorts of sexual problems. However, this is what some people who have partners with MS have said:

> 'I know my husband feels inadequate because he is impotent. And I wish I could say I don't mind but I do.'

> 'I think it's especially hard for young couples like ourselves. We've only been married a few years and we've never really had a sex life.'

> 'It's sad because there's no room for spontaneous expression. We still have feelings for each other, but it's so much effort that I've just lost all interest.'

It would be wrong to assume that MS always causes problems in sexual relationships. It doesn't.

> 'We've always been lucky. We've always had a good sexual relationship and we still do. MS has not affected our sex life.'

> 'It's difficult physically to make love, but there's more to sex than that.'

Although it is not a laughing matter, people sometimes see a funny side to things as well:

> 'I heard something on the radio about this fellow who went to an impotence clinic... It made me laugh... The gadgetry you can have fitted down there! To have to go through all that... I'd rather get into bed with my cocoa.'

Some sexual problems are of a different sort. Quite a few carers find that they lose sexual desire altogether for their partner. This seems to happen if they have to carry out very intimate and personal tasks for them. It can become almost impossible to make love. People with MS can come to feel the same way too.

> 'When you spend a lot of time doing very intimate things for another person, the other person ceases to be someone you want to have a sexual relationship with, although I'm just as

> committed to him.'
>
> 'Physically it's very difficult, if not impossible. But something happens emotionally when they're so dependent. I just don't fancy her any more.'
>
> 'Deep down it worries me . . . I think we ought to but I just don't want to.'

Clearly this sort of problem is not unusual. This might in itself be reassuring, especially if you have felt you weren't 'normal' to have these sorts of feelings, or if you felt guilty about having them. As long as you are both comfortable, it can suit couples to carry on more as caring friends. Many close and loving relationships can survive and flourish without sex.

Of course, there is more to a sexual relationship than sexual intercourse. There is no 'right' way of relating to someone sexually, and couples find many ways of giving pleasure to each other.

> 'We still have a loving caring relationship although sex is not possible. I don't think we miss it. We're very much in love. In fact our love has deepened over the years.'
>
> 'Sex is no longer possible, but we have some lovely cuddles.'

This sort of arrangement will not work for everyone. Both people with MS and their carers may feel sexually frustrated and want to turn elsewhere. Some partners know that whatever the personal frustration and sacrifice they will never break faith. For others the matter cannot be so clear-cut and this causes them great anguish and conscience-searching. The question of sexual fidelity is too complex and delicate a subject to discuss here in any depth. But it is important to acknowledge that it can be a serious issue for people with MS and their partners.

Advice

These days it is possible to get sensitive advice and help for sexual problems caused by MS. You can write to various organisations for information or you can talk to a specialist advisor or counsellor. But most people have never had any advice, and many others would be too embarrassed to seek it. It can be difficult enough to talk about such a personal matter with your partner, let alone with anyone else. Strange as it may seem though, many people say that once they have plucked up courage, it is worth it. Often it can be easier to talk to someone you don't know, such as a counsellor. And it can help you to talk frankly and openly to each other:

> 'I though I would die of shame, but she made me feel that it was all normal. I thought it would be really embarrassing, but in a funny sort of way she was very matter of fact, and it made it seem all right to talk like that. What is also good is that she suggested some ways I could try talking to my husband.'

3. Families

CHILDREN

Should you have them?

People with MS and their partners often question whether they can or should have children. They also ask whether having or bringing up children will make the MS worse.

There are no absolute answers to these questions. In most cases, MS does not stop you from having children. And as far as is known pregnancy does not cause MS. But as the age at which women have children coincides with the most usual age for the onset of MS, it can be easy to think that having a baby brought on the MS. Nor does giving birth appear to affect the long-term course of the disease, although some women have a relapse in the year after their baby's birth.

Many parents are concerned that their children will develop MS. Although recent research suggests that there may be a genetic link in some forms of MS, it has not been pinpointed. It seems that some sort of 'trigger' - from the enviroment, or a person's diet, or a virus - is needed as well for MS to develop. Most people decide that the chance of their children getting MS is not great enough to stop them from having children.

Some people with MS, especially in the past, were advised against having children because of the strains involved in bringing them up. Of course, raising children causes stress and worry for all parents at times - this is quite 'normal'. But children also provide fun, love and purpose in life which outweigh the worries for most parents.

> 'We all have a good laugh about it at times, the children as well - if Dad falls over 'nothing' in the kitchen, for example.'

> 'The girls support me, although they've done their fair bit of rebelling. Having the children keeps you sane because you've got them to think about as well. It gives you another outlet. I wouldn't be without them.'

> 'My wife is still very close to our daughter. Although she can't do much for herself now, she can still type with one finger and she writes to her every day. It's a lifeline. It gives her something to think about and stops her feeling bored. It makes our daughter seem nearer although she's several thousand miles away. She can't write every day, of course, but she rings up from time to time, and she comes over. It makes life so much better.'

Children living at home

How are children affected by having a brother, sister, mother or father with MS? Many parents think that their children are well-adjusted to MS in the family, and that there can be positive gains as well:

> 'Our children are 16 and 18 now, so they've grown up with it. I don't think outwardly they have been affected - but then their father doesn't have it very badly.'

> 'Mine's so small it seems totally natural to her.'

> 'I've always felt my children are better off living in a loving family with MS than in a family with social problems such as alcoholism or sexual abuse. They are also learning positive attitudes to disability.'

> 'In my experience, children learn compassion, sensitivity, gentleness and kindness, and a much greater understanding of disabled people.'

Some parents think that their children 'miss out' and are upset in various ways.

> 'I feel my children have missed out on a lot of things - although they never complain.'

> 'The children miss out because of his tiredness - it gets us all down at times. They can't understand why Daddy has to sleep so much! They used to play cricket and football with him. They don't really understand why they can't now.'

> 'I've got a teenage daughter of 17. I think the sad thing is that she's lost her mother. They get on fine, but there's not the intimate chatting and doing things together - choosing clothes, going places. . .There's been a loss there for my wife and my daughter.'

> 'It's been tough on the children too. I know I take it out on them - they get a real yelling sometimes. You ask them to grow up quickly and shoulder some of the responsibility. Sometimes I feel that's not right.'

Parents are sometimes unsure how their children are affected. They can see how their children behave, but behaviour is not always a good guide to *feelings*. Children who are disturbed by having a family member with MS may become very naughty or extremely good, whereas others may behave 'normally'. Parents can feel they simply do not know what their children really *understand* or feel:

> 'My boy has never known his dad out of a wheelchair, and he's nine now. But if he draws a picture of him he's still standing up!'

> 'I don't know what they really think. They don't want to talk to me. I ask them and I talk to them - but they don't talk back to me.'

It is only to be expected that children will misunderstand things and experience pain at times. They can feel very guilty about having parent with MS. They may blame themselves for having caused their parent's illness in the first place, or they may believe they have made a parent worse by behaving badly. It can also be difficult for children to sort out fact from fantasy - what they imagine about MS may be worse than the reality.

Some are afraid that their ill parent will die, or tht they too will develop the disease, but are too frightened to ask.

This is not to say that all children react in this way. It varies from child to child and family to family, but most children will have some of these thoughts.

Parents can in fact do a lot to dispel misunderstandings. Although it is often difficult for parents and children to talk frankly to each other it is important to try. Children need to know the basic facts about MS - even quite young ones can understand simple explanations. You may find that this will put their minds at rest.

> 'We explained that Mum was ill, and that she would be ill for the rest of her life, and that things would have to change. We tried to explain as much as we could and they seem to have grasped most of it.'

> 'We've tried to talk to the children. We were afraid they'd get hold of the wrong end of the stick if they asked other people. So we sat down as a family and talked about it and explained things. I think that's important. We think they understand.'

You may find that you can't find ways to talk about how your children *feel*. This shouldn't really surprise you. Young children may not have the words to express how they feel, and teenagers are well-known for keeping inner thoughts from their parents. They may well resent your 'prying'. This is all quite normal. Even so, you can let them know that you understand how difficult things must be for them too.

Not talking about feelings only really becomes a problem if you suspect that your children are trying to bury painful or difficult feelings which continue to disturb them. Some people have only been able to talk about their childhood experiences when they became adult. From such accounts it is clear that some children who have grown up in a family with MS had mixed feelings that were extremely difficult for them to cope with. Sometimes it is hard for children to shake off these feelings even as an adult, and guilt hampers them from leading an independent life.

> 'My sister and I argued so much and caused so much trouble at home that I've often wondered if we made Mum ill. This thought never really leaves me, although I've never spoken to my sister about it.'

> 'I feel that when I was growing up I was denied the freedom to have natural adolescent tantrums, to be rude and selfish, to be reassured - my mother always got there first. I was the one who had to reassure her.'

If you think your children are bottling up their emotions it might help if they talk to someone else. Sometimes meeting other children who have parents with MS does the trick. Sometimes they may need to talk to someone, such as a teacher or trained counsellor, who is skilled in getting them to discuss their feelings.

Children as carers

Children can raise other sorts of problems:

> 'I was a self-centred adolescent with my own problems but I was being forced into the role of carer.'

Occasionally even quite young children may be drawn into caring for a parent or sibling who has MS, taking responsibilities that are beyond their years. This can happen for many reasons, sometimes simply because there is no-one else. It is not known just how common it is for children to become carers in this way, because it is often kept quiet within the family. This makes it difficult to know how to protect and help children who find themselves in such circumstances.

THE WIDER FAMILY

Relatives outside the immediate family can be a tremendous support:

> 'In our worse moments I am so thankful that we have good relations who are such towers of strength.'

Unfortunately, relatives may not always be understanding and helpful. Many familes are not especially close, but even so you may expect help when there are troubles and feel hurt and angry when this doesn't happen. Sometimes even quite near relatives, such as parents or brothers and sisters, can let you down:

> 'His brother won't accept it. We've been married 13 years but they've never asked us to their home.'

> 'Some families can't cope with it. My wife's father for example, he can accept it, but her mother won't talk about it - her own daughter!'

And even grown children may not always react as their parents might hope:

> 'My elder daughter doesn't accept it. She doesn't help out.'

> 'How much can you expect your grown up children to do? I don't think you can - they've got their own lives to lead. It would be nice if they asked sometimes, though.'

This apparent rejection can be most hurtful. Yet often it is not intended. It can be hard to comprehend how scared and threatened other people can be, and easy to misunderstand their reactions. Relatives have to go through a period of acceptance too, but as they are often removed from the day to day experience of MS it can be easier for them to get stuck. What can seem to you, the carer, like cruel rejection may simply be a relative's means of self-protection.

Many carers and people with MS believe that they have to help their relatives to accept the situation, and must 'educate' them into being carers. Not all carers feel able to do this, and it is perfectly understandable why. It can be difficult to put aside your feelings of hurt and anger, and barriers can be erected on both sides. And you may ask yourself why you should always have to be the one to make the effort. But many carers have found the attempt worthwhile. Given time to adjust, many relatives who once seemed unconcerned and uncaring can be brought round:

> 'My mother-in-law didn't want to know at first. It seems almost unbelievable now, but for a time she thought MS was contagious! We had some hard talking and cleared that one up. But it was still some time before she would come and visit us. Fortunately, we're now getting back to how we used to be. She seems to have accepted that we're still the same people, and that things haven't really changed that much.'

> 'John's daughter from his first marriage is nearly 17 now. The first time she visited us she'd never seen him in a wheechair. She went through a withdrawal phase and then we fought for the rest of the visit. Yet she's written to say she's coming again.'

4. Other People

FRIENDS

Friends can be a great source of support and comfort:

> 'I have a good friend who sat with him all night when I was ill myself.'

> 'Most of the time I'm genuinely cheerful. But when I'm not it's really useful to go and have a chat with my friend round the corner.'

But it can be all too easy for relationships to become strained and to lose touch altogether with friends who have no experience of MS. You have to actively keep up friendships, whether separate or shared. And this is not so easy when you can't get out as often as you would like, and if you are not able to continue activities you once enjoyed together. Some of the effects of MS can make you feel embarrased too and this can make it difficult to continue to see friends. You can find yourselves just drifting apart.

> 'It's awkward having to deal with the tiredness. People don't really understand why we have to leave early. I feel embarrassed about it.'

> 'He finds it hard to control his emotions and sometimes he cries in front of people. Afterwards I know he's so embarrassed.'

> 'I find it's slightly difficult... a quarter of an hour to go to the lavatory. People can't understand why it takes so long. They don't ask, but I know they're curious, speculating about what goes on.'

Relations can become strained for various other reasons. Friends who have no experience of MS can react badly to the news and their fear or embarrassment can mean they turn away from you.

Others may never really understand what MS is and how it affects you. There can be fault on all sides here – friends may not ask, carers and people with MS may not explain. You may even feel that you can't let on to friends how you really feel about things, fearing that if you complain about your situation then they won't stay around for long.

> 'People pretend to know all about MS rather than ask for details, or they are embarrassed to ask and talk about it.'

> 'I don't think they realise. I think they believe we're okay. I don't think they realise how much I have to do. To look at her you wouldn't know. She sits in a chair and she looks normal and well. But it's partly my fault because I can't bring myself to say anything.'

> 'How long does a friend remain a friend if you spend your time moaning about how awful your situation is?'

> 'People don't realise what it's like. We don't get any medals and we don't want any. But I get very bitter. My friends – who I thought were my friends – they don't care a hoot.'

It is not always easy for friends to know how to cope with a changed relationship. They may want to help but not know how to. They may fear that they will be interfering. Some carers believe that you have to make an extra effort to keep good friends with you, and that you can only do that by being honest and frank with them, and giving them the opportunity to respond positively towards you. Of course, you risk losing them as well, but in that case you're probably better off without them. Many carers and people with MS find there is still truth in the old maxim that there's 'nothing like trouble to show you who your real friends are'.

PROFESSIONALS

> 'My GP shrugged his shoulders when I asked him what would happen to my wife. His attitude was, 'You'll just have to get on with it'. That was the sum total of support available to me.'

The woman in the above quote was diagnosed many years ago, but her husband clearly still feels extremely bitter about the totally inadequate response made by his GP. These days, more is understood about MS, and medical training places more emphasis on the skills of communicating and relating to patients. Even so, many carers and people with MS are still angry about their experiences with doctors and other professionals. Some people with MS have bitter feelings about having been labelled 'neurotic' before they were diagnosed – something which could have gone on for several years. Many suspect that their doctor kept the diagnosis from them, yet others feel that they were told in a callous and unsympathetic manner. Many more feel there was a lack of support afterwards, or feel they were let down by the specialist who could not give them all the answers. Others feel they were virtually dismissed as soon as the diagnosis was made.

What makes some doctors behave in this apparently insensitive way? Some are not very good at handling strong feelings in their patients, so try to avoid confronting them directly with upsetting news. Many feel that their patients need to be protected. General Practitioners (GPs) are likely to have only a few people on their list with MS and may not be expert in dealing with the disorder. They may feel uncomfortable becaue they can offer so little in the way of treatments. Some doctors may even be unaware that their behaviour is inconsiderate. However, none of this excuses brusque or insensitive treatment or makes it any easier to put up with, and in some cases it might be best to try to change your doctor.

Many carers and people with MS also have unpleasant experiences dealing with officials from the DHSS or other services. It can take a long time to get benefits and services, and the support of a social worker is often hard to come by these days other than for an emergency. It's not surprising that people get frustrated by all the forms to fill in, and the waiting. You may also feel humiliated and degraded by your privacy being invaded, and the commonly expressed feeling that benefits are given out grudgingly.

> 'I get angry at having to be angry. Why do we have to struggle for everything – for every small benefit?'

As many carers admit, they often get angry with the people they have to deal with when it is really the system that is at fault.

Fortunately, some doctors and other professionals are supportive and able to get things done:

> 'We had a GP who was very understanding and 'with it'. I'd get on the phone if my husband's symptoms developed and we'd have a talk about what to do.'

> 'My wife's occupational therapist has been marvellous. I don't know what I'd have done without her. She came round and said you need this, that and the other, how have to got by without? And the next week there it all was!'

> 'A few months ago my daughter spent some time in hospital where she was greatly helped by a young consultant who inspired our confidence and respect.'

COPING WITH OTHER PEOPLE

Going out together to the shops or any public place can require considerable organisation. Both of you can feel that it is too much effort when faced with inadequate toilet facilities and the practical difficulties of, for example, long flights of steps or lack of wheelchair access. The thought of other people's behaviour and attitudes can put you off too. Although carers relate both good and bad experiences of strangers' responses to MS, it is often the negative responses which are most easily recalled because they can cause so much pain and embarrassment.

> 'People in the streets really bring it home to you. They think a person with MS is drunk.'

> 'People thought he was drunk. I know they did. I overheard so many comments from complete strangers. Eventually we persuaded him to use a stick – much against his will. At first he did anything but lean on it. But it did the trick!'

> 'When you're in the street with a wheelchair people start shouting. Because you can't walk, they think you can't hear!'

Of course carers realise that most people do not mean to offend or upset – they are usually just unaware that their lack of knowledge about MS, or their commonly-held beliefs about disabled people, come over as prejudice and insensitivity. This doesn't, of course, make it any easier to put up with, and people with MS and their carers can feel exasperated and angry, upset and embarrassed. Carers can come to feel aggressively protective on behalf of the person with MS, who can so easily be patronised or belittled. Many feel that the onus is always on them to do something about it and that they have to be blunt to make any headway.

> 'It drives us both mad – the 'Does he take sugar' syndrome. He may be disabled and weary but he can still speak and use his brain! I am direct. I say, 'Don't ask me, ask him!' regularly. It embarrasses the asker, but does seem to have the desired effect.'

Some carers and people with MS feel very strongly that disabled people and their families must be prepared to 'educate' the general public, rather than expecting people to 'know better' and getting angry when people are inconsiderate. Carers and disabled people should explain politely and firmly why, for example, they are walking slowly along a crowded pavement.

Sometimes going out can make you very anxious because you may have to deal with things that you can cope with perfectly well at home, but which can cause you acute embarrassment in public. For example, having to deal with bodily functions.

> 'I remember the first time it happened. I was out with my husband and suddenly the chair was wet. What do you do? Your stomach sinks, and you think, 'Oh dear. This is it.' The first time is horrible, but it's so much worse for them. And of course you do get over it. It doesn't embarrass me at all now.'

In fact, many carers are relieved to discover that once they overcome their initial fear and embarrassment, other people can be surprisingly discreet and accepting about all sorts of things.

> 'I take my wife in the Ladies and no-one bats an eyelid.'

> 'Yes, I go into men's lavatories. I've had a couple of odd looks, but they seem to pick up why I'm there, and nobody has ever said anything unpleasant.'

> 'Toilets used to be a problem, but not any more. Now if the bag needs emptying and I can't find a disabled toilet, I'll find a quiet corner. You can't let these things stop you going out.'

> 'I find a lot of people are kind and quite helpful. But perhaps that's because I'm a woman pushing a man.'

5. Useful Information

Living with MS is mainly about difficulties people have with their relationships and feelings. As this booklet shows, people with MS and their families are resourceful and come up with a wide range of custom-made solutions to their difficulties.

To some extent, how much you rely on yourselves, and how much you draw on other people and services, depends on what sort of help is available. If you are well supported by family and friends you may be able to 'keep things within the family'. And that is how some people prefer it. If you are not, or if your circumstances change, you may choose or need to draw on outside help. A great number of carers say they would like occasional help and support, perhaps to deal with particular problems, or difficult 'patches'.

The question then becomes 'How do I find out what help there is, and how do I get it?' Sometimes it can be very straightforward. But as most carers know from experience, getting the support you need - either emotional or practical - can be a struggle.

Many people with MS and their carers say the ideal would be to have a 'special worker' to sort things out for them. This person would start the ball rolling and would call on you. They would know what was available and how to get it, they would be caring and understanding, and at the same time efficient and tough to get things done!

This ideal is difficult to put into practice. Although around the country there are one or two schemes with paid workers to help and advise carers, most people with MS and their carers will have to sort things out for themselves. This final section aims to get you started. It describes some services, organisations and publications which can provide both practical and emotional support, and suggests how to get them.

INFORMATION

One of the organisations listed in this chapter should be able to point you in the right direction for information and advice about MS, state benefits and services, relief care, holidays, leisure and sports activities, diet, aids and adaptations, research, emotional support, and just about any other area that you might want to find out about. Most of the organisations produce information leaflets, pamphlets and resource lists. They will usually be able to refer you to another source if they cannot answer your particular questions.

Libraries, Citizens Advice Bureaux and other local advice centres (where they exist) can be useful places to try as well, especially for information about what is available in your area.

HELP IN YOUR HOME & RELIEF CARE

a) Help from Social Services

The person with MS may be entitled to a Home Help, the Meals on Wheels service, or the advice of an Occupational Therapist. Occasionally, you may want or need to arrange some kind of relief care in your home, such as a sitter, or care attendant. Or you may want information about day or residential care. You can find out about many of these services from your Local Authority Social Services Department. They will probably also have information about some services provided by voluntary organisations.

To contact your Social Services Department you need to find the phone number (or numbers) of your borough, metropolitan or county council. Look it up under its name e.g. Wandsworth Borough Council, Kent County Council. Sometimes the Social Services Department is listed, sometimes you will have to go through a general enquiries number. It may take you a while to find the right number.

b) Help from the NHS

You may need the help of a district nurse or continence advisor (where they exist). You should ask your doctor about these and other services which may be available (health visitors, bathing attendants, day care provision, residential breaks). He or she will need to make arrangements for you, and the person with MS, or will explain how you can arrange it yourselves.

c) Help from voluntary organisations and groups

The range of services they provide is enormous and growing. Many offer help in the home and short breaks of various kinds. Your library and area Citizens Advice Bureau keep directories of all national and local voluntary organisations and charities.

There may be a local Crossroads Care Attendant Scheme where you live. These schemes provide a trained Care Attendant to help in your home and give you a break. Often this service is free. Contact the headquarters for more information (address on page 45).

SUPPORT GROUPS, ADVICE AND COUNSELLING

Many carers, and people with MS, get a great deal of support from talking to others who share similar experiences. Often families and friends can fill this need. But when this isn't possible, outside sources may be able to help. An understanding 'outsider' can at the least offer a fresh view on things.

Several of the organisations listed below organise support and social groups, and self-help groups. Such groups are now in most parts of the country. Some are for people with MS and their families together, others are specially for carers. If there is not a carers' group in your area the Carers National Association (address below) can give you information on how to set up a self-help support group.

At times coping with MS or caring for someone who is ill can become overwhelming. Many people - those with MS and their carers - find that skilled counselling can help them to get over these very difficult patches.

Having counselling doesn't mean that there is something wrong with you - it's just useful for some people to talk in confidence to a trained outsider about difficulties in their life and relationships. Counselling can help you to see things more clearly, to sort out your emotions and, for some people, even help them to put their lives back into some sort of order. Many of the organisations below provide advice services, offer professional counselling, or can help you to find a counsellor near to your home.

Some people find talking with an understanding social worker an efective form of 'counselling'. Social workers can advise on a range of personal, practical and financial problems. You may already have a social worker assigned to your family. If not, you can contact one through your Local Authority (see above).

FINANCIAL ADVICE

If you need advice about benefits try ringing Freephone DHSS (ask the operator to put you through). Some voluntary organisations and charities can advise you or may give small grants. You can find out about these from a Citizens Advice Bureau, or by looking in a charities directory in the library (there are several directories; ask the librarian to help you).

USEFUL ORGANISATIONS

ARMS (Action for Research into Multiple Sclerosis)

Arms is an organisation set up and run by and for people who have MS, their families and friends. ARMS carries out research, provides information about MS, runs over 50 local social and therapy centres, and runs a 24-hour telephone counselling service: London: 01 222 3123; Glasgow: 041 637 2262; Birmingham: 021 476 4229.

ARMS Head Office
4A Chapel Hill
Stansted
Essex
CM24 8AG
Tel: 0279 815553

Association of Crossroads Care Attendant Schemes Ltd

10 Regent Place
Rugby
Warwickshire
CV21 2PN
Tel: 0788 73653

The British Sports Association for the Disabled

Hayward House
Barnard Crescent
Aylesbury
Bucks
HP21 8PP

Carers National Association

The Association is a self-help and pressure group for people caring for someone at home. It runs *local* support groups for carers.

Carers' National Association

29 Chilworth Mews
London
W2 3RG
Tel: 01 724 7776

Dial UK (National Association of Disablement Information and Advice Lines)

Victoria Buildings
117 High Street
Clay Cross
Chesterfield
Derbyshire
S45 9DZ
Tel: 0246 250055

Dial UK has local centres throughout the country which offer a full and confidential advice service on any matter concerning disability. You can get information about local centres from the headquarters above.

Disability Alliance

25 Denmark Street
London
WC2H 8NJ
Tel: 01 240 0806

The Disability Alliance is a pressure group of organisations concerned to improve income and benefits for disabled people. It produces a comprehensive guide for disabled people and their families called the *Disability Rights Handbook*.

Disabled Living Foundation
380/384 Harrow Road
London
W9 2HV
Tel: 01 289 6111

The Disabled Living Foundation provides an information service on all aspects of coping with a disability, including incontinence. It runs a number of centres around the country where aids are exhibited and can be tried out.

The Multiple Sclerosis Society of Great Britain and Northern Ireland
25 Effie Road
Fulham
London
SW6 1EE
Tel: 01 736 6267

The MS Society supports a major programme of research and provides information about MS, including a quarterly magazine and a monthly bulletin. It has a large advice and welfare department and a range of short-stay and holiday centres. There are over 350 local branches throughout the UK which provide social and welfare support as well as raise funds for research.

RADAR (The Royal Association for Disability and Rehabilitation)
25 Mortimer Street
London
W1N 8AB
Tel: 01 637 5400

RADAR is a voluntary organisation which provides information and acts as a pressure group to improve the environment for all physically disabled people. It specialises in information about access, employment, holidays, housing and mobility.

SPOD: (The Association to Aid the Sexual and Personal Relationships of People with a Disability)
286 Camden Road
London
N7 OBJ
Tel: 01 607 8851

SPOD provides information and advice on sexual and relationship problems for people with disabilities and their partners. They produce leaflets and give advice to individuals. If counselling is needed they will put you in touch with someone in your area.

BOOKS and PUBLICATIONS

Three personal accounts from people who have MS. Each book gives advice and information which show the diversity of approaches. Each book is available from bookshops.

Multiple Sclerosis – a personal exploration by Dr Alexander Burnfield, Souvenir Press, London 1985.

Multiple Sclerosis – a self-help guide to its management by Judy Graham, (2nd Ed.) Thorsons Publishers, 1987.

Coping with Multiple Sclerosis by Cynthia Benz, Optima, 1988.

A book exploring the personal and social consequences of living with MS based on the experiences and life stories of people with MS and their relatives.

Multiple Sclerosis by Ian Robinson, Routledge, 1988. Available from bookshops.

Two booklets dealing with particular aspects of MS, both available from ARMS Research Unit, Central Middlesex Hospital, Acton Lane, London NW10 7NS.

Emotional Reactions to MS by Julia Segal.

MS and Pregnancy by Alec Forti and Julia Segal.

Books about caring in general.

Caring at Home by Nancy Kohner, National Extension College, 1988. An extremely useful and easy to read guide to all aspects of caring for someone at home. It has an extensive section on useful organisations and publications.
Available from Bailey's Distribution Ltd., Dept. D/KPF, Warner House, Folkestone, Kent CT19 6PH. Cheques payable to Bailey's Distribution Ltd. Price £2.50 incl. P&P.

Caring Together: Guidelines for carers' self-help and support groups by Judy Wilson, National Extension College, 1988. Available from Bailey's Distribution Ltd. (address as above). Price £3.95 incl. P&P.

Taking a Break: a guide for people caring at home, published by the King's Fund Informal Caring Programme, 1987. Free to carers. Send your name and address to: *Taking a Break,* Newcastle upon Tyne X. (Non-carers please send 60p to cover costs, payable to King Edward's Hospital Fund for London).

Keeping fit while caring, by Christine Darby, published by the Family Welfare Association, 1985. This book is written by a carer so it is based on experience. Available at £3.45 from The Family Welfare Association, 501-101 Kingsland Road, London E8 4AU.

Who Cares?, King's Fund/BBC 1989. A video and handbook for carers' groups. Available from Bailey's Distribution Ltd. (address as above). Price £9.50 incl. VAT + P&P.

8572 020000 0485