Yasmin Gunaratnam CALL FOR CARE





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Call for Care

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Yasmin Gunaratnam

Health Education Authority King's Fund Centre

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Yasmin Gunaratnam

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1Introduction

Are you one of the many Asian people looking after an elderly friend or relative?

If you are, this book has been written for you.

Twe been looking after him for about seven years now. I can't say that it has been easy ... most of the time I'm tired and worn out, but he is still my husband and it was the right decision for me to keep him at home.'

I do everything, the cleaning and shopping and looking after her \dots But I am an old man and it is getting more and more difficult for me. We only have one son who lives near us \dots I think that a lot of people think that we Asians have a lot of help from our family, more help than English people, but it is just not true.'

'How can this book help me?'

This book was written after talking to many Asian people who looked after an elderly person. We spoke to a large number of people and found that they shared many problems and needs. This book looks at some of these subjects such as getting help or how to apply for welfare benefits, and aims to help you to find a way to start tackling your own problems. It also looks at some of the particular experiences of Asian people such as those of racism, which can affect the way you look after someone.

'Is it really worth reading this book when I can't speak English?'

Yes! You don't have to speak English to benefit from this book. It contains specific advice and suggestions about how to get what you want when you

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don't speak English. In Chapter 2 there are letters for those who do not speak English which can help you to get support from local services.

'Will this book give me all the information that I need?'

Not necessarily. You should look at this book as a starting point from which you will have to put in some time and energy to get results. It tells you about many of the choices open to you and the person you look after so that you can make an informed decision about what you both want. Because this book is for Asian people throughout the country, it is quite general. It does not give you names and addresses of services where you live but it can help you to start finding out about what is available and how to go about getting it.

'How can looking after someone make me special?'

You may be a wife, a daughter, a grandson, a niece or a friend, but looking after someone makes you more than this. You may experience difficulties which have nothing to do with the fact that you are a wife, for example, but have everything to do with the fact that you have to look after your disabled husband. There are special services to help people like you and people who are ill or disabled.

The hard work of looking after someone is very slowly being recognised and people like you are often given the name of 'carers'. A carer is anyone who spends time and energy looking after a person who is ill or disabled:

Mostly it is moral support I give him because he is quite independent. I make sure that he eats the right things and I do the shopping and cleaning and take him to hospital appointments. It is strange that even though I have heard of "carers" I have never thought of myself as being one because my dad can do some things for himself.'

I think that it is difficult for us Asian people to see ourselves as "carers" ... the idea is not something that is a part of our culture or language, it is just another part of family life.'

I never used to think about looking after my mother-in-law as being something that I could be proud of. I used to try to do everything, work, look after her and the family without recognising the extra work I was doing. Now if I'm late for work or I haven't cooked dinner on time I tell people it's because I have been looking after her. It has been better for me to bring that part of my life into the open.'

Carer is a relatively new term which many Asian people are not familiar with; it has usually been used by and about white people. You don't have to use the same name to describe what you do, but it is good to recognise the work you do by giving it a name like caring and it may also help you to be noticed by local services.

'What is the best way to use this book?'

You may not need to know everything that is in this book. It may be helpful to read the short descriptions at the beginning of each chapter before you turn to any particular part of the book.

2Starting off

This chapter is about getting in touch with services for the first time and looks at:

- who to contact about services
- how to get an interpreter if you do not speak English
- 'letters' for non-English speakers that ask for information and help

'Services for carers? What services?'

There are a whole range of services and people who can provide help for you and the person you care for. What you both have to do is get yourself noticed

'How do I find out about what is available?'

"The most difficult thing for me was finding out about what we were entitled to ... All these people go on about "fighting for your rights", but we couldn't fight because we didn't know what our rights were.'

If it wasn't for Rupert at the community centre, I don't know what we would have done. He helped us with our benefits and spoke to the social services and housing people for us. I feel safe with him.'

I didn't know there was any help for people like me.'

If you do not know what is available in your area there are a few key people who can be good 'starting points' for you. Make sure that they know that you and the person you care for are looking for support and help.

The best people to approach first are:

- a doctor
- someone from social services
- a worker at a community group

However, there are also other people who can help you, and the most important step is to find someone whom you trust and can approach for help. You could even give this book to a friend and ask them to help you get in touch with services.

'I don't know what I want.'

It is difficult because I haven't got a clue about what is on offer to us so you don't know the right questions to ask and who you should ask.'

It can be difficult to ask for help if you do not know what is available. But if getting all the information you need is difficult, or the thought of too much information puts you off, don't worry!

A good tactic, once you have found someone to help you, is to start by talking about what you and the person you care for need and then let the other person tell you what services can help you. Try to put some time aside to think about your situation and, if possible, discuss it with the person you care for. This can be quite simple and straightforward:

'One day as a part of the work I do with him anyway we each made a list of ten things we would like to do... it was good for me doing that. It's different than just moaning about things because it's not your anger that comes out, it is your hopes.'

The following example is an extract from a list that a carer and her father made up together:

Things we would like to do

Carer	Father
To get up later	To be able to walk
To visit my friends	To go shopping in Tescos
To get more help	To learn to swim

Obviously you will not be able to get everything you want and sometimes the person you care for may not be able to tell you what they want. But by looking at your life and thinking carefully about things that would make it

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better you will be nearer to finding a useful service. For example, the carer's needs could be met by the following services:

Carer's needs	Services
To get up later	Short stay in residential home for her father A worker from a local scheme to get her father up in the morning A holiday for her father
To get more help	District nurse Home-help Help from local community schemes for carers

The father's needs could also be met, for example:

Father's needs	Services
To go shopping in Tescos	Local schemes which, for example, take disabled people shopping, for day trips out, etc.
To learn to swim	Local swimming clubs for disabled people

Making a list or thinking about everyday problems may seem too simple or basic, but you do not have to have unusual needs in order to get services. You do not, for example, have to wait until you are a physical wreck before you can get services that will give you a rest from caring. Most services aim to fit in with your everyday lives.

'They told me all about the services and then later they told me that I couldn't get them.'

If you are told that you cannot get a service, such as Meals-on-Wheels, you don't have to take the 'No' as being the end of the story. It might be worth asking some of these questions:

- Why am I not able to get this service?
- If I am not able to get it now, will I be able to get it in the future?
- Can you suggest any other service that can help me?

If you are not satisfied with the reasons you are given, get help from an advice or community centre.

'How do I get myself noticed and find out about services when I don't speak English?'

If you do not speak English you may still be able to get in touch with services to ask for support and help. You can use copies of the letters on pages 9–10 to get an interpreter, let people know that you are a carer and to find out about services.

Listed below are some of the things you can do if you don't speak English.

Finding out about interpreters

Unfortunately many organisations still do not provide language interpreters as a part of their service. If you want to find out if an organisation can provide an interpreter for you, you can use the letter which asks the organisation to provide you with details of interpreters locally (see page 9).

You could also ask a friend or relative to contact the organisation before you make an appointment to find out if they provide interpreters or whether they have an Interpreting and Translation Unit' Remember always to make it clear what language and dialect you speak.

Using a friend or relative to interpret for you

A friend or relative who speaks English can accompany you to any appointments. Doctors, social workers and other workers will usually not object to an interpreter as long as you have explained why the person is there. Ask your interpreter to make it clear what language and dialect you speak and to make sure that this is written down on your records. There are, however, some disadvantages to using friends or relatives to interpret for you:

- Will the person keep your business private?
- The fact that someone speaks your language does not mean that she or he is a good interpreter. Good interpreters should interpret precisely what is being said and not just interpret what they think is important.

Asian community centres and Asian workers

Try to find out if there are any local Asian community centres or advice centres which have special sessions for Asian language speakers (see page 64, which tells you how to find out about services). These organisations will provide you with free advice and may even make telephone calls and write letters for you to help you and the person you look after get what you need.

How to use the letters for non-English speakers

There are two different letters:

- a letter to help you get an interpreter (page 9)
- a letter to put you in touch with services for carers (page 10)

Although the letters are different the way that you fill them in is the same. If you need more than one copy of the letter, ask a friend or someone at your advice or community centre to photocopy the letter for you. Many post offices, libraries and newsagents have photocopying machines, where you can make a copy of the letter for a small fee.

If you get an answer to the letter it will probably be in English. If you do not know anyone who can translate the letter for you, take it to your local Asian community group or to your Mosque or Temple.

The most important thing is to write (or to ask someone to write) your name and address in the top right hand corner of the letter and your phone number if you have one.

In the spaces towards the end of the letter you should fill in details about the language and dialect you speak and the name of any language(s) you can read.

Finally sign the letter at the bottom and cut the letter out and send it to the appropriate organisation.

Make a note of the address to which you sent the letter, and the date on which you sent it, and keep a copy in your own language.

INTERPRETER'S L'ETTER

This letter has been produced as part of the Health Education Authority/King's Fund *Call for Care* Information Pack to help Asian carers who do not speak English to find out about local services. If you are not able to provide any appropriate translated material, information in English would still be useful.

NAME:

ADDRESS:

TELEPHONE NUMBER:

DATE:

Dear Madam/Sir,

Re: Interpreting services

I am a carer who is looking after an elderly person. I am sending you this letter to find out if you provide an interpreting service for people who do not speak English. If you are not able to help me I would be grateful if you could provide me with any details of interpreters or interpreting services that I could use.

My first language is:

My dialect is:

I can read:

I look forward to hearing from you.

Yours faithfully,

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SERVICES LETTER

This letter has been produced as part of the Health Education Authority/King's Fund *Call for Care* Information Pack to help Asian carers who do not speak English to find out about local services. If you are not able to provide a response or information in the appropriate language, information in English may still be useful.

NAME:

ADDRESS:

TELEPHONE NUMBER:

DATE:

Dear Madam/Sir.

Re: Services for carers and the person they care for

I am a carer who is looking after an elderly person. I am sending you this letter in the hope that you will help me to find out about services for me and the person I look after.

I do not speak English and I would be grateful if you could arrange for someone who speaks my language either to telephone me or meet with me to discuss local services.

My first language is:

My dialect is:

I can read:

I look forward to hearing from you.

Yours faithfully,

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Services to meet your needs

This chapter:

- looks at common needs of carers and services that can meet those needs
- gives information charts with brief details about services.

You will be able to get almost all of the services mentioned here privately, where you will have to pay the full cost of the service yourself. However, it is always best to ask someone, such as your doctor or social worker, to recommend a good private agency to you.

It can be difficult to find services that recognise the importance of different Asian languages, religions and cultures, but don't give up hope. Many services are flexible and will adapt to meet different needs. What you have to do is to make your needs known:

I explained to my social worker that I couldn't leave him with someone who didn't speak our language. I am sure that she thought that I was being difficult at first, but then I said "What will happen if he wants a glass of water or he wants to go to the toilet?" She understood then and even though I had to wait a couple of more months until they found someone who could speak Urdu at least I can get out without worrying.'

If you feel uneasy about using a service try to:

- talk about your feelings with the people who provide the service
- find out all that you can about a service
- let the people who provide the service know as much about you and the person you care for as possible
- be prepared to let people do things differently, but make sure that the people who provide the service know which things you will not be prepared to change

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Actually using a service can be a practical way of lessening your concerns. Many carers find that even though some of their feelings may not go away altogether, the benefits of getting a good service far outweigh the disadvantages of caring alone.

'Who should I contact about getting a service that I want?'

As in the previous chapter the main people you should contact about any of the services mentioned are:

- a doctor
- someone from social services
- an advice centre

'I just need a rest.'

All carers will at some time need to have a rest away from caring:

I am going crazy without a break. I don't even get to eat sometimes – is it a life for me? I have to be frank, I just don't have any time. Who looks after me? No one. I need help \dots I thought that I was strong, but after a year my health has gone down.'

Even though you could do with a rest, it can be difficult to make the decision to have a break. It is quite usual for carers to feel guilty or uneasy about leaving the person they care for, even if it is only for a few hours. Sometimes the person you care for may not want to spend time away from you and this can be an extra worry:

He gets very emotional so I tried to be as positive as I could about the holiday ... A few days before he was due to go away, he kept crying and saying that he didn't want to go. On the day that he left we both ended up in tears ... A week later he came back and said that he had had a really good time and that he wouldn't mind going again. He is such a rogue like that.'

The emotions and concerns that taking a break often bring up are very real, but try not to let these feelings stop you from getting the rest that you need. Some carers find it useful to think about the benefits that a break can bring. For example, trying to provide 'the best' for the person you care for is not possible if you are feeling tired and resentful. Having a rest can actually make you a better carer. Opening up the relationship between you

and the person you care for can also be good. Spending time away from each other can help both of you to become more independent.

There are many different services that can fit in with your needs, whether you just want a couple of hours to visit friends or you want a few days of complete rest. You should discuss your needs and problems with the person who is arranging your services; they should then be able to suggest the type of break that will suit both you and the person you care for. Whether you will have to pay for a service and the cost will depend upon the area where you live. Always find out about the cost of a service before you decide to use it.

Services that can give you a rest

What I need	Services to help
Some time off for a little while	Sitting services Someone will stay with the person you care for
	Care attendant schemes Trained people will look after the person you care for
	Day centres The person you care for goes to a special centre where workers will look after her/him
	Clubs There are many types, such as lunch or stroke clubs where the person you care for can go for a few hours
Some time off	Holidays for the person you care for
for a long time	Nursing homes Provide accommodation, meals and nursing care
	Residential homes Provide accommodation, meals and personal care

'If I want to stop looking after him, what can I do?'

It is difficult for all carers to make a decision to stop or change the way that they look after someone. In addition to feelings of guilt or failure some Asian carers also worry that other Asian people will 'look down' on them for making such a decision. If you have difficulty deciding what to do always talk to someone about your concerns. A sympathetic doctor or social worker and friends and relatives can all be helpful.

There are many different services that can take over the job of caring. You may, however, also have to think about how the person you care for will fit in to a system of care which mainly provides for white people:

"The home was very nice and the staff were helpful, but when we had a look around the place I just knew that she wouldn't fit in \dots I couldn't see her eating comflakes for breakfast or playing bingo \dots '

If it seems that there are no appropriate services for the person you care for then you should get in touch with your social worker or someone from the social services department of your council (see page 63). They should be able to help you sort something out. If you are still not satisfied then you should go to your local Community Relations or Race Equality Council for advice on taking the matter further.

To choose the right service you will need to take time and ask questions. Remember that even when you have made a decision, you can still change your mind at any time. You can also try some services for a trial period to see if things work out.

Private services

If you are unable to pay the full cost of the care you may be able to get help from the Department of Social Security. An advice centre can provide information about this.

The main services on offer

What is it called?	What is it?
Residential care	Accommodation, with all meals and personal care provided
Nursing home	Like residential care, but it also provides care from nurses
Hospital care	For those who need hospital treatment and nursing care, usually only for short stays
Hospices	Provide nursing care for people who are dying, either in your home or in a special hospital

Financial arrangements

If the person you care for is admitted on a long term basis to any of the places described above, this may affect the money they get from any benefits, and you will also have to take into account any payment for the care. It can be complicated to sort out yourself, so if you have any doubts ask for advice from your social worker or local advice centre.

'I just need some help with doing all the everyday things around the house.'

Some of the services for carers are to help you with everyday problems. Depending upon where you live, services can help you with things such as housework, washing or meals. It is always a good idea to talk to service providers before you accept a service. Try and find out, for example, not only about what a home-help will do but also what she or he will not be able to do. This should avoid any misunderstandings later.

Services to help you in the home

What I need	Services to help	How much?
Some help with everyday work	Home-helps Can help you with jobs around the house, such as cleaning or washing	Free or you may have to pay a small fee
	Meals-on-wheels Lunch is brought to your home if you have difficulty cooking; you may be able to get Asian food	A small fee
	Washing clothes A service for people who are unable to do their own washing or if you are looking after someone who is incontinent (see page 17)	Free or you may have to pay a small fee
	'Good Neighbour' schemes Volunteers who can do shopping, housework, and small jobs around the house and help with the person you care for	Usually free

'It would be good if there was someone who could come and tell me if I was looking after her properly.'

Nobody trains you or teaches you how to be a carer. It is not something that you can plan to do. It just happens. Most carers simply learn by trial and error how to do things such as nursing, washing or lifting the person they care for. This can be a hard way of learning; you may, for example, unintentionally end up hurting yourself or the person you care for, or it may take you a long time to find a simple and efficient way of doing things.

There are professionals who can give you advice about how to do things in a safe and proper way which will help you and the person you care for.

Help with 'doing things properly'

What I need	Services to help	How much?
Someone to tell if I am looking after her properly	Your doctor (GP) Will be able to give you advice about looking after someone	Free
	Health visitor These are special nurses who can give you advice at home and refer you to other services	Free
	District nurse As well as providing nursing care, the nurse will be able to give you advice	Free
	Occupational therapist Can give advice about disabilities and everyday living and give you advice about equipment (see page 32) that can help both of you	Free
	Physiotherapist Can give the person you care for treatment if they have difficulty moving, and also advise you about moving, lifting, turning the person	Free
	Community psychiatric nurse These are nurses for people with mental health problems. As well as giving nursing care they can give you advice about problems and tell you how to deal with difficult behaviour (see page 23)	
	Continence advisers They are trained to help and give advice about people who are unable to control their bladder and bowels. They will be able to tell you about items like pads that can help the problem	Free

'I don't know what is wrong with him.'

I don't understand why he says these funny things. He just started saying them one day. He used to run away sometimes even. He would ask me to give him his allowance book and when I gave it to him he would take it and run out of the house.'

If you are looking after someone who has an illness or disability, it is important to know some basic details about it. Information can help you to deal with day to day practicalities, emergencies and future plans.

You can get information about the health of the person you care for from:

- your doctor
- a doctor at a hospital or clinic
- special organisations that provide information about particular health conditions

Special organisations

There are many organisations which do work around different illnesses and disabilities. Part of their work is to give advice and help to people with the particular condition and their carers. You can find out if there is an organisation for a particular health condition from your doctor or social worker.

'Can you give me any information about transport?'

There are many transport services to help carers and the people they care for. For example, there are schemes that can enable disabled people to use public transport at a reduced cost, there are special community transport schemes and there are schemes for people who own their own cars. To find out what is available in your area contact a community or advice centre. A free booklet, in English, produced by the Department of Transport will tell you everything you need to know about transport for disabled people. The booklet is called *Door to Door* and is available from

Department of Transport, Door to Door Guide Freepost South Ruislip Middlesex HA4 0NZ You may also be entitled to get some of the benefits that are available to elderly and disabled people to provide help with travelling costs. You can find out about the benefits from your local advice or community centre.

Transport services

What I need	Services to help	How much?
Help with travelling	Dial-a-Ride Offers a transport service to disabled people and their carers	You usually have to pay a mileage cost
	Community transport Some schemes offer a special service for disabled people and their carers	Mileage cost
	London taxi card scheme A door to door service for disabled people and their carers; details from London Regional Transport	You are able to get up to £7 of travel for £1
	British Rail Disabled Person's Railcard and Senior Citizen's Railcard, available from any BR Station	The card(s) will give you some money off fares
	Car parking Orange Badge Scheme	The badge allows disabled people to park their cars free of charge subject to waiting restrictions

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Emotions and difficulties

This chapter is about carers' feelings and experiences and looks at:

- concerns about the future
- feelings of frustration and anger
- carers' groups
- coping with difficult behaviour from the person you care for

'I worry a lot about the future.'

It is not as if you sit down one day and think about "The Future". It is like a massive big question that is always there and you just see it from time to time, like when you dream about going on holiday or working.'

'Sometimes you feel frightened by it and all the questions that go with it, like "What if something happened to me?" or "What if she got worse or died?" ... You don't feel confident to make any plans or think about details.'

For many carers 'the future' is not something that can always be looked forward to with hope. You may not even want to think about it. It is, however, only natural to have mixed feelings about what the coming years may hold for you and the person you care for.

Some carers, no matter how much they love the person they care for, may sometimes think of a time in the future when they are no longer carers and they are able to do other things:

I feel guilty just talking about it, but yes there are times when I think about not having to look after him. I don't think about him being dead or anything. I just think about me.'

Even though you may be aware of some of the difficulties of being a carer,

it can also be unbearable to think about your life in the future without the person you care for:

If anything happened to him, my life would be finished as well. I don't think that I would be able to manage... Because I have to look after him we are very close. He is not just a father to me, he is my whole life.'

Thinking about your own death can also be a big worry:

'She is so dependent upon me, I don't think that she could cope with anyone else looking after her or with living in one of those homes or anything.'

If your worries about the future concern practical issues such as what would happen if one of you died then you should find Chapter 9 *Death and dying* useful.

If you are worried by your own feelings and emotions it is important that you try and talk about them. Carers' groups are often very useful for this, as other carers will usually know exactly how you feel. Some carers prefer to talk to trained counsellors who can help them to understand their feelings. You will usually have to pay for the service so find out about any costs before you agree to see a counsellor. You can get details about local counsellors from your doctor or social worker or by sending a stamped addressed envelope to the organisation below. If you would like to see an Asian counsellor you can also try asking the organisation for any details or advice about contacting Asian counsellors:

British Association of Counselling 37a Sheep Street Rugby Warks CV21 3BX Tel: 0788 78328/9

Dealing with feelings of frustration and anger

I do get fed up with it sometimes, it is nothing to do with him, it's just the whole situation, being tired, not being able to go out, everything.'

I just find myself getting angry or bursting into tears about nothing."

When you are caring for someone, it is easy to get so involved with day-to-day pressures that you forget to give time and space to yourself. You can end up putting yourself last, so that while the person you care for may get the best care in the world you end up run down and frustrated.

Even if it is difficult, it is important that you also give time and priority to yourself. Examples of how other carers have done this are:

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- keeping a 'special time', for example, one morning a week or one weekend a month where you do something for yourself
- making an effort to keep in touch with friends of your own
- taking part in community or cultural activities
- making sure that you get out of the house regularly
- joining a local carers' group
- talking about your caring and feelings with people you trust

Being violent towards the person you care for

I could feel the anger rising inside me, it was like I was another person ... then one day when I was helping him to get dressed, he wasn't paying attention and that was it, I shouted at him and shook him really hard.'

Violence towards the person you care for can take many forms. It can include hitting, shouting and making the person upset or not allowing the person to do certain things.

For carers, violence is usually a sign of being under too much pressure or being frustrated and unhappy with caring. It does not mean that you are a 'bad' person or that you want to harm the person you care for. If you are able to, it is always best to talk about the situation with someone you trust, such as your doctor or social worker. This is not always easy, as you may feel too ashamed or guilty to talk honestly about what is happening. If this is the case then don't worry. You can always take things in stages:

I first talked to a worker at the community centre. It took me months to actually get around to talking about the violence ... I started by just saying that I was finding it difficult to cope and that I was worried about taking things out on her.'

'What are carers' groups?'

There are many different types of carers' groups all over the country. At its most basic, a carers' group is somewhere that carers can meet together to talk and share their experiences and problems. The group will often help to find someone who can look after the person you care for, so that you can go to the group. As well as being able to talk to other carers, some groups can

also be more active by helping carers to get services or even by campaigning for a better deal for carers.

Unfortunately there are not many Asian carers' groups and if you do not speak English it may be difficult for you to find a group that meets your needs. But don't let this put you off. You can find out about local carers' groups from your social services. If there is no local group that meets your needs, you can ask social services to put you in touch with other Asian carers or to help you to start your own carers' group.

Coping with difficult behaviour

Caring for an elderly person can be hard work, especially if you also have to cope with unusual or difficult behaviour:

'She asks me the same questions over and over again.'

'He gets really mad sometimes and bangs his head on the wall, two or three times.'

Before he had the stroke he was always very gentle. I was shattered when one day for no reason he tried to hit me with his walking stick.'

'Sometimes he just does his toilet on the floor.'

Such behaviour is often a part of the medical condition of the person you care for and has nothing to do with you or your relationship to the person. This can be particularly hard to understand and accept if the behaviour is directed at you.

Even though there may not be a 'cure' for such behaviour, it is important that you talk to your doctor about what is happening. This will ensure that the person you care for receives proper medical attention and it will also help you to understand the behaviour.

Some carers find that, even though they may understand the behaviour, it still can annoy, anger, embarrass or hurt them. You may feel unable to do certain things such as go out with the person you care for or invite friends to your home:

It was just too much worry to have friends visit us. I would be on a knife edge all the time not knowing what she might say or do.'

Some carers try to cope with this by warning people that the person they care for can sometimes do or say unusual things. Many carers find their own way of handling difficult situations:

I only tell people that are important to me, otherwise I usually try and make a joke out of it or I just talk loudly over her so that they don't hear what she is saying ... We all have a laugh about it when they have gone.'

Coping with violence

'She started by getting angry about nothing or saying that I had done something bad. She went through different stages, throwing things, shouting and then trying to hit me.'

Try not to react with violence or anger – it can sometimes make the situation worse. If you think that you are in danger, get yourself out of the situation as soon as you are able to.

It often helps to try and take the person's mind off what they are doing. Take them into another room, start talking about something else or get them involved in doing something else.

5

Racial discrimination and violence

This chapter is about how you can sometimes be treated badly because you are Asian. It looks at:

- what you can do
- where you can get support
- how you may be able to use the law to help you

The first part of this section looks at what you can do about individuals and services and the second part looks at violence and abuse that you may suffer because you are Asian.

'It is not always that easy to do something about it.'

There have probably been many times in your life when you have been treated badly because you are Asian. You have also probably noticed how others, such as African or Chinese peoples, often experience the same thing. Being treated badly because of your colour or race is often called racism, or racial discrimination, and in the case of violence, racial harassment. Sometimes it is difficult to know whether you have been treated badly because of your race. At other times it is obvious and sometimes even though you can't explain it, you just know.

"The home-help was always quite rude to me as if I was just nothing ... it is not something that I can explain properly in words. I just know in my heart that she didn't like having to work for Black people."

Everybody has their own way of dealing with racist behaviour, but it is important to know that you can take some action against someone who treats you, or the person you care for, badly.

'So what can I do about it?'

If you do want to take some action, there are three main things you can do:

- you can try to sort the matter out directly with the people involved
- you can make an official complaint
- you can ask someone else to take the matter up for you

The experiences of these carers may give you some ideas about what you may be able to do:

Mr Ali

Mr Ali is now 70 years old. He is not in good health himself and has been taking care of his wife for more than ten years. Five years ago the Alis had talked to their local Meals-on-Wheels Coordinator and asked for halal meat and Asian food to be a part of the service. They were told that the Council could not start 'giving in to individual likes, otherwise everybody else would be asking for special treatment'. Mr Ali talked the matter over with his local Asian pensioners' group and found out that a lot of other people had also complained:

'We were angry because there are a lot of Asian people where we live and the council were treating us as if we were asking for something unreasonable ... but why should we have to pay for food which most of us had to throw away?'

The group gradually won the support of other local organisations. After eighteen months of hard work, writing letters and going to meetings with the council, Asian meals were introduced as part of the Meals-on-Wheels service.

Davinder Kaur

Davinder helps her mother look after her father who had a stroke two years ago. When Davinder's father was first admitted to hospital after his stroke one nurse was particularly unhelpful to the family:

I think I had just had enough of her that day ... then she got annoyed with my mother for massaging my father's head and she shouted at my Mum "Why are you touching him? All you Asian women mollycoddle your men". That was it. I took her aside and told her really calmly to keep her racist comments to herself otherwise I would make a complaint about her. She started trying to say that she didn't mean anything by it and all that rubbish. She was all meek and mild after that and went out of her way to be helpful, sickening isn't it?"

'I took the matter up, they listened very carefully, but nothing has changed.'

Sometimes when you take matters up with workers, managers or community groups, they are understanding but you still do not get the results you want. In these cases the best advice is to 'go to the top' and take the matter up with politicians or specialist organisations. This can take up much time in telephoning people or writing letters. It is often a good idea to get the help of a good advice or community centre.

Organisations that are experienced in dealing with racism are:

- Your local Community Relations or Race Equality Council (see page 63)
- Your nearest Commission for Racial Equality (see page 65)
- Your council's Race Unit or Race Relations Unit (not all councils have one, see page 63)

If you contact any of the workers in the above organisations or any others, it might be helpful to keep the following questions in mind:

- What can be done about my case?
- What help can you give me? What are you not able to do for me?
- 'Can we draw up some sort of "plan" with all the different stages of what might happen and how much time it should all take, so that I know what to expect?'
- 'Can you keep me informed about what is happening?'

Racism and the law

It is often quite difficult to prove racism in the courts, but in many cases the threat of using legal powers can be enough to get what you are entitled to. The name of the law that exists to try and stop certain forms of racism is the Race Relations Act of 1976.

You can get advice about your rights under the Act from either your local Community Relations or Race Equality Council (see page 63). If you do not have a local Community Relations or Race Equality Council then you should contact the Commission for Racial Equality which is listed on page 65. If you do not speak English you should ask someone else to telephone the organisations for you first, as they should be able to arrange an interpreter for you, or put you in touch with a worker who speaks your language.

Racial harassment

I don't know the names of the boys who do it, but they throw rubbish in our garden, and make fun of the way we dress and talk. They are only little but I get really frightened when I come around the corner and I see them.'

Racial harassment can take many forms, including verbal insults, abusive letters, physical violence or the threat of violence to you, your family or your home. It can unsettle you and make you feel afraid and unsafe.

Racial harassment can be particularly frightening if you are looking after an elderly person who is ill or disabled. You may worry that they might not be able to defend themselves, or get away in a hurry. As you both have to spend a lot of time inside the house you may feel 'trapped' within your own home, or unable to relax in what should be a safe place.

Organisations and people that can help you

Although it might seem that you are alone or that racial harassment is only your problem, help is available specifically for those people who are suffering racial harassment. The main agencies who can help you are listed in the table opposite.

If you go to anybody for help you should make two things clear:

- that you have been subject to abuse or violence because of your race
- that you have someone living with you who is elderly and ill or disabled

This information could make a difference to how your case is treated.

Who you can go to	What they can do
Council housing department	If you are a council tenant
	 repair any damage quickly make your house secure move you to another house take the attackers to court
	If you are not a council tenant
	Give you general advice about what you can do and tell you about other organisations that can help
Council social services	Refer your case to another organisation that can help
	Help you with your case
	Make arrangements to ensure that the person you care for is kept safe
Your councillor/MP	Take your case up with council departments, the police and community organisations
	Give you advice
Community/Advice/ Law Centres	Give you advice and take your case up with the council or police
	Give you any practical support you might need
The Commission for Racial Equality	Give you general advice and legal advice
	Put you in touch with local organisations
The police	Try to find the attacker(s)
	Start legal proceedings against the attacker(s)
	Give you advice about making your home safe

If you don't get the help you want from an agency, don't give up. Take the matter further. Complain to managers about how you have been treated, go to your councillor or MP, and remember that you do not have to take 'no' for an answer. Most acts of racial harassment are against the law and you should be taken seriously. A young girl, for example, whose family had suffered many incidents of violence and abuse finally wrote to the Prime Minister and the national newspapers asking for support.

'What should I do in an emergency?'

If you or your family or your home are in danger ring the police on 999

If you or any members of your family have been injured, however slightly, get some medical attention as soon as possible. It is important to get medical attention not only for the sake of your injuries but also because doctors' reports can help to support your case with the council, police and other agencies. Tell the doctor exactly what happened to you and make sure that this information is written down on your notes.

'Can I get any compensation for what happened to me?'

If you have been injured as a result of a violent attack you may be eligible to get compensation from the Criminal Injuries Compensation Board. If you have not reported the incident to the police your case may not be considered for compensation, but it is always worth applying anyway.

You can make a claim for compensation up to three years after the incident.

Applying for compensation can be quite complicated, so it is best to ask an advice centre or law centre to do this for you. Local Victim Support Schemes are also experienced in applying for compensation. You can find out about your local scheme from an advice centre or a local police station.

If you want to apply for compensation yourself you can get information and an application form (in English) from:

The Criminal Injuries Compensation Board Whittington House Alfred Place London WC1E 7LG Tel: 071-636 9501

6 Housing

This chapter looks at:

- how you can use special equipment to help you care for someone at home
- how to get help and expert advice on making any changes to your home
- how to get help with keeping your home in good condition
- where to get advice and help with housing problems

Making your home a more comfortable place

It is only when something like this happens to someone close to you that you start to notice things, like how steep the stairs are and how dangerous the glass doors are. It makes you look at your home and other places with different eyes.'

For many disabled people and their carers everyday things, like climbing the stairs and using the toilet, are big problems which need a lot of time and organisation. If you find it difficult to look after the person you care for in your home as it is at the moment, there are basic steps you can take to make things easier, without moving house! You can buy, borrow or hire special equipment to help you and the person you care for (for example, stair lifts or walking aids). You can also make actual changes to your home.

Finding out about equipment

If you want to find out about free or cheap equipment or about borrowing or hiring, you can ask for information from:

- your council social services department, your social worker or your occupational therapist (if you are in contact with one)
- the hospital or day centre which the person you look after goes to
- your doctor, health centre, health visitor or district nurse

Special organisations

You can also try getting in touch with some of the specialist organisations that do work around a particular disability or illness (see below) who may be able to give you advice about equipment and other organisations. Arthritis Care, for example, have set up a free telephone helpline to give advice to arthritis sufferers and their carers on many different subjects such as equipment, diet and welfare benefits. For free advice for people with arthritis call freephone: 0800 289170 (between 2 pm and 5 pm).

Buying equipment

Some organisations sell equipment for disabled people. Many of them produce catalogues which you can look at before you make a visit. If possible, take the person you care for with you when you visit an organisation so that they can try out some of the equipment for themselves.

Some of the main organisations to contact are:

The Disabled Living Foundation 380–384 Harrow Road London W9 2HU Tel: 071-289 6111

The Royal National Institute for the Blind 224 Great Portland Street London W1N 6AA Tel: 071-388 1266 ask for the Resource Centre

The Royal National Institute for the Deaf 105 Gower Street London WC1E 6AH Tel: 071-387 8033 The Breakthrough Trust Charles W. Gillett Centre Selly Oak Colleges Birmingham B29 6LE Tel: 021-472 6447

* The Breakthrough Trust offers a free advice service for people who are deaf or have hearing difficulties.

Borrowing and hiring equipment

If you cannot buy your own equipment or if you are waiting for equipment to arrive, you can either borrow it free of charge or hire it. Organisations that can provide this service are:

- your local hospital ask if the hospital has a Medical Loans
 Department. If they do not have one, ask to be put in touch with
 the Occupational Therapist.
- The British Red Cross you can find your local branch in the phone book or by ringing Directory Enquiries (dial 142 or 192). When you get through to the organisation ask for details of their medical loan service.
- The Electronic Aids Loan Service this is a national agency which provides free advice and information on electrical equipment for disabled people. They will let you borrow any suitable equipment free of charge. You can get information about the service by sending a stamped addressed envelope, 9 inches by 4 inches to:

Electronic Aids Loan Service Willowbrook Swanbourne Road Mursley Bucks MK17 0JA Tel: 029 672 533

Making changes to your home

Although special equipment can make a big difference both inside and outside the home, you may sometimes need to make more permanent changes to your home. Examples of such changes are:

■ grab rails fitted to walls to help with walking, balance, getting in and out of the bath or standing up and sitting down

Call for Care

- a mechanical chair lift to take someone up and down the stairs
- a ramp instead of a door step, so that a wheelchair can get in and out without trouble

The best people to contact about making adjustments to your home are:

- your social services department or social worker
- your occupational therapist (if you have one)

There is also a national organisation which can give you free advice about making suitable changes to your home:

Centre on the Environment for the Handicapped 35 Smith Street London SW1P 3BJ Tel: 071-222 7980

If you are a council tenant the council should make any necessary changes to your home free of charge. Don't make any changes to your home without the council's knowledge.

Keeping your home in good condition

The biggest problem is with the house, it is on two levels and it is very difficult to get to the toilet which is outside. We do not have heating fixed for the whole of the house.'

We've got cockroaches everywhere. We cannot eat or cook, they fly off from everywhere; the cupboards, the kitchen, everywhere.'

'We can't do anything about the house because we have not got any money. That is the problem when you own your own house; there is no one to help you.'

There is no reason why you should put up with unhealthy or dangerous housing conditions. Even if you own your own home you can still get help to put your home in order. When you ask for help, always make it clear that you are caring for someone who is ill or disabled as this can give more importance to your case.

Council tenants

The council is only responsible for conditions that they have been told about, so it is important that you:

keep a record of any telephone call or visit that you make to the council to report something that has gone wrong

- put any complaints or requests in writing if possible, and keep a copy of the letter
- keep any items that have been damaged and also the receipts, if you have them

If the council still does nothing after you have contacted them and given them a reasonable time to respond, you should:

- contact an advice or community centre
- if you have a good Tenants' Association ask them to help you
- take the matter up with your councillor or MP

Housing association and private rented houses

If you live in a housing association property that is in need of repair you should let the housing association know as soon as possible (follow the advice above to council tenants about reporting bad conditions).

If you are living in private rented accommodation it can be difficult to get your landlord to do repairs and the action you can take will depend upon whether you are a 'protected tenant'. You should never take any action until you have found out what kind of tenancy you have. If, for example, you are not a protected tenant you could face eviction, so be very careful. The landlord is only responsible for conditions that she or he is aware of, so follow the advice above to council tenants about reporting bad conditions.

If your problem is not sorted out:

- get advice from a local community or advice centre
- contact your environmental health officer at your local council. It is part of his job to inspect houses and make sure that they are in good condition.

If you own your own home

A big worry for many home owners is finding the money to repair and keep their home in good condition. If you have very little money coming in and you cannot afford the upkeep of your house, you can apply for money to help you. The main options open to home owners are:

applying to their local council for a Home Improvement Grant. You
can get more details about it from your council's housing
department or ask at your council's main telephone switchboard
for the department that deals with Home Improvement Grants

- applying to the Department of Social Security for a Community Care Grant which you can use to pay for small repairs. People who are sick or disabled are supposed to be given priority when the grants are decided. You can apply for the grant by getting Form \$\mathbf{s}\mathbf{300}\mathbf{0}\mathbf{0}\mathbf{0}\mid hich is available from your local social security office or advice centre.
- applying to your bank or building society for a loan to do the work (before you do this you should seek help from an advice centre)

In some areas of the country, there are 'Care and Repair' schemes which give elderly home owners free help by:

- identifying the work that needs doing and finding a good builder
- getting council grants or loans from building societies
- getting quotations, placing orders and keeping a check on the work that is done

To find out about whether there are any special schemes like this in your area, it is best to contact your council housing department, a housing aid or advice centre or a Citizens Advice Bureau.

Getting advice about housing problems

Information on housing can be quite complicated and the information that you will need depends on the kind of accommodation that you live in. There are, however, many agencies that can help and advise you about housing problems.

Wherever you go always let them know that you look after an elderly person who is disabled or ill. This is because certain agencies will come to your home to help you if they know that you are a carer and also because you and the person you look after might be eligible for special housing provisions.

For help and advice you can go to:

your local Council Housing Department – you do not have to be a council tenant to get information and advice from your council's Housing Department. Even if they are not able to help, they should be able to give you details of a local organisation who can.

your local Housing Aid or Housing Advice Centre - These centres mainly deal with people who live in private rented homes (paying rent to a landlord) or people who own their own homes. Your local Council Housing

Department will be able to tell you if there is a housing aid or advice centre near you. You may also be able to find out about one from the 'Community Information' pages of your Thomson's Local Directory under the 'Looking For Advice' section. You could also try telephoning Directory Enquiries and asking for the telephone number (dial 142 or 192).

your local Citizens Advice Bureau or Advice Centre (see page 63 on how to find out about your local centres).



7

Welfare benefits

This chapter looks at:

- where you can get advice and help with claiming benefits
- how to claim benefits
- what you should do if you think a wrong decision has been made about your benefits
- brief details about the main benefits

'What are welfare benefits?'

Welfare benefits are a system of Government payments made to some people who are in need of extra money to live on.

Finding out about benefits and claiming them can be quite daunting and confusing. In fact there are thousands of people who are not claiming money that they are entitled to.

This chapter gives you details of most of the benefits that you and the person you look after may be able to claim. It is important to point out, however, that there is no general 'right' to claim benefits. You can only get some benefits if you have paid enough National Insurance contributions, and your immigration status can also affect whether you get any benefits. An advice centre will be able to tell you if you are entitled to claim benefits.

'Where can I get advice about benefits?'

There are many organisations where you live that help people to claim their benefits. If you can speak English you should be able to get free and

confidential help from any of the organisations below, or you can try telephoning the Department of Social Security advice line which will give you free advice about any of the benefits. If you cannot speak English it is best to find either an Asian community centre or Asian worker in an organisation (see page 64) who can help you.

There is good news for those who speak Urdu and Punjabi because the Department of Social Security has set up telephone lines where you can get free advice about claiming any benefits. The numbers are:

DSS Free Telephone Advice (the lines can be quite busy so if you get an engaged tone keep trying)

For English speakers: 0800 666555 For Urdu speakers: 0800 289188 For Punjabi speakers: 0800 521360

Local organisations which may be able to give you advice about benefits are:

- local Citizens Advice Bureaux and advice centres (see page 63)
- law centres (see page 64)
- local community centres (see page 64)
- local social services (see page 63) or your social worker

A booklet called *Which Benefit?* produced by the DSS provides more information about all the benefits and tells you who can get them. The booklet is also produced in Bengali, Gujarati, Hindi, Punjabi and Urdu. You can get a copy from your local DSS office or advice or community centre.

'I just don't feel right about asking for money.'

Even though the whole system of welfare benefits exists to help people, many people still feel uneasy or unhappy about claiming money that they are entitled to:

I don't like to apply for money. Some people say that I should apply, but I don't. I'm not a beggar. I'm not greedy.'

I never ask for anything, especially money. I don't like to ask.'

Even if you feel unhappy about having to apply for benefits, you should try to think of the benefits system as a service, like a hospital or a doctor, that can meet some of your needs. It is not 'greedy' or 'bad' to apply for money that can make a difference to your lives just as it is not 'bad' to get treatment

when you are sick. Rather than being 'hand outs' to 'beggars', welfare benefits are paid for by you and your family through taxes and National Insurance and so belong to you. As one carer put it:

I don't think that anyone feels really all right about claiming benefits. I got myself into a state thinking about it ... but at the end of it all I knew that I owed it to myself and my mum to try and make our lives as good as possible. Anyway benefits aren't given to us as a favour are they? They are there because we need them.'

'How can I claim a benefit by myself?'

If you feel confident about claiming a benefit either for yourself or the person you look after, you can get claim forms from your local post office, advice or community centre or local social security office. For some benefits you do not need a claim form and the Quick reference section (pages 42–46) will tell you about this.

You will need some basic information for most of your claims and it is a good idea to keep all this information together either in a folder or written down in a book. The information includes:

- your date of birth and the date of birth of the person you look after. If you do not know your exact date of birth you can give the date in your passport(s)
- your National Insurance numbers
- your doctor's name and address
- details of any other benefits that you and the person you look after are receiving, including the name of the benefit and the amount of money that you receive

'I don't know how they work out what money I get.'

If you would like to know more about how your money is worked out you can ask your local social security office to give you written details about your benefits. If you don't speak or read English you can ask an advice or community centre to help you get the information that you want.

Leaflet **N 196** (in English) will give you details of the different rates of payment for benefits and will also tell you how benefits are worked out.

'I'm sure they have made a mistake about my money.'

You have the right to challenge many of the decisions that are made about your benefits.

There is a system of appeals for people who think a mistake has been made about their benefits. Appeals are a part of the benefits system, so you won't be causing anyone trouble by asking for your case to be looked at. It often pays to be persistent if you think a mistake has been made, and people who do appeal often get what they asked for.

As the appeal system can be complicated, it is worth getting help from an advice or community centre. The main points to bear in mind are:

- you should appeal about a decision within three months (although you can sometimes appeal outside this time)
- you have to say in writing that you want to appeal. If you cannot write you can ask someone to write the letter for you
- you have the right to be told how the decision about your benefit was made
- you may need to give the social security office some extra information; for example, a letter from your doctor

If you can read English, leaflets **NI 246** How To Appeal and a more detailed leaflet **NI 260** A Guide To Reviews And Appeals will give you more information about appeals. The leaflets are available from your local social security office or an advice or community centre.

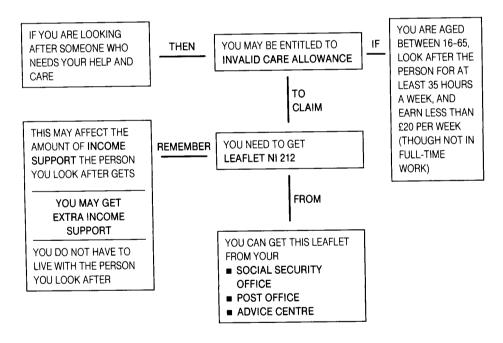
'What benefits may we be able to get?'

The Quick reference section (overleaf) will give you an idea about the benefits you and the person you care for may be able to claim. It also tells you how to get claim forms to apply for the benefits. If you want any more information or help get advice (see page 63).

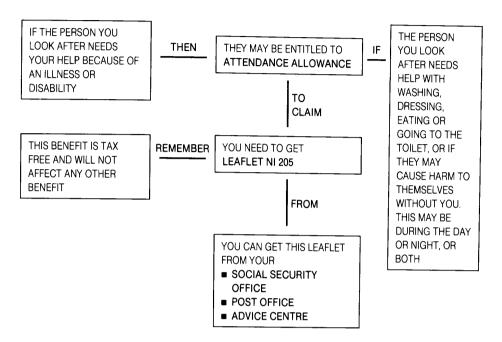
Quick reference section

These are not all of the benefits that you may be entitled to. If you want more information about all the benefits available read the DSS Which Benefit? leaflet, which is also produced in Asian languages (see page 39). If you cannot read get advice from an advice or community centre (see page 63).

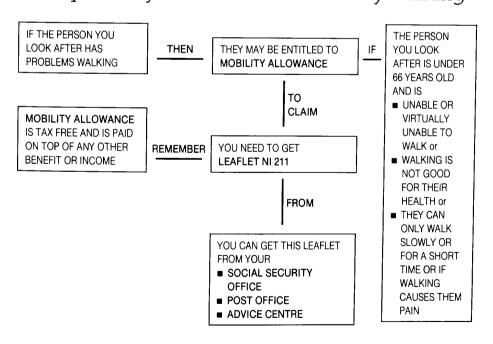
If you are caring for someone who is ill or disabled



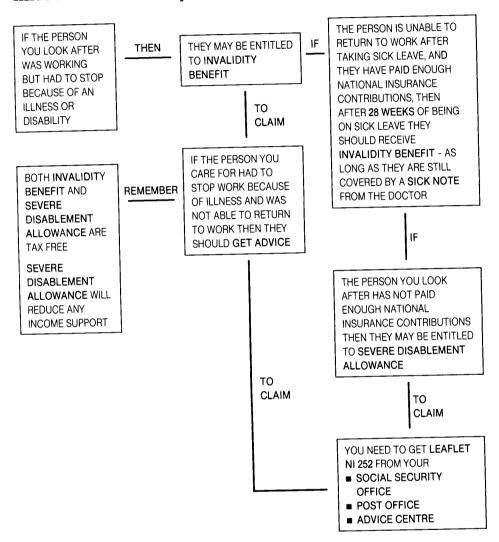
If the person you care for needs a lot of looking after



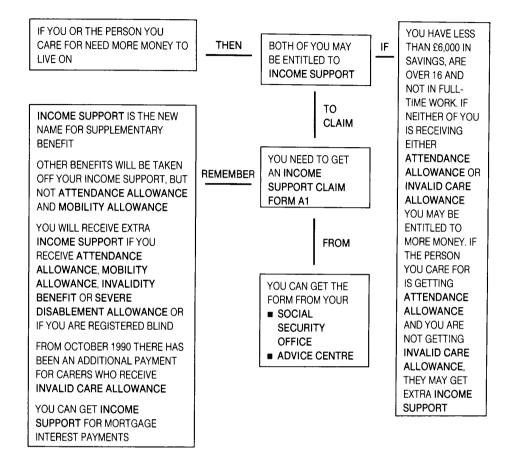
If the person you care for has difficulty walking



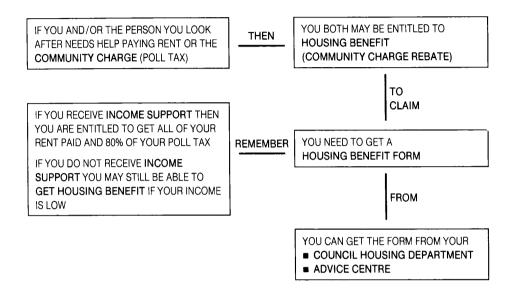
If the person you care for is under 65 years of age and has had to stop working because of an illness or disability



If you cannot manage to live on the money you have



If you and/or the person you care for needs more money to help pay the rent or Community Charge



8

Going home

This chapter is about going to your country of origin and looks at:

- immigration matters
- benefits while you are away
- medical treatment when you are in another country
- your housing rights when you leave the country
- travelling in the plane with the person you look after

It is my mum's dream to live in Pakistan again, she thinks that we will get a lot more help there.'

I went to India with my husband, we wanted to settle there ... we only stayed for two years. It was different for us going back after so long, there was nothing for us there.'

Even though Asian people have a right to live, work and stay in this country, it is often the case that your country of origin will always remain 'home' to you. 'Going home' is an issue that is close to the minds and hearts of many Asian carers and the people they look after. However, there are also many emotional and practical issues to think about.

'I'm thinking about taking her home for good.'

Caring for someone can be hard work, and you may feel lonely, particularly if you have few friends and relatives near you to give you help and support. It can be more difficult if you do not speak English or you do not know where

Call for Care

to go for help. Because of such difficulties some Asian carers and the people they care for think about returning to their country of origin.

'At least in Bangladesh all the family can help to look after him. We always help each other with everything, babies, children and with the old people.'

Before you make any decisions it is a good idea to think seriously about the everyday reality of looking after someone in your home country. For example:

- Are your friends and family willing to help you with caring?
- Where will you live?
- Will you have enough money to live on?
- Will you have to get any special documents before you are allowed to live in your home country again?
- Will the person you care for be able to get medical treatment for their condition?

It is best not to make a firm decision without careful consideration. Some carers have tried things out by going home for a couple of months before making a final decision. Going for a short period of time is also a good idea because you won't have to lose out on all your welfare benefits or give up a council or housing association house.

Whether you go home for a short stay or you go for much longer, there is some basic information you should be aware of.

'Do we have to get special permission to go to the country?'

If you have a British passport you may have to get a visa or an exemption stamp in your passport before being allowed into your home country. Depending upon how long you stay, you may have to renew your visa after a certain period, for example, after six months.

You should never buy your air tickets without checking whether you need any special documents.

Even if you have the passport of your home country always check first whether you need any special documents. You can get advice on this and issues to do with a British passport from your local advice centre. You can also try contacting your home country's embassy or consulate in this country. You can find out the address and phone number of your embassy from an advice centre or by telephoning Directory Enquiries on 142 or 192.

'Will we still be able to get our benefits when we are away?'

This will depend upon how much National Insurance contributions you have paid and how long you are away. If you are leaving this country permanently you will usually only be entitled to your pension. Working out what you are entitled to can be complicated so it is best to ask an advice centre to help you. You can also get free advice from the social security freephone numbers for English, Urdu and Punjabi speakers:

For English speakers: 0800 666555 For Urdu speakers: 0800 289188 For Punjabi speakers: 0800 521360

If you can speak English you can also get advice from:

DSS Overseas Branch Newcastle upon Tyne NE98 1YX

Some important details about the main benefits are:

Pensions

Retirement and a Widow's Pension can usually be paid to you anywhere in the world. You can ask your local social security office about arrangements for the payment of your money; for example, it can be paid at your address in your home country or to a bank or building society in this country.

Invalid Care Allowance

You can get this benefit if you are only leaving the country for a short period. You should let the social security office know that you are going away and send your order book to:

ICA Unit, DSS
Palatine House
Lancaster Road
Preston PR1 1HB

Attendance and Mobility Allowance

You can get both of these benefits if you are out of the country for less than

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six months. You should write and let the social security office know if you are going away for longer than four weeks. You should write to:

Attendance Allowance Unit or Mobility Allowance Unit Norcross Blackpool FY5 3TA

If you can read English, leaflet **NI 38**, Social Security Abroad, will give you details about how leaving the country may affect your benefits. The leaflet should be available at your local social security office or advice centre.

If you are in any doubt you should get advice before you write to the social security office.

'What happens if she gets ill when we are away?'

One of the most important things to bear in mind when you are going home, particularly if it is for a long time, is what will happen if either of you needs medical treatment while you are away.

Before going there are a number of things that you should do:

- tell your doctor where you are going and for how long
- ask your doctor for a check-up for you and the person you care for
- make sure that you have enough medicine for your stay (although this would not be possible if you are going to live in another country)
- ask the doctor to write down the name of any illness and the name of any medicine you are given; take this with you when you leave the country
- if the person you care for has to attend a hospital clinic, tell the hospital doctor about the details of your trip

You should also consider the fact that while you are away you will have to pay for any medical treatment you may need. You may be able to get private medical insurance from an insurance company. Your local advice centre can help you with this. You should always get the insurance before you leave this country.

'What will happen to our house when we are away?'

If you are living in a council or housing association house, you may have to give up the house if you are out of the country for a long time. This will not be the case, however, if other members of your family are still living in the house while you are away. As different councils have different rules about how long you can be away from the country and still keep your house, it is best to find out what the rules are in your area before you make any decision.

'I am a bit worried about making the travelling arrangements.'

If the person you care for is in poor health or has a physical disability, travelling a long distance by air can be worrying. There are, however, a number of things you can do to make the journey easier. If you can read English, there is a good, free leaflet called *Care in the Air* which gives advice to travellers who have a disability. It is available from:

The Air Transport Users Committee (AUC) Kingsway House 103 Kingsway London WC2B 6QX Tel: 071-242 3882

Some of the main points recommended by the leaflet are to:

- let the airline know, when you are booking your tickets, that you are travelling with someone who is ill or disabled. Tell them what help you will need in the plane, at the airport and at any stops in your journey
- make sure that the person you care for has the necessary medical clearance to fly; for example, a card signed by your doctor
- make sure that you will be able to manage with the toilets on the airplane or take something that will help you; for example, a urine bottle
- the day before you are due to go, check again with the airline that they have your details

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make sure that you arrive at the airport in plenty of time. It is usual for airlines to ask disabled people to check in earlier than other passengers

If you want to get more expert advice about air travel and the disabled you can contact either the Disabled Living Foundation (see page 32) or the Holiday Officer at the Royal Association for Disability and Rehabilitation (see page 69).

9

Death and dying

This chapter looks at:

- what you can do if you are looking after someone who is dying
- arrangements that can be made before death
- what to do if the person you care for dies
- coping after the person you care for has died

'I don't like to think about it.'

It is never easy to think about death and dying. Yet when you are caring for another person it is important to think about the future. In practical ways it can help to bring some security into both your lives. It is possible, for example, to ensure that your money is spent on providing care for the person you care for if you should die before them. If you live in a council house which is in the name of the person you care for, it is also possible to ensure that you can still live there after their death.

Fortunately many of the arrangements you can make before death are quite straightforward and there are also experts to do any hard work for you. Once you have made arrangements you can put them to the back of your mind and get on with other things. You will probably feel quite relieved and even pleased with yourself for being so organised:

'Once I had made a will, it was a great load off my mind. I felt really proud of myself for getting it all taken care of.'

'I've been told that she is dying, what can I do?'

If the person you care for is dying, you will both need a lot of support. Talk to people about how you feel and also ask for any help you need. Many carers find that their doctor is the best person to start with. She or he will be able to tell you about local support and services available for both of you. Your social worker can also be a good source of support. Examples of services that can help you are:

Help in the home

There are Home Care Teams and Hospital Support Teams of nursing staff, who can give you help with looking after someone who is dying. There are also special nurses called Macmillan Nurses who can give help to people with cancer and their families. These services are usually free and you can find out about them from your doctor, social worker, hospital or community nurse.

Special hospitals for people who are dying (hospices)

A hospice is a hospital that only cares for people who are dying. Hospices can also sometimes take people in for short periods of time to give their carers a break. The Hospice Information Service (see page 68) or your doctor can give you details about local hospices.

Getting organised

When someone dies there are always official arrangements that need to be made. It is a good idea, therefore, to make sure that any important documents are easy to find. The main details and documents that are needed are:

- a will, if there is one
- National Insurance card
- passport
- bank and any savings books
- insurance policies
- details of any welfare benefits received

Legal arrangements

A will (to do with property and money)

A will is a document which records a person's wishes to be carried out after their death. It is mostly used to pass on property or money to other people. It is always best to make a will, to ensure that any property and money are passed on to the right people. Wills can also help to avoid problems and ill feeling after a death. Because it is a legal document it is best to get advice about making a will either from a solicitor (see page 64), law or advice centre.

Assignment (to do with rented housing)

If you live with the person you care for in a privately rented, council or housing association house it is important that you know in whose name the tenancy is. To avoid any problems it is best to try and have your name included on the tenancy. If this is not possible you may be able to get a legal agreement, called an 'assignment', which will entitle you to inherit the tenancy. As you cannot draw up an assignment yourself you should go to an advice or community centre for help.

'What should I do if he dies?'

It is impossible to be fully prepared for death. Even if you know someone is going to die, it does not make it any easier to cope:

I knew for months that he was dying, but I wasn't ready for it when it happened. I just couldn't believe it, it was like it was all happening to another person and not me.'

Unfortunately, as well as having to deal with your own feelings, you may also have to take responsibility for making funeral and other arrangements. Don't worry too much about making mistakes; there will always be other people who can help you. Many Asian carers find that their Mosque or Temple can be very helpful at the time of a death. Even if you do not formally practise your religion, you may still be able to find help and understanding.

Practical arrangements that need to be made after a death are:

- a medical certificate has to be given by a doctor
- the death has to be registered within five days
- a funeral needs to be arranged

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Free leaflets in English from your local social security office will give you more details about what you should do. The leaflets you need are **D49** What to do after a death and **F29** Help when someone dies.

Organising a funeral

If the person has made a will, it is important to get a copy of it before the funeral is arranged. This is because some people leave instructions in their will about what they would like to happen to their body.

Your local Mosque or Temple will be able to advise and help you with arranging a traditional funeral. In other cases you should contact a funeral director. If you do not know a good funeral director, it is best to ask the doctor for advice about who you should contact. It is always best to ask for a written estimate of how much the funeral will cost. Funeral directors who are members of the National Association of Funeral Directors have to offer a simple funeral at a low cost.

If you receive either Family Credit, Income Support or Housing Benefit, and you are unable to pay for the funeral, you may be able to get a grant from the Social Fund. The grant will meet the cost of a simple funeral and an extra payment can be made to cover the cost of any religious requirements. Contact an advice centre for more information.

Arranging for the body to be taken to another country

Arranging a funeral in another country can be difficult without proper help and it is also expensive. You can get further advice from your Mosque or Temple, who usually have their own funeral directors and services. The funeral director will usually make the legal arrangements for taking the body out of the country.

'What should I do about her money and property?'

If there is a will the named executor will deal with the dead person's property. Before an executor can do anything, she or he will usually have to apply for a Grant of Probate. If there is no will, close relatives of the dead person can apply for a Grant of Letters of Administration which will allow

them to deal with the dead person's property. Whichever grant you are applying for the forms are the same and you can get them from:

The Probate Personal Application Department Principal Registry of the Family Division 5th Floor, Golden Cross House Duncannon Street London WC2N 4JF Tel: 071-214 3015 or 214 3116

'How can I manage without her?'

I used to think about what it would be like when he died. I thought I would feel relieved... You do feel as if a weight has been lifted from you but you also feel like a part of you is missing.'

'All the neighbours and our friends were so good. They brought food to the house and stayed with me... our people are so good at those times.'

Carers' feelings of grief and loss are special and different. Carers often say that caring for another person brings both people a lot closer to each other. It is common for a carer's whole life to be wrapped up in the life of the person they care for. This means that the death of the person you care for not only affects you emotionally, but can also completely change your day-to-day life.

No one will be able to tell you exactly how you will feel or what you should do, because your feelings will be unique to you. It is important to recognise that there is no one 'right' way that you should feel at any time. Some people feel grief immediately, for others it is a feeling that comes out over a period of time. Some are able to talk about their feelings freely, others find it too difficult. Feelings also change with time so it is best to just trust your own feelings and do what feels right for you.

For many Asian carers grief is something that is also a community issue; religious ceremonies and customs of sharing grief can be an enormous help. However, your feelings may not come out at periods of mourning, and you may need more support. It can be difficult if you do not know other Asians where you live or you do not have friends and relatives near you.

Carers' groups (see page 22) can be a good source of support when the person you have cared for has died. Carers' groups often have contact with people who used to be carers and who will understand what you are going through. If you particularly want to talk to another Asian person you should try contacting your Mosque, Temple or Asian community centre. If you can

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speak English and you would just like to speak to someone about how you feel there are services that can give you support. For example, CRUSE (see page 67) is a group that gives support to husbands, wives and children. Your advice or community centre and doctor should also be able to tell you about any local groups that can help you.

10

When all else fails

'I've tried so many things and nothing seems to work.'

You may be one of the many Asian people who know a lot about services in your area and know exactly what you and the person you look after need, but you just can't seem to get it. You may have done 'everything by the book', contacted social services, gone to your community centre and yet you still feel unhappy about the response you have received.

If you feel dissatisfied about any services you receive, whether from your GP, social services or hospital, there are a number of things that you can do:

- try to identify what you are unhappy about
- you should always try to approach the person who provides the service and tell them what you are dissatisfied with and what you would like. This can be difficult if the person concerned is your main problem or they are rude and unhelpful.

You can also ask them to suggest ways of how you might be able to solve your problem or if they know of any alternatives you can try.

if you are not getting anywhere with one person, try and get some independent advice or get someone else to take up the matter on your behalf. The best people to contact are:

Citizens Advice Bureau or Advice Centre

(See page 63.)

Community Relations or Race Equality Council

If you feel that because you are Asian you have been treated badly, or have been denied the services to which you are entitled, you should contact these organisations. They were specifically set up to help people who have been treated unfairly because of their colour or race (see page 63, about how to contact them).

Community Health Council

This agency represents the interests of local residents, including the problems they are having with any health services. They have had much experience of dealing with complaints and will advise on how to get what you need from health services. Your doctor, social worker or advice centre will be able to tell you how to contact your local Community Health Council.

Family Health Services Authority

These organisations are also concerned with health services and deal with issues relating to GPs, dentists and opticians. If you want to make a complaint to your FHSA you should do so, preferably in writing, within thirteen weeks of what happened. If you are not sure about whether to make a complaint, or if you cannot write, you can ask someone at the FHSA for advice. You can find out the address of your local FHSA from your library or GP.

Your local councillor

If you have a problem with council services such as social services, council day centres or Meals-on-Wheels, you can discuss the matter with your councillor. Your councillor can also give you advice on many other problems. Councillors usually have advice sessions where you can go without an appointment to get free and private advice. You can get details about your local councillor from your town hall or an advice centre.

Your MP (Member of Parliament)

It is usually best to take a matter up with your MP only after you have been to your local councillor or advice centre. Like councillors, MPs also have advice sessions for local residents. Take along any letters or documents that are relevant to your problem or attach copies to your letter. Your town hall or an advice centre will give you details about your MP.

Your Ombudsman

An Ombudsman is an official who has powers to look into complaints about different local services. There are different Ombudsmen for different types of complaints and the services are free and confidential.

The Ombudsman should be used as a last resort after you have tried other ways to sort out your problem.

The three main Ombudsmen you are most likely to need are:

The Local Ombudsman – looks into complaints about local councils. Before you go to this Ombudsman you should have gone to a representative of the council (a council officer); then to your councillor and if you are still unsatisfied you should ask your councillor to pass the matter on to the Ombudsman. You can get details about this Ombudsman from:

The Commissioner for Local Administration 21 Queen Anne's Gate London SW1H 9BV

Tel: 071-222 5622

or

29 Castlegate York YO1 1RN

Tel: 0904 30151/2/3

The Health Service Ombudsman – looks into complaints about health authorities. Your complaint should normally reach this Ombudsman within a year from when the matter first came to your attention. However, this time limit is flexible, so if you are complaining late you should explain why.

This Ombudsman cannot investigate a complaint until you have first been to your local Area Health Authority. You can get further details from:

The Health Service Commissioner for England Church House Great Smith Street London SW1P 3BW

Tel: 071-212 0455 or 212 7676

The Parliamentary Ombudsman – deals with complaints about government departments such as the Department of Social Security. You can only take a matter up with this Ombudsman if your complaint is referred through an MP. Information is available from:

The Parliamentary Commissioner for Administration Church House Great Smith Street London SW1P 3BW Tel: 071-212 6271

11

Finding out about ...

This chapter will tell you how to find out about *some* of the main agencies and people mentioned throughout the book. The agencies and people listed should be able to give you more information about your local services.

If you do not speak English you may find it useful to use the letters on pages 9 and 10, which can put you in touch with local services.

Telephone services

If you can read English, your local telephone directory will list most agencies mentioned in this book. Many of the community and council services mentioned can be found in the Thomson's Local Directory in the 'Community Information' section. If you can speak English you can ring Directory Enquiries on 142 or 192 and ask the operator to give you the details of any local or national organisations and services.

Before you get in touch with anyone

Make sure you have the following:

- a list or clear thoughts about what help and information you would like
- information about you and the person you care for, for example, your dates of birth, medical cards etc.

'How do I find a doctor?'

In an emergency you can go to any local doctor (GP). However, it is always best to register with a doctor before you or the person you care for get ill.

Your library should have a list of all local doctors, or you can try to register with any local doctor by going along to the surgery and taking your medical card with you. A doctor does not always have to accept you as a patient, but everyone has the right to be registered with a GP.

If you cannot speak English, your local Family Practitioner Committee or Community Health Council may be able to help you find a doctor who can speak your language.

'How do I find a social worker?'

Social workers are based mainly in council social services offices and in hospitals. A small number work from doctors' surgeries and health clinics. To get in touch with a social worker it is best to contact your nearest social services office. You can find the telephone number in the telephone directory under the name of your local council.

'How do I find an advice centre?'

Some of the most common advice centres are called Citizens Advice Bureaux or Neighbourhood Advice Centres. Your local library should have a list of all local advice centres.

'How do I find my local Community Relations or Race Equality Council?'

If there is a Community Relations or Race Equality Council in your area, the address and phone number will be listed under the 'General Information' section in the 'Community Information' pages of your Thomson's Local Directory. The Commission for Racial Equality listed on page 65 will also be able to tell you how to contact your local Community Relations or Race Equality Council.

'How do I find an Asian community organisation?'

You can get details of any local Asian community centres or organisations from your Community Relations Council or the Commission for Racial Equality (see page 65).

'How do I find a solicitor?'

The best way to find a good solicitor is to ask friends, advice or community centres to recommend one whom they know is good.

You can get free or cheap advice from a solicitor who works in the Legal Aid Scheme. If you are getting Family Credit or Income Support you can get *free advice* under a system that is called the Green Form Scheme.

Some private solicitors provide a first interview where you are given general advice for a fixed fee of $\pounds 5$.

Local Citizens Advice Bureaux, law centres and libraries should have a list of local solicitors in the Legal Aid Scheme and also details of solicitors who offer a fixed fee interview. Ask for the *Solicitors Regional Directory* or *Legal Aid List*.

A quick way to tell if a solicitor does Legal Aid work is to look for this sign in the window or on the door.



Useful addresses

Black and Asian Organisations

Asian Family Counselling Service 74 The Avenue London W13 8LB Tel: 081-997 5749

Asian People with Disabilities Alliance Ground Floor Willesden Hospital Harlesden Road London NW10 3RY Tel: 081-459 5793

Association of Blind Asians 322 Upper Street London N1 2XQ Tel: 071-226 1950

Commission for Racial Equality Elliot House 10–12 Allington Street London SW1E 5EH Tel: 071-828 7022

Ethnic Switchboard 2B Lessingham Avenue London SW17 8LU Tel: 081-682 0216/7

Call for Care

Joint Council for the Welfare of Immigrants 115 Old Street London EC1 9JR Tel: 071-251 8706

London Interpreting Project 20 Compton Terrace London N1 2UN Tel: 071-359 6798

Standing Conference of Ethnic Minority Senior Citizens 5–5A Westminster Bridge Road London SE1 7XW Tel: 071-928 0095

General Organisations

Action for Victims of Medical Accidents Bank Chambers 1 London Road Forest Hill London SE23 3TP Tel: 081-291 2793

Age Concern England Astral House 1268 London Road London SW16 4ER Tel: 081-679 8000

Alzheimer's Disease Society 158–160 Balham High Road, London SW12 9BN Tel: 081-675 6557

Association of Crossroads Care Attendant Schemes Ltd 10 Regent Place Rugby Warwickshire CV21 2PN Tel: 0788 573653 British Red Cross Society 9 Grosvenor Crescent London SW1X 7EJ Tel: 071-235 5454

Cancerlink 17 Britannia Street London WC1X 9JN Tel: 071-833 2451

Carers National Association 29 Chilworth Mews London W2 3RG Tel: 071-724 7776

Chest Heart and Stroke Association 123–127 Whitecross Street London EC1Y 8JJ Tel: 071-490 7999

Counsel and Care for the Elderly Twyman House, Lower Ground Floor 16 Bonny Street London NW1 9PG Tel: 071-485 1550

CRUSE – Bereavement Care 126 Sheen Road Richmond Surrey TW9 1UR Tel: 081-940 4818

DIAL UK (Disablement Information and Advice Lines)
Park Lodge
St Catherine's Hospital
Tickhill Road
Balby
Doncaster DN4 8QN
Tel: 0302 310123

Call for Care

Disability Alliance Universal House 88-94 Wentworth Street London El 7SA Tel: 071-247 8776

Headway (The National Head Injuries Association) 7 King Edward Court King Edward Street Nottingham NG1 1EW Tel: 0602 240800

Health Rights
Unit 110
Bon Marché Buildings
444 Brixton Road
London SW9 8EJ
Tel: 071-274 400 ext 377

Help the Aged 16–18 St James' Walk London EC1R OBE Tel: 071-253 0253

Hospice Information Service 51 Lawrie Park Road London SE26 6DZ Tel: 081-778 9252

Institute for Complementary Medicine 21 Portland Place London W1N 3AF Tel: 071-636 9543

London Dial a Ride Users Association St Margarets 25 Leighton Road London NW5 2QD Tel: 071-482 2325 Motability 2nd Floor, Gate House Westgate, The High Harlow Essex CM20 1HR Tel: 0279 635666

Motor Neurone Disease Association PO Box 246 Northampton NN1 2PR Tel: 0604 22269/250505

Multiple Sclerosis Society 25 Effie Road London SW6 1EE Tel: 071-736 6267

Muscular Dystrophy Group of Great Britain and Northern Ireland Nattrass House 35 Macaulay Road London SW4 0QP Tel: 071 720 8055

Parkinson's Disease Society 22 Upper Woburn Place London WC1H 0RA Tel: 071-383 3513

RADAR (Royal Association for Disability and Rehabilitation) 25 Mortimer Street London W1N 8AB Tel: 071-637 5400

Royal National Institute for the Blind 224 Great Portland Street London W1N 6AA Tel: 071-388 1266

Royal National Institute for the Deaf 105 Gower Street London WC1E 6AH Tel: 071-387 8033

Call for Care

Spastics Society 12 Park Crescent London W1N 4EQ Tel: 071-636 5020

Spinal Injuries Association Yeoman House 76 St James's Lane London N10 3DF Tel: 081-444 2121

Terrence Higgins Trust 52–54 Gray's Inn Road London WC1X 8JU Tel: 071-831 0330

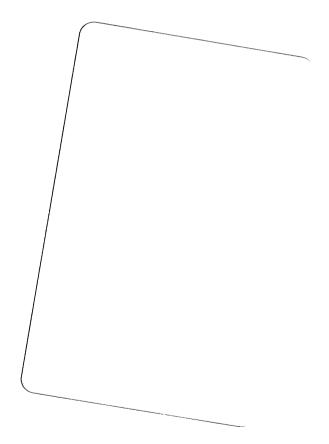
Organisations that produce information in Asian languages

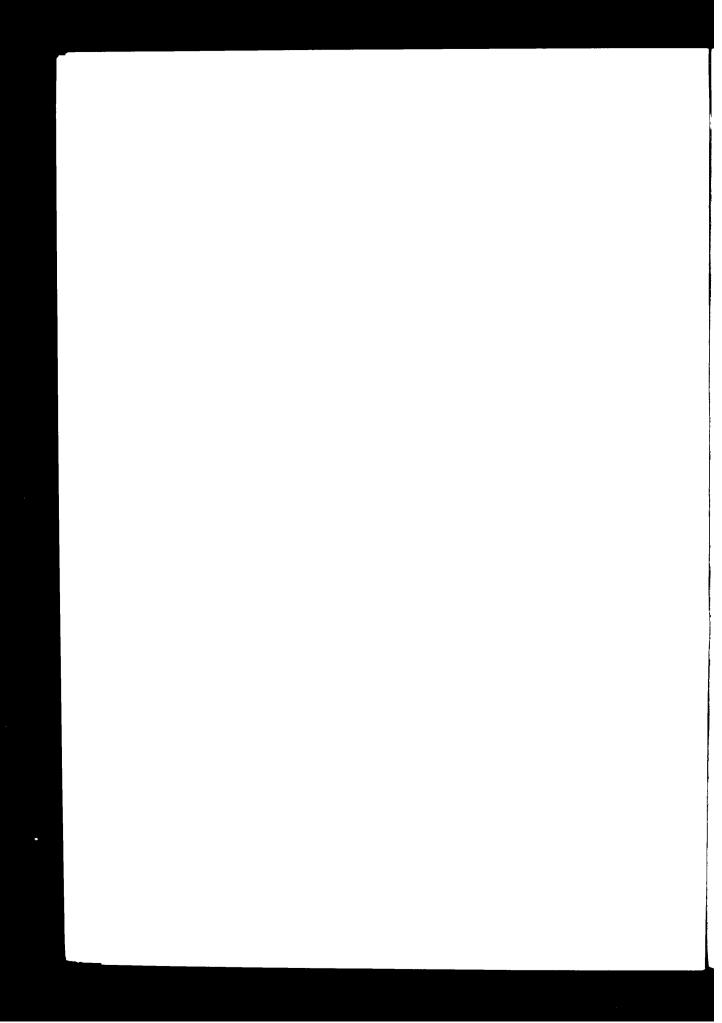
British Diabetic Association 10 Queen Anne Street London W1M 0BD Tel: 071-323 1531

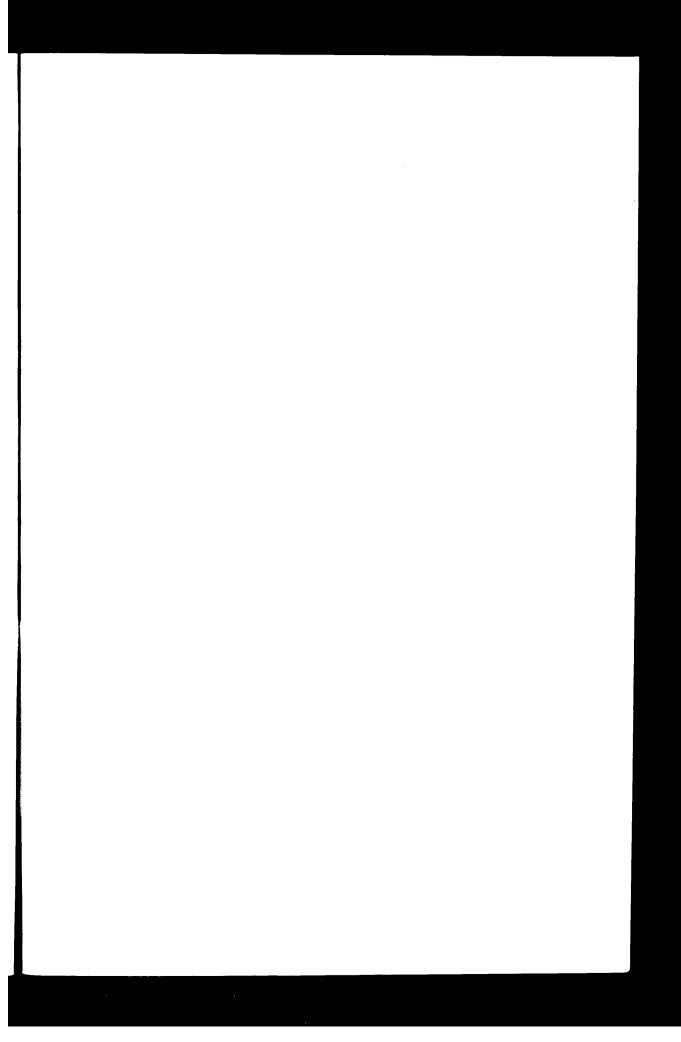
British Red Cross 9 Grosvenor Crescent London SW1X 7EJ Tel: 071-235 5454

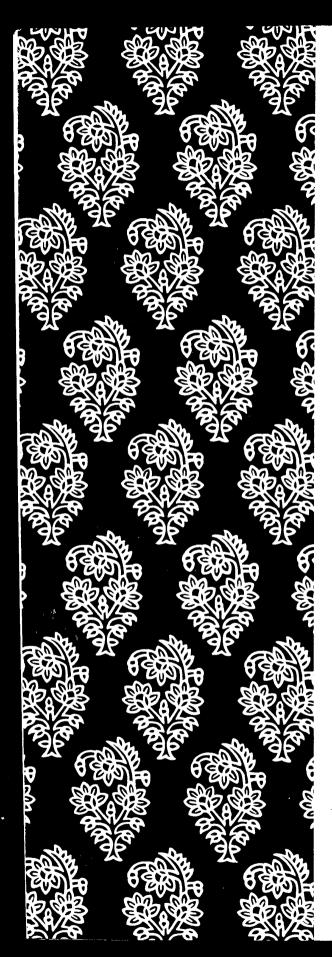
Mind Publications 4th Floor 24–32 Stephenson Way London NW1 2HD Tel: 071-387 9126

National Schizophrenia Fellowship National Advice Centre 197 Kings Cross Road London WC1X 9BZ Tel: 071-837 6436 National Schizophrenia Fellowship National Office 28 Castle Street Kingston upon Thames Surrey KT1 1SS Tel: 081-547 3937









CALL FOR CARE

Advice for Asian Carers of Elderly People

Yasmin Gunaratnam

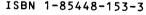
Call for Care is the only book in the UK aimed specifically at Asian carers of elderly people. It was written after extensive consultations with carers, service providers and community groups and offers information and advice to carers on how to:

- get help when you don't speak English
- make contact with services for the first time
- apply for welfare benefits
- deal with housing problems
- make a journey to the country of origin
- cope with death and dying.

It informs carers of their right to services, support and fair treatment and will be invaluable to those working with carers as well as to the carers themselves.

This book is also available in Urdu, Punjabi, Gujarati and Bengali.

£1.95





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