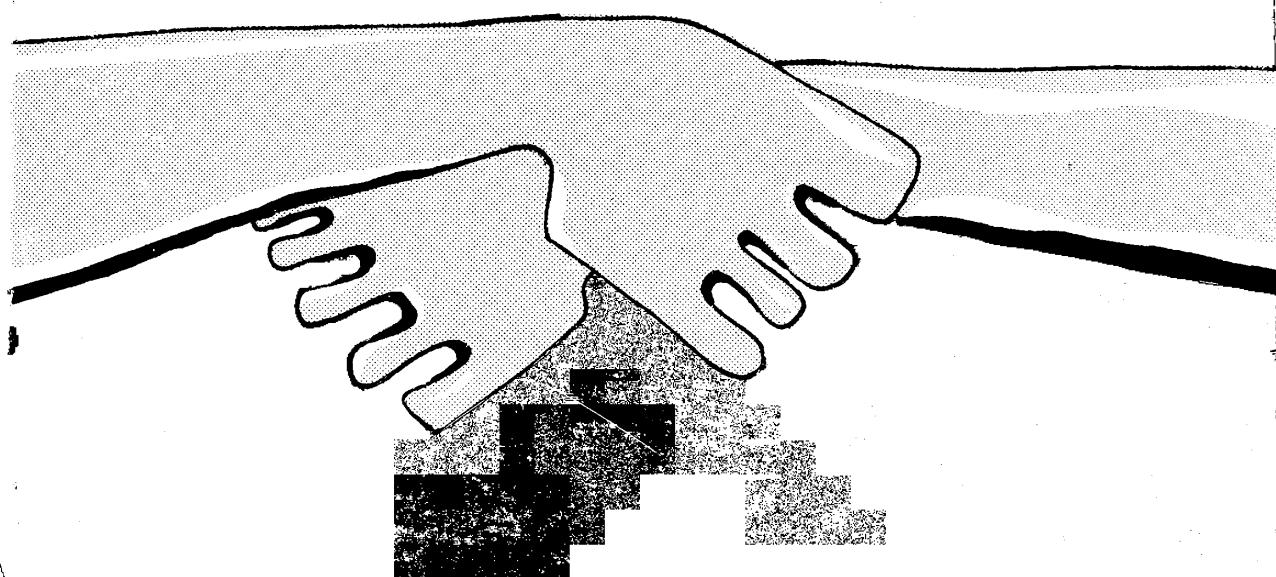


THE SUPPORT YOU NEED

Dr Lynda Eribo



Information for Carers of Afro-Caribbean
elderly people

**KING'S
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QBFN (Eri)

Published by the King's Fund Centre
126 Albert Street
London
NW1 7NF

Tel: 071 267 6111

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| 26 JUNE 1991 | £2-00 |

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ISBN 0 903060 957

Distributed by Bailey Distribution Ltd
Dept KFP
Learoyd Road
Montfield Industrial Estate
New Romney
Kent
TN28 8XU

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



The King's Fund Centre is part of the
King Edward's Hospital Fund for London

Printed by Adept Press 273 Abbeydale Road Wembley Middx HA0 1PZ

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Acknowledgements

One of the benefits of a research project such as this is that it enables the researcher to meet and work with many different people.

It is a great pleasure for me to name those who have so freely contributed their invaluable time and specialist knowledge in supporting the project and reading and commenting on the booklet. Amongst these are the members of the Advisory Group: Carol Baxter, Lucy Brown, Yogesh Chauhan, Tenagne Geressu, Hilreth McPherson, Vuyiswa Ngqobongwana, Euline Walcott, Pearl Wilson.

My sincere thanks are also extended to the various Afro-Caribbean organisations without whose co-operation it would have been impossible to meet so many carers for the project.

Special thanks to Garth Williams, the Principal Officer of The West Indian Women's Association (WIWA); Lydia Yee, Development Officer, King's Fund Centre; Jenny Lawther, Rainbow Publishing (admin worker) and to my daughter Sophia Eribo who supported me throughout the project.

Cover design and illustrations: Chike Azuonye

Editing: Angela Lewis

Welfare rights information checked by: Maxine Higham

This booklet is dedicated to the 51 carers whose generous contribution of their caring experience, their views and their suggestions, has formed the basis for the content of this booklet.



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Foreword

With the heightened awareness of carers and their caring roles in recent years, more information aimed specifically at them has been produced offering signposts to such services as taking time off, help in the home, welfare benefits and setting up local carers groups. However, there has not been much written for carers of particular racial groups for instance, recognising differing needs and concepts of caring.

THE SUPPORT YOU NEED is therefore intended to serve as a much needed source of information aimed at Afro-Caribbean carers of elderly people and those who support them. This unique book offers, for the first time, information around what services are available to these carers and whom to approach for help. It acknowledges the important roles played by Afro-Caribbean community organisations and encourages statutory agencies to extend their services to include Afro-Caribbean carers of elderly people.

The research for this book has been based around interviews with 51 carers offering their valuable time. They gave us a glimpse into the lives of Afro-Caribbean carers of elderly people and we are very grateful to them for this opportunity. We hope that the clear and straightforward presentation of this book will help carers in their caring roles, to find the services they need and not feel alone in asking for help. For all those concerned with providing support for Afro-Caribbean carers, THE SUPPORT YOU NEED contains information to draw on in understanding the issues facing these carers.

We hope that producing this book will mark a starting point for local authorities, health authorities, community projects and voluntary organisations to acknowledge and to offer the support expressed by these carers for themselves and those they care for.

Lydia Yee (King's Fund Centre Carers Unit)

Garth Williams (West Indian Womens Association)

Dear Carer

This is a book which is mostly for you and partly for those who should help you.

Have you been looking after, or are about to look after a relative or friend who is frail and elderly; someone who is partially or totally in need of your help because of physical or mental illness, or disability, and who is dependent on you? Then this book will be of use to you.

The care you provide might range from personal care such as bathing and toileting, physical help such as lifting, practical help such as gardening, cooking, helping with paperwork and finance, helping with visits outside the home, assisting with medicine, with safety, providing company, or it may include all of these. Caring is not an easy task. I am sure there are times when you feel you cannot cope or need help. This booklet will make a difference, it will help.

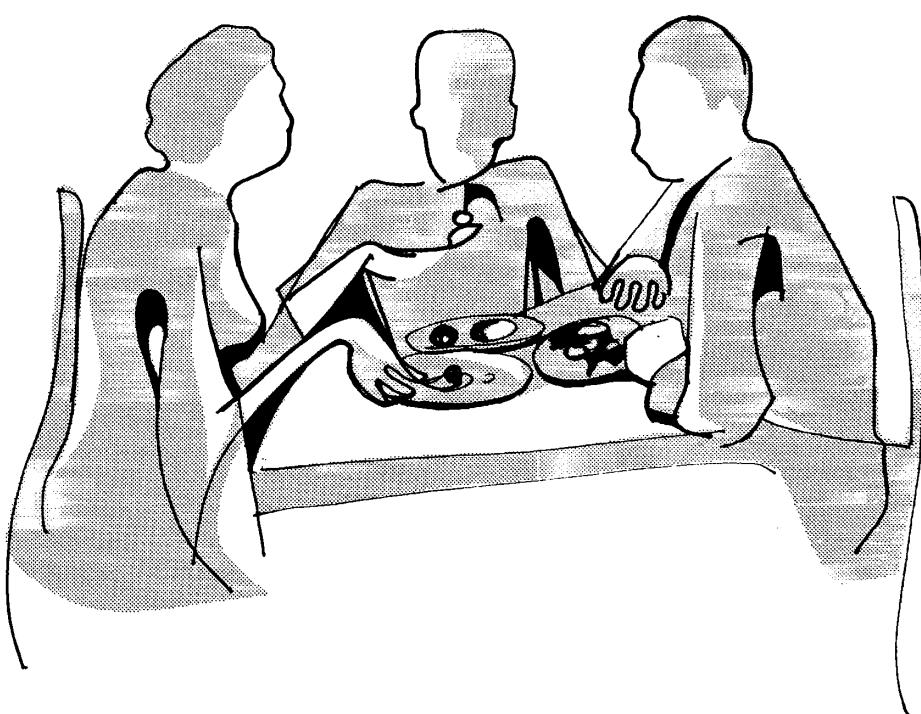
You will find information about benefits and existing services available to you and suggestions as to how you can obtain the most use from them. There is also a list of names and addresses of useful organisations and publications at the end. This booklet could make a big difference in your life as a carer and that of the person you care for.

I cannot guarantee that this book can give you immediate or positive results. It aims to help you recognise your role as a carer and to encourage you in your caring role to take the positive and necessary actions that can influence changes and improvements in your life and the life of the person you care for.

Lynda Eribi

CHAPTER

**Do you Realise
You are a Carer?**



"I cannot put him in a home — our culture teaches us to look after our old people in the family home, not put them in old people's homes."

"No one knows we are here. Who or where do we complain to? We do not see anybody so we just carry on."

If you are looking after someone at home — someone old, young, physically or mentally disabled or handicapped, ill or frail, then you are a carer. This booklet focuses on carers of Afro-Caribbean elderly people.

You may be male or female, young or old. You may be married to the person you are looking after or you may be looking after a partner, mother, relative, friend or even a neighbour.

Carers of Afro-Caribbeans are people of both sexes and of different age groups. Carers are usually spouses, children, children in law, relatives or even friends or neighbours.

It is important that you realise you are a carer because this means that you are entitled to certain benefits and support from authorities. In the Caribbean the elderly people receive a lot of support from within the family, so caring is taken for granted. The word 'carer' is not used.

How do you feel about caring?

— Do you feel that you are responsible for looking after the person you provide care for because you are family?

"He is my husband. Our children live very far so I have to look after him."

— Are you embarrassed about an illness, eg. incontinence, dementia, etc?

"How could I admit to anyone that my husband wets the bed? I was so embarrassed that I made every excuse to avoid visitors. I have to use disinfectant to kill the smell."

Some elderly Afro-Caribbeans and their carers feel ashamed or embarrassed about certain illnesses and disabilities. This often makes them more isolated from people around them and discourages them from seeking help from their own community groups and voluntary organisations.

- Do you realise there is information available that can help you and do you know how to find it?

“The length of waiting time you have to spend to get any information makes it impossible to get information and sometimes you are not given the right information.”

- Do you feel that the whole social welfare system is too complicated to work out and that there is too much red tape to be bothered with it?

“You have to fill in forms upon forms, you get confused along the way and you just give up.”

- Do you feel reluctant to apply because you feel you will encounter racism and discrimination?

“Our needs are not met and the racist attitude of some of our service providers makes things even worse for us.”

- Do you think that you will have to fight so hard for every little thing it is not worth the effort?

“Somebody came from the local authority to assess our situation. She decided that a bath is needed on the ground floor because of Mike’s heart condition and this is how we got the bath downstairs.”

Caring can be very time consuming. The amount of time and practical work put into it depends on the degree of the illness or disability of the person you are caring for. The longer you have been in a caring role the more likely you are to feel stress and strain.

“I have been looking after him now for twelve years and this is beginning to tell on me because I am getting older and he is not getting better. I have to do everything for him.”

Some carers work hard both day and night performing many duties ranging from helping the patient in and out of bed, helping to turn in bed, helping around the house, toileting, listening to complaints, to dispensing drugs. All this requires a great deal of energy and patience. It is important that you know that there is help and support available for you and the person you care for.

“Since the home help comes twice a week I am able to run around during those hours to do a few things away from home without having to worry about him being on his own.”

You may need help and support to care successfully. This help and support is available in different forms. All you need to do is have enough information to find out more about available services and benefits, and this book will help you.

“She seems to look forward to the days the lady from the sitting service visits. She seems to enjoy the company of others, not just mine.”

Most carers do not ask for support. If you do ask for support and you are turned down, don't be discouraged from trying other avenues. Talk to your local councillor, your advice centre or your church minister.

If the situation becomes desperate then go directly to your Member of Parliament. MPs are ordinary people who are paid to listen to you and help you as best they can. If you are unsure about going on your own, bring a family member or friend with you.

“When my application was turned down for rehousing, my daughter encouraged me to appeal. I am glad I did because I won the appeal.”

Major areas of concern for Afro-Caribbean carers of the elderly people

Many carers will say that they are worried about the lack of information and are unhappy that they care alone and often feel isolated. You, as an Afro-Caribbean carer, are likely to have additional worries — you are not alone, many others share these concerns.

It may also be helpful to point out some of these issues to people who are helping you so that they may understand the kinds of worries and fears you may have and, by gaining a better understanding of you and the person you care for, be able to provide practical and useful assistance.

The issues

1. As an Afro-Caribbean carer do you need financial support to provide a good standard of care?

Are you an elderly person who does not have money yourself? As an Afro-Caribbean elderly person, and carer, you were probably employed in a job which didn't pay very much and you might not have any private income or private pensions. Perhaps there is no one in your family to help you financially because of unemployment, or if they are employed they might not earn very much money.

Unemployment, low income and poverty in the Afro-Caribbean community can mean that family members are able to offer little or no financial support. Often, the family or state support that Afro-Caribbean carers desperately need for survival is not available (please see Chapter 7 for information on financial and legal help).

"I came to Britain first. When he joined me he got into the private building trade and this does not carry any pension so we have to manage on my pension and income support."

2. The person you look after may think a lot about their home country, they may be homesick and long for their family and friends 'back home'. Like most elderly people, the past is usually extremely important. This is even more true for the elderly Caribbean person who feels very isolated and alone in Britain.

"Back home old people are respected and supported by members of the family and neighbours, but here nobody knows we exist, they don't want to know how we are coping."

3. Because they often have ties with their home countries, elderly Afro-Caribbeans frequently worry about their poor financial situation and the high expectations of relatives at home.

"Out of my meagre pension I still have to send a part of it to my 85 year old father at home."

4. You may have some difficulties finding and paying for food preferred by the elderly person you are caring for. Although these foods are imported and available they can be more expensive to buy.

"He likes the Afro-Caribbean meals. This was no problem when we both earned but now we just can't afford it."

5. Do you or the person you care for feel disappointed because you stayed longer in Britain than you planned?

You, or the elderly Afro-Caribbean person you care for, may feel that you have failed because you only intended to work for a specific time in Britain before returning to the Caribbean. You may also feel that the basic needs of elderly Afro-Caribbeans are still ignored by Government even after all these years.

"Our needs are not met and the racist attitude of some service providers makes things worse for us."

6. You, or the person you care for, may have been treated badly by professionals or other individuals because you are black. From your experience of racism you may feel that you will be prevented from getting your benefits and entitlements. You may be worried about approaching the authorities for assistance.

"They make you feel and look like a beggar. We are not beggars."

7. You may expect other members of the family to help, as they would have done back home, but feel that they do not do so here. You, or the person you care for, may be unwilling to ask for help from outside agencies and you may be distressed by the lack of family support.

"They say I'm not entitled to home help because my stepchildren live with us and should be helping but children brought up here adopt a different attitude from those back home."

8. Do you sometimes neglect your own needs because you feel there is no help available and you have to do everything for the person you care for? As an Afro-Caribbean carer, what is the hardest part of caring?

"Everything. He can't do anything for himself so I have to do everything for him."

9. As you may be doing everything alone for the person you are caring for, you might not have any professional help. You probably don't have the support of any professionals like a social worker or health visitor so you might not know where to go for information or assistance.

"We don't have a social worker or anyone to give us information or support."

10. You may feel reluctant to use some services as they don't cater for the person you are caring for.

"I had to leave him in a home for two weeks while I buried my father — he had lost so much weight when I came back. I was told he wouldn't touch his food. He did not like it in the home."

11. As a carer, are you concerned about how changes in the National Health Service will affect you and the person you are caring for? Do you worry that your situation will become even more desperate than it is now?

"Things are bad for us now.... Who knows what is next with the cuts in the NHS and local authorities!"

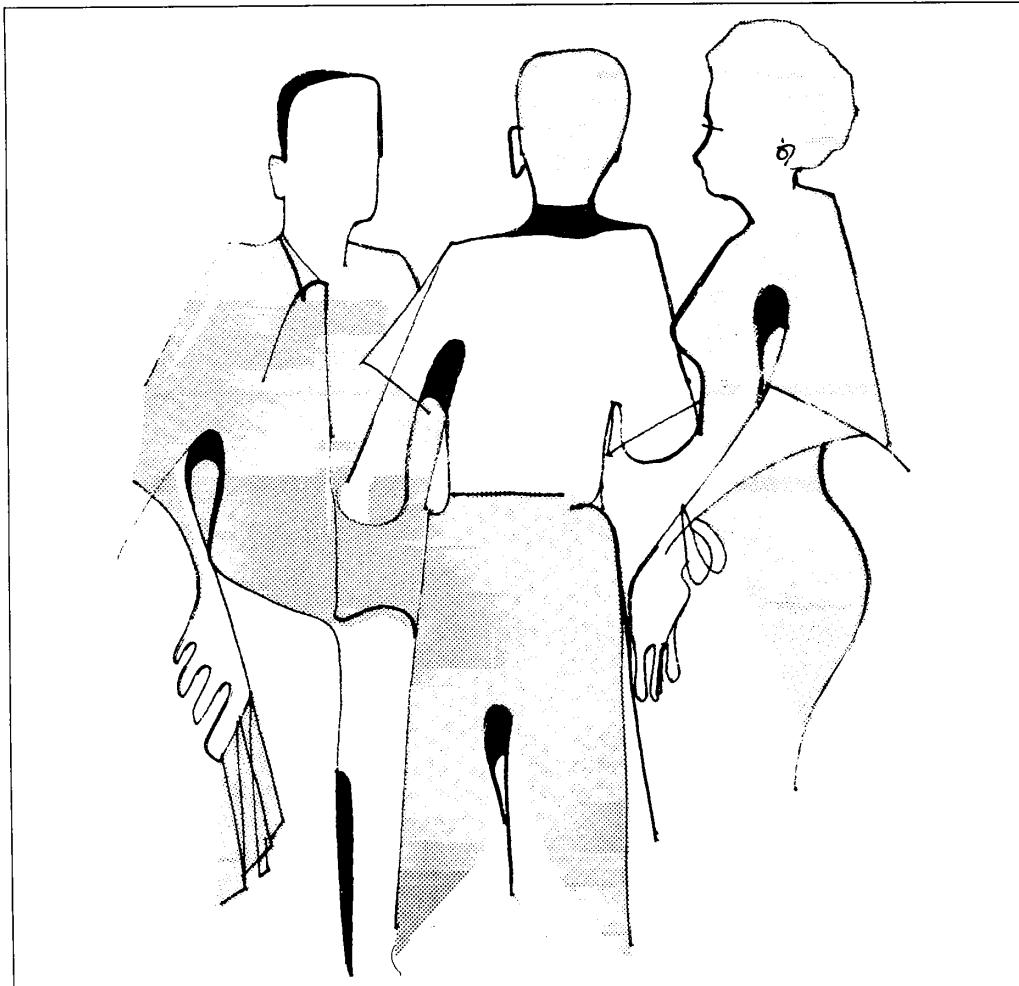
12. As an elderly Afro-Caribbean carer yourself, have you ever had problems with the immigration authority when a relative from the Caribbean has tried to come and help you? Has this experience stopped you from getting family help and do you struggle along by yourself?

It may be helpful to share these worries with the people who are helping you.

"My mother is 76 years old and she cares for my father, 74 years, who is confined to a wheel chair by a multiple stroke. It was very difficult to obtain a visitor's visa to come and support both of them for a while."

CHAPTER

Carers Support and Self Help Groups



What is a Carer's Support Group?

Do you belong to any support group? Would you like the support of other Afro-Caribbean carers who are in a similar position?

“Sometimes I think of getting together with others in a similar situation but I do not know how and where to start.”

“Since joining the group I have come to realise that I am not alone and tips and advice from friends in the group have been very helpful.”

There are many people who are experiencing a situation similar to yours who are living in your area. Forming or joining a support group will not solve all your problems but “a problem shared is a problem halved”. People who join support groups find them very helpful.

“When I lost my husband, the group stood by me and I don't know what I would have done without their support.”

How can I identify a support group?

Support groups come under different names such as ‘support group’; ‘self-help group’ or ‘carers group’. Some groups operate under the name of a national society or organisation. Whatever the group is called they all care about carers and carers’ needs.

How do I find out about a support group in my area?

You can get information about support groups in your area from a social worker, health visitor, citizens' advice bureau, your GP, the hospital, nurses, Age Concern, Help the Aged, various national organisations, local community centres and voluntary groups. For more details see the list of useful addresses at the end of the booklet.

How do groups get started?

If there is an existing support group which meets your needs in your area you can join in, but if your needs are not met you may want to start one yourself. Positive thinking and action is very important at this stage. You can do it if you are determined enough. You may ask yourself some of the following questions.

Why do I want to start a group?

Sometimes you may be lucky to find a group started by professionals, eg. social workers or health visitors, as this is done on a voluntary basis. In the absence of such a person or group then you might get things moving. However, you will soon find out that there are others

like you who are willing to provide support and to join the group.

Will it meet my needs and that of the person I care for?

You will soon find out how helpful a support group can be, particularly if geared towards your specific needs and that of the person you care for.

"Before I joined the group I used to think I was tongue-tied, but now I am a chatterbox. I really look forward to our monthly meeting."

How will I find out about times for meetings?

Support group meetings are held at regular intervals and can be fixed at times suitable to members. This will help to keep you organised and show you that you can find time for yourself as well.

"At first I thought I would not find the time to attend meetings but somehow I got myself organised and I now see coming to meetings as a way of relaxing."

How do I contact other carers?

Once you realise you are not alone in the caring job you can try to reach others. You can get information about carers from Afro-Caribbean organisations such as clubs for elderly people, community centres and self-help centres. Alternatively, try your GP, Age Concern, Help the Aged or the Elderly Unit of Social Services in your area.

Where do we meet?

Any place can be a meeting place. Some successful support groups started meeting in a living room of one of the carers before a suitable place is found. Possible meeting places are church halls, premises which Afro-Caribbean clubs use as meeting places, day centres, clinics, etc. Some checking and planning may be required to obtain suitable premises.

What happens in a group?

You can share information about caring and holidays. You can work together to demand improvements for carers in your area. You will have people to talk to who share your experiences.

"Last year our group went on a weekend trip to Paris. We really enjoyed ourselves. When I got back it was like starting a new job."

Where can I get support to run the group?

You may be lucky to get help from interested members and you can

also get help from outside agencies. Outside help and information can range from voluntary organisations, statutory organisations (eg. local authority), community centres, churches and libraries or private individuals. You will find some helpful information and advice on setting up and running groups in the booklet "Caring Together", published by the King's Fund Centre Carers Unit, and from your local Community Voluntary Services.

Will it work out?

Other carers have found that their groups have been successful with the help of "Caring Together" (as above) and local Community Voluntary Services. It is your group. You can show other organisations how you and your group need to be cared for. In helping others you are helping to change this society into a caring society.

It is encouraging that there are some support groups which are already operating with great success. One such group is based at the Annie Wood Resource Centre in Birmingham (see Afro-Caribbean Organisations Contacted For The Project section at the end of this booklet). You may wish to contact them to find out more about how they started and what they do. The address can be found in the List of Useful Addresses at the end of this booklet.

Annie Wood Resource Centre

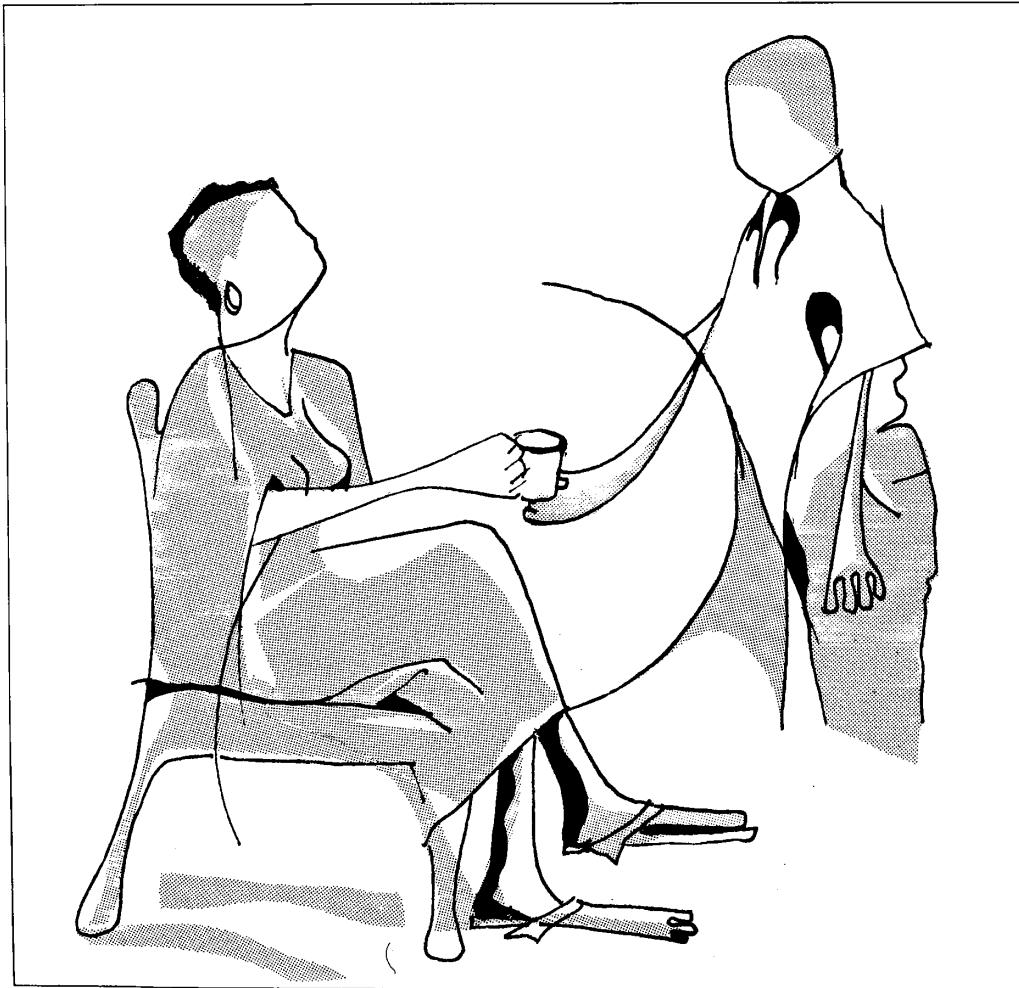
This group first met in January 1989 and has a group of twelve carers who attend meetings once every three weeks. The group is supported by a steering committee with a district nurse, social worker, assistant development worker and a community worker. The committee members assist in the development and running of the group and provide a listening ear and advice in times of need.

The carers who belong to this group have made friends amongst the group and seem happy and relaxed. The group arranges outings, invites speakers to come and talk on a wide range of issues and provides a valuable source of social contact for its members. It has also been very supportive in times of bereavement. Bereaved carers are invited to remain as members of the group and are able to share their experience with other members.

All the carers feel they are able to talk freely and share with each other. They are much happier people for the experience. Hopefully other support groups will be able to follow the positive example set by the Annie Wood Resource Centre. They have shown that not only can it be done but that it is already being done.

CHAPTER

Help within the Afro-Caribbean Community



Caring for each other

People in Britain's Afro-Caribbean community have always helped each other (often because no one else does). Church groups, voluntary organisations and other community groups have become an important part of Afro-Caribbean self-help.

When Afro-Caribbeans came to Britain in the 1950s and 1960s many came mainly to find employment. Most people could only find employment in jobs requiring manual work which were important in rebuilding Britain after the Second World War.

British governments did not make special provisions for Afro-Caribbean people. Many believed that they would be 'going home' one day. Consequently, no specific plans were made to meet the needs of the ageing Black population who had come from a different climate and a different culture. Because there were no specific government provisions, Afro-Caribbeans had to develop their own communal activities to care for themselves and each other. The church has always been extremely important both as a meeting place and a place of worship. West Indian restaurants were also useful meeting places in addition to providing Caribbean meals.

The practice of 'looking out for each other' developed further and a number of Afro-Caribbean voluntary organisations began to emerge. Almost all of the existing Afro-Caribbean organisations, especially those catering for elderly people, have been founded by small groups of concerned, active Afro-Caribbeans.

Many of these organisations are non-profit making, usually funded by donations and occasionally, partly funded by grants from local authorities, health authorities or central government. Most of these organisations have to lobby and fight for recognition annually. Although most of these organisations have similar aims, ie. to provide a service for Afro-Caribbean elderly people, they are often unable to provide this service continuously because of the lack of adequate financial support.

Types of Afro-Caribbean organisations

The bulk of the work for elderly people and their carers falls on Afro-Caribbean voluntary organisations. These organisations operate under different titles such as Luncheon Clubs, Pensioners Clubs, Black Elderly, Golden Age, Support Group, and are mostly identified by the words "West Indian" or "Afro-Caribbean". The Annie Wood Resource Centre in Birmingham described in Chapter 3 and the West Indian Women's

Association (WIWA) are examples of this type of organisation. Both carers and the person they care for can use the services of these organisations.

Services provided by Afro-Caribbean organisations

Afro-Caribbean community organisations provide various services and activities for Afro-Caribbean carers. They aim to help you in the following ways:

1. Campaign to improve the quality of life for elderly and infirm people by ensuring that local authorities and statutory bodies provide services which are relevant and meet their specific needs.
2. Bring Afro-Caribbeans together to develop friendship and banish loneliness and isolation.

“Sometimes you meet friends you have lost hopes of ever meeting. We also make new friends and we do have plenty to talk about, the memories keep on coming.”

“One reason I like coming to the club is that you don’t have to shut up because you are worried about your English, we can just talk ... that I think makes a lot of difference.”

3. Provide hot, traditional Afro-Caribbean meals at low cost for members.

“Coming to the club three times a week guarantees a good meal a day for those three days. Where else can you get that kind of meal for the kind of money we pay?”

4. Support elderly disabled people and their carers.

“John is quite happy coming to the group. This gives me time to run around and get things done before he returns at 4.30 p.m.”

5. Provide information and support on:

- pensions
- welfare rights
- health issues
- housing
- other relevant needs of elderly people and their carers,
eg. emotional, recreational, personal.

“My local Afro-Caribbean organisation helped us to press the Housing Department for a ground floor flat. Can you imagine the struggle to get him to the sixth floor when the lift breaks down!”

6. Provide a listening ear and a helping hand.
7. Provide entertainment and cultural activities.

"The cultural show was very relaxing — John liked it and we are too old to take part in carnivals now."

8. Organise group trips, outings and holidays for elderly people and their carers.

"Stella and I had plenty to talk about after the trip. It was marvellous!"

9. Provide support in times of need and grief.

"I was so isolated after the death of my wife, I felt so empty until I became a member of the club — now I'm back to life."

You and your local Afro-Caribbean organisation

Lack of financial support often means that these organisations are unable to do everything they would wish to but, in spite of difficulties, they continue to help fellow Afro-Caribbeans.

As a carer, it is best to visit your local Afro-Caribbean organisation or group and see what they can offer you. They may only be able to meet some of your needs but if you join you may not only receive the benefits but also help to "look out for others" by contributing to make changes and to build on the group's achievements.

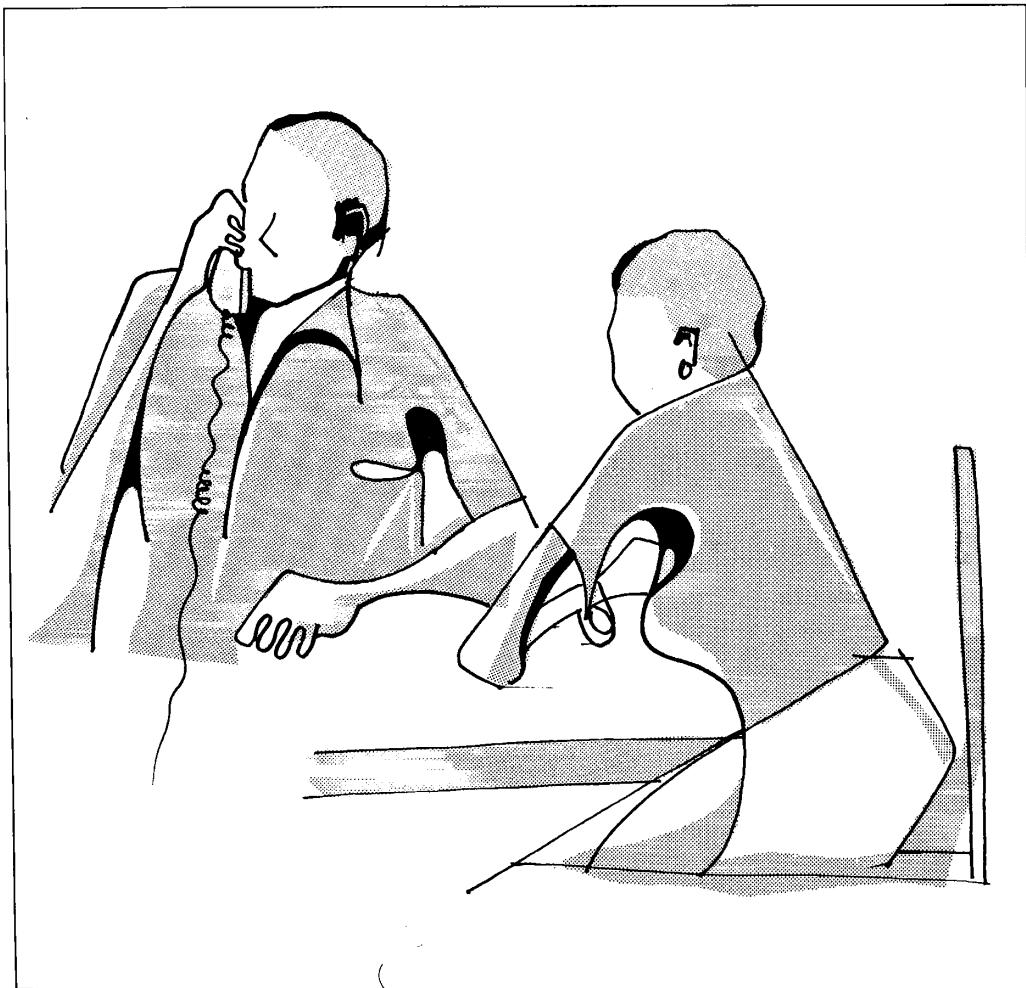
You can find out about these organisations and groups from contacting your local:

Afro-Caribbean Churches;
Council for Racial Equality;*
Council for Voluntary Organisations.*

* These addresses and telephone numbers can be found in the telephone directory.

CHAPTER

Asking for Help



Whom to turn to and what they have to offer

Many Afro-Caribbean carers of elderly people do not ask local authorities for help.

"In our thirty-five years in the country we have never claimed, we have always worked for our money. We see claiming as charity."

Do not be afraid or ashamed to ask for your rights or entitlements. If you do not ask you may never know what services are available to you.

The Disabled Person's (Services, Consultation and Representation) Act 1986 states that local authorities, by law, must assess carers needs if requested. If you have any difficulties in getting an assessment done, contact your local advice centre.

The Disabled Persons (Services, Consultation and Representation) Act 1986 states as follows:

"If a person, or his or her Carer, ask a local authority to assess his or her needs, that local authority has a duty to make the assessment. They must assess the person's needs for:

- a) help in the home;
- b) recreational facilities both in and outside the home;
- c) assistance with transport to such facilities;
- d) aids and adaptations;
- e) holidays, meals, telephones.

When the local authority makes the assessment, they have to take into account the ability of the carer to continue to provide care on a regular basis."

There are some important groups of people who may be able to help you obtain services. They are:

- 1) your general practitioner (GP);
- 2) social workers;
- 3) hospital specialists;
- 4) health visitors;
- 5) district nurses;
- 6) occupational therapists;
- 7) community psychiatric nurses;
- 8) the housing department;
- 9) local Citizens' Advice Bureau;
- 10) local advice centre.

1. The role of your GP

GP's are paid to care for the health of all patients registered in their practice. A good GP is expected to offer not only treatment but also advice and support. A GP is one of the best sources of information on medical services, nursing, and other services outside hospitals. Most carers and the person they care for usually find it better to continue with their usual GP, whom they have known for many years. If for any reason you wish to change your GP you are free to do so, but before you do you should check the following.

A few things to find out before you change your GP

- 1) Does the appointment system work and are surgery hours convenient to you?
- 2) Is the GP prepared to visit at home on a regular basis?
- 3) Are there nurses, health visitors, counsellors or other staff attached to the practice?
- 4) Does the GP have a good attitude to patients, eg. being helpful and a good listener?
- 5) Does the GP have particular experience with, or knowledge of, elderly and physically or mentally ill people if that is what you require?
- 6) Do the premises have wheelchair access?
- 7) If the GP is not Afro-Caribbean does he/she understand your culture and your particular requirements?

It may be unrealistic to find a GP with all of the above. Select those points which are particularly important to you and the person you care for.

Some services you can obtain through your GP

Talk to your GP about your specific needs and he/she can make a referral to any of the following people who will provide a confidential and professional service:

- 1) a health visitor;
- 2) a district nurse;
- 3) a physiotherapist;
- 4) a community psychiatric nurse;
- 5) an occupational therapist;
- 6) a speech therapist;
- 7) a continence adviser;
- 8) equipment such as a wheelchair;
- 9) referral to a hospital for the person you care for;
- 10) admission of the person you care for to a hospital/home to give you a short break.

2. Social Workers

Social workers are employed by local authorities to help and advise on a wide range of personal, practical and financial problems. Social workers have a legal duty to inform you about local authority services and assess your need. Social workers have information about local voluntary and self-help groups. If you would like to get more information about getting a social worker contact your local social services department.

A good social worker will:

- give you advice and information about all the services you can get from — your local council (eg. meals on wheels, home help, a stay in a home, etc.); the National Health Service; voluntary organisations;
- help you get these services organised;
- support you if you are making applications for benefits, grants, or any service;
- give you regular support, talking through your worries and problems and helping you decide what to do about them.

A good, friendly and sympathetic social worker can make your life a lot easier and happier. If you find your social worker unhelpful and you want to ask for another worker, you can contact your social worker's senior, team leader or team manager.

3. Hospital Specialists

Hospital specialists are doctors who have undergone special training in a particular medical field and as a result have become an authority in the field.

The person you care for may require a hospital specialist's (consultant's) attention. Such referral comes from your GP who will refer you to the right specialist. If this has not happened you can request one. This can help to put your mind at rest because you and the person you care for will feel confident of a correct diagnosis and correct treatment.

Below is a list of some hospital specialists relevant to elderly people and their carers.

- Geriatricians specialise in disorders and diseases of the elderly.
- Orthopaedic surgeons specialise in disorders and diseases or injury of the bones, eg. fractures and hip replacement.
- Neurologists specialise in disorders and diseases of the nervous system and the brain.

- Rheumatologists specialise in disorders and diseases of the joints.
- Urologists specialise in disorders and diseases of the kidneys, urethers, bladder, prostate and urethra.
- Psychogeriatricians specialise in mental disorder and disease in the elderly.
- Endocrinologists specialise in hormone imbalance.
- Gynaecologists specialise in disorders and diseases of the female organs.

What a hospital specialist can help organise for you

- a day hospital for the person you care for;
- a short stay in hospital for the person you care for, whether for assessment, for treatment, or to give you a break;
- support back at home through a hospital social worker.

5. District Nurses

District nurses are nurses with special home nursing training and can be a useful source of information. They can pay you regular visits in your own home to help you with the following:

- giving injections;
- changing dressings;
- helping with bathing (although this will vary from area to area);
- toileting;
- lifting;
- turning;
- advice on coping generally, particularly with incontinence and arranging for free incontinence and other home nursing aids.

A good district nurse will not only advise but pass on knowledge to carers about some home nursing skills such as lifting a patient, preventing or treating bed sores, etc.

Things a district nurse may be able to organise for you (subject to availability in your locality)

- bed rails or a raised or special bed;
- a "ripple" or other special mattress or a sheepskin, to prevent bed sores;
- an electric or manual hoist above a bed and/or bath;
- a bath seat;
- a raised lavatory seat, commode or urinal;
- incontinence pad, pants, drawsheets, etc.;
- a laundry service;
- a visit from a continence adviser;

- an auxiliary nurse to help both carer and the person cared for;
- a night nurse.

6. Health Visitors

Health visitors can talk to you about any special concerns you have about health. Health visitors work alongside district nurses. Health visitors can help you plan for the future and help you work out what you might want from a district nurse or other workers. Health visitors can help you with the following:

- help and advice on day to day problems and anxieties;
- suggest practical ways of coping;
- tell you about local services, both statutory and voluntary and help you make contacts;
- arrangements for aids and adaptations.

7. Occupational Therapists

Occupational therapists are employed by the local authority and are based in social services departments. Their duties include visiting people in their homes to teach them, and their carers, useful practical skills to help them cope with their disabilities. As well as advising on new aids and equipment, or adapting existing aids and equipment, occupational therapists can help arrange for you to obtain them. Most hospitals have an occupational therapy department. You can contact them while the person you are caring for is in the hospital through the ward nurse or doctor.

Some help you can get through an occupational therapist

Various pieces of equipment to help with everyday living can be obtained such as:

- chairs with high seats;
- adapted cutlery;
- washing aids;
- dressing aids;
- handrails beside the bath and/or lavatory;
- a wheelchair or buggy;
- a commode.

They can also assist with various adaptations to your home such as:

- handrails on stairs or next to the bath, lavatory, etc.
- widening doors for a wheelchair;
- ramp for wheelchair access;

- a lavatory and/or shower downstairs;
- a hoist over the bath;
- a stairlift, or lift that will take a wheelchair.

These are nurses with special psychiatric training and experience. They visit people with mental health problems in their homes. Duties of community psychiatric nurses are:

- visiting people with mental health problems at home;
- checking on the wellbeing of the patient and their carer;
- advising on problems and sometimes dispensing medication;
- helping speak to a patient's GP or psychiatrist where there is anxiety over medication;
- acting as a support to the carer.

How can I get a community psychiatric nurse?

You can arrange one through your GP, hospital psychiatrist, geriatrician or psychogeriatrician. You can also contact your local community psychiatric nursing department for help and advice.

9. Speech Therapist

Speech therapists have specialised training to help adults and children who have impaired speech or language disorders.

In elderly people, speech is sometimes impaired as a result of a stroke or other head injuries, a brain tumour or cancer of the throat. This can make swallowing difficult.

Duties of speech therapist

- assessing a patient's situation;
- advising on problems;
- acting as a support to both patient and carer;
- giving information, advice and practical help on coping with the problems and in some cases restoring patients' confidence to enable them to regain their speech.

How can I get a speech therapist?

- through your GP;
- hospital specialist;
- health visitor;
- contact VOCAL (see List of Useful Addresses)

10. Local Citizens' Advice Bureau (CAB)

The local Citizens' Advice Bureau offers a wide range of advice and information ranging from information about what benefits and services are available to you. Your local advice centre is another good source of information.

11. The Housing Department

The Housing Department is a department within your local authority that deals with your housing problems if you rent from them. They have a responsibility to assess and upgrade your accommodation. They are responsible for the practical changes around your home to make the home adaptable to the person you care for.

Housing can be categorised as follows:

- 1) owner occupier;
- 2) council accommodation;
- 3) housing association accommodation
- 4) privately rented

The most popular kind of accommodation falls within the first three categories.

Housing rights

As a carer you may be worried about your accommodation after the person you care for dies. If you are an *owner-occupier* and the person you care for wills the property to you then you need not worry. This also applies to joint ownership. (See note below on 'owner occupier'.)

If you are in *council accommodation* and the house is in the name of the person you care for then you will need to get either an assignment or a succession.

A succession is when a tenancy is passed to someone else after the tenant's death.

How to qualify for succession

You can qualify for succession if:

- you are occupying the accommodation as your only main home;
- you are the tenant's spouse, ie. husband or wife;
- you are a member of the tenant's family although the conditions listed below must be fulfilled —

- * if you are in privately rented accommodation then you must be able to prove that you have been living there for at least two years prior to the tenant's death;
- * if you are in council or housing association accommodation, then a 12 month period of residence is the accepted length of time.

Kind of succession

For private rented accommodation there can be two types of succession:

- after the death of the original tenant the spouse or a family member can take over;
- if the spouse of a family member dies the tenancy can be passed on to a successor who has to be a member of *BOTH* the original tenant's family and the first successor's family.

For example, Mrs Jones has her son and daughter Michael and Sarah living with her. She dies in 1988, and Michael succeeds to the tenancy. Sarah stays on with him, but he dies in 1990. Sarah is entitled to succeed as she is obviously a member of both her mother's and brother's family, and fulfilled the residence requirement of two years.

There is only one type of succession for council or housing association accommodation:

- further tenancy terminates when the spouse or family member of the original tenant dies.

Due to the complexity surrounding housing and accommodation law it is advisable to contact your local Citizens' Advice Bureau, Advice Centre, Law Centre or Housing Centre.

Notes on types of housing

Owner occupier and council accommodation

The local authority has a legal obligation to provide suitable housing for you and the person you care for under the Housing Act (1985) Part III. In order to qualify for this you need to fall within the category known as *priority need*.

The interpretation of priority need varies from borough to borough. In order to check if you qualify contact your local authority housing office or Town Hall.

Housing Association accommodation

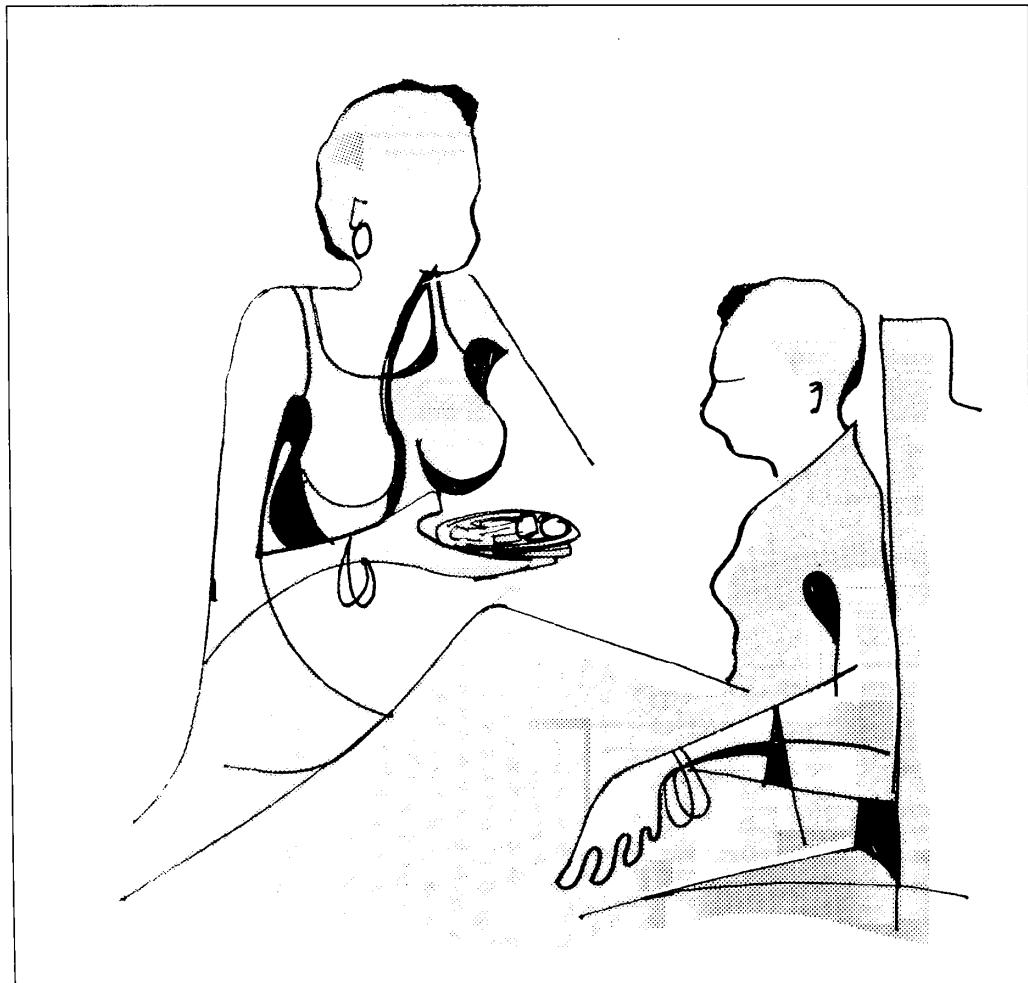
If you do not qualify for local authority housing you may wish to turn to the *not for the profit sector*. The Housing Association is an example of this. Housing Associations are small to medium sized organisations which usually cater for specialist housing needs.

Privately rented

The private renting sector is usually profit based and therefore tends to be expensive. It is usually concentrated on general rather than specialist housing.

CHAPTER

Obtaining Help at Home



Practical difficulties and coping with pressure

There are no strict rules for coping. As you continue in your role as carer then you will find which are the tasks you find difficult and it will be necessary to adapt to your situation in the best way possible. This is how one Afro-Caribbean carer copes:

"He is too heavy for me to lift in and out of the bath, chair, etc. Once I tried to lift him up on his chair when he fell — I cannot describe the sharp pain I felt in my back. I will never try to do it alone any more, he now has to wait until I get help.

How can I get help?

You can get help with coping techniques from your health visitor, GP, hospital specialist or social worker. They can also advise and sometimes arrange for equipment to help you cope with practical difficulties in and around your home.

Some organisations produce leaflets which give information on how to cope in specific conditions. You will find a list of useful organisations at the end of this booklet. It will be worthwhile contacting some of these organisations which are relevant to your needs to provide you with more information.

1. Home help may come under different names:

- home help;
- home care;
- domiciliary care;
- community care;
- community aides or assistants.

What can a home help do?

If you need help with cleaning, shopping, cooking and personal care, home helps and home care assistants can assist you with these tasks. However, services given by home helps can vary from borough to borough.

Is this service free of charge?

A means tested fee is attached to this service — that is your ability to pay is based on your financial situation. In some cases payment is not required.

How do I find a home help?

Contact home help organisers at your local authority or council.

2. Sitting and minding services

Sitting or minding the person you care for in your home is one of the services provided by some local authorities, the district health authority or voluntary organisations.

You can get help with sitting and minding for a few hours during the day or night.

What can these services provide?

Sitters or minders can help with:

- household or caring tasks;
- companionship for the person you care for.

In providing either of the above services the carer is given a short break from the role of providing care.

Is this service free of charge?

A small fee may be required.

How do I obtain a sitter or minder?

Your social services department may have information about any sitting or minding service in your area.

3. Care Attendants

These are service providers within a Care Attendant Scheme. Their service is designed to meet the specific needs of the carer and the person cared for.

How can I identify this service?

These schemes come under the following names:

- Home Care Attendant Schemes;
- Home Care Assistant Schemes;
- Crossroads Care Attendant Schemes;
- Extended Home Help Schemes;
- Neighbourhood Care Attendant Schemes;
- Family Support Services;
- Cheshire Family Support Schemes.

What services do they provide?

Care attendants provide help with the practical services involved in work around the house — washing, dressing, minding, companionship, ie. all the day-to-day services you, as carer, provide for the person you care for.

How often can this service be provided?

Some of these schemes are quite new and are designed to meet the individual's specific needs. You can ask for a care attendant for only a few hours a day or longer. The services provided by care attendants do not clash with other services you may already be receiving. A small fee may be attached.

How do I obtain a care attendant?

It is best to contact your local Department of Social Services or an advice centre for information about any of the schemes in your area.

4. Night-time care

Only a few care attendant schemes provide night-time care and therefore the demand tends to be greater than the service provided.

This is a service required by carers who care for someone needing attention during the night who is unable to obtain support from family or friends on a night shift basis.

Where can I obtain this kind of help?

Contact your local social services department. If you are unable to find someone to come and sleep at your home you may be able to have the person you care for placed in a hospital to enable you to take a break.

Night Nurses can be obtained through private nursing agencies but this can be very expensive.

5. Meals on Wheels

If the person you look after has difficulty in cooking, a hot mid-day meal can be delivered to their home five working days a week. In some cases a weekend service is available. Over the last few years meals preferred by Afro-Caribbeans have been incorporated in this service.

How can the person I care for qualify for Meals on Wheels?

- If you do not live with the person you care for, and he or she can not prepare meals.
- If you go to work during the day.
- If you, the carer, are unwell you may be able to get Meals on Wheels for both the person you care for and for yourself.

6. Laundry service

In some areas social service departments run a laundry service, whilst

in others this service is provided for by the District Health Authority. This service is not provided at all in some areas, but you may be able to get help with laundry from home help services who will provide assistance with washing bed linen and/or your clothes.

Who can qualify for this service?

- People who have difficulty controlling their bladder or bowel;
- very ill persons with an ill or frail carer;
- handicapped persons with a carer who is unable to cope with the washing of the sheets and bed clothes used by the person being cared for.

Is this service free of charge?

There is a small charge attached to this service but the person you care for may be entitled to free laundry as an additional payment by the DSS.

How to find help

Contact your social worker, district nurse, health visitor, GP or your local social services department or District Health Authority.

7. Adaptations to your home

For information about this service please see Chapter 7 for details.

8. Transport

Out and about

Getting about can be a worry to carers and the person they care for. There are a few solutions to this problem.

Public transport

If the person you care for is registered as disabled, he or she is eligible for a railcard which offers a discount fare for them and their companion.

If you want more information about disabled person's railcards you can get a leaflet from your local railway station.

Alternative forms of transport

There are other schemes provided by local authorities and voluntary organisations, for example, Dial-a-Ride or Ring-a-Ride. These offer door-to-door service for those unable to use public transport. These methods of transport are suitable for people in wheelchairs.

A taxicard system is another service available only to disabled persons living in London. Using this service means that for the first £7 on the meter you will pay £1, but you will be required to pay for any extra amount on the meter after the first £7. To register for this service you need to get a Taxicard application form from your local Social Services department. You will also need a photograph of the person you care for, signed by a doctor, to register for this service.

Other special fares

There are other special fares available at reduced rates from local authorities to people with disabilities. Contact your local transport authority and ask about concessionary fares.

Check your local council or voluntary or community transport services. You can obtain help from the hospital for transport to and from hospital. To find out about this service check with the nursing staff or sister.

Can I get help with my own transport?

You are able to obtain help to buy your own car or adapt your car for the use of a disabled or handicapped person. This applies whether the person is the driver or the passenger.

How do I go about obtaining this help?

You can contact the following agencies:

- Disabled Living Foundation (see List of Useful Addresses)
- Royal Association for Disability and Rehabilitation (RADAR) (see List of Useful Addresses)

Is this service free of charge?

Some of these services are not free. The Mobility Advice and Vehicle Information Services offer free general information on transport to people with disabilities.

Fees are charged for some of the services:

- £10 a session to help you become accustomed to your vehicle;
- £10 to advise you on car adaptation for driver and passengers;
- £50 to assess and advise you or the recently disabled person who may want to drive.

Hire Purchase

If you, or the person you care for, want to hire an adapted car for people with disabilities, this can be arranged by an organisation called 'Assistance and Independence for Disabled Persons' (see List of Useful

Addresses). This organisation has specifically adapted cars and they also arrange special insurance for people with disabilities.

Alternatively, if you, or the person you care for, qualify for a Mobility Allowance you might consider using this allowance to buy or lease a car. You can do this through 'Motability', a Government supported voluntary organisation. This scheme is only available to people who qualify for Mobility Allowance (see the section on Mobility Allowance, Chapter 7).

How can I obtain this help?

For further information contact your local social security office, community centre or Citizens' Advice Bureau.

Parking concessions

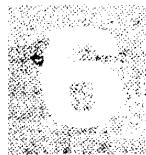
There is also an orange badge or sticker scheme which gives parking concessions to severely disabled or blind people and their drivers. You are qualified for the sticker if:

- you receive mobility allowance;
- you are blind;
- you use a vehicle supplied by a government department;
- you have a permanent disability which prevents you walking or makes walking difficult. (This condition has to be confirmed by a letter from your GP.)

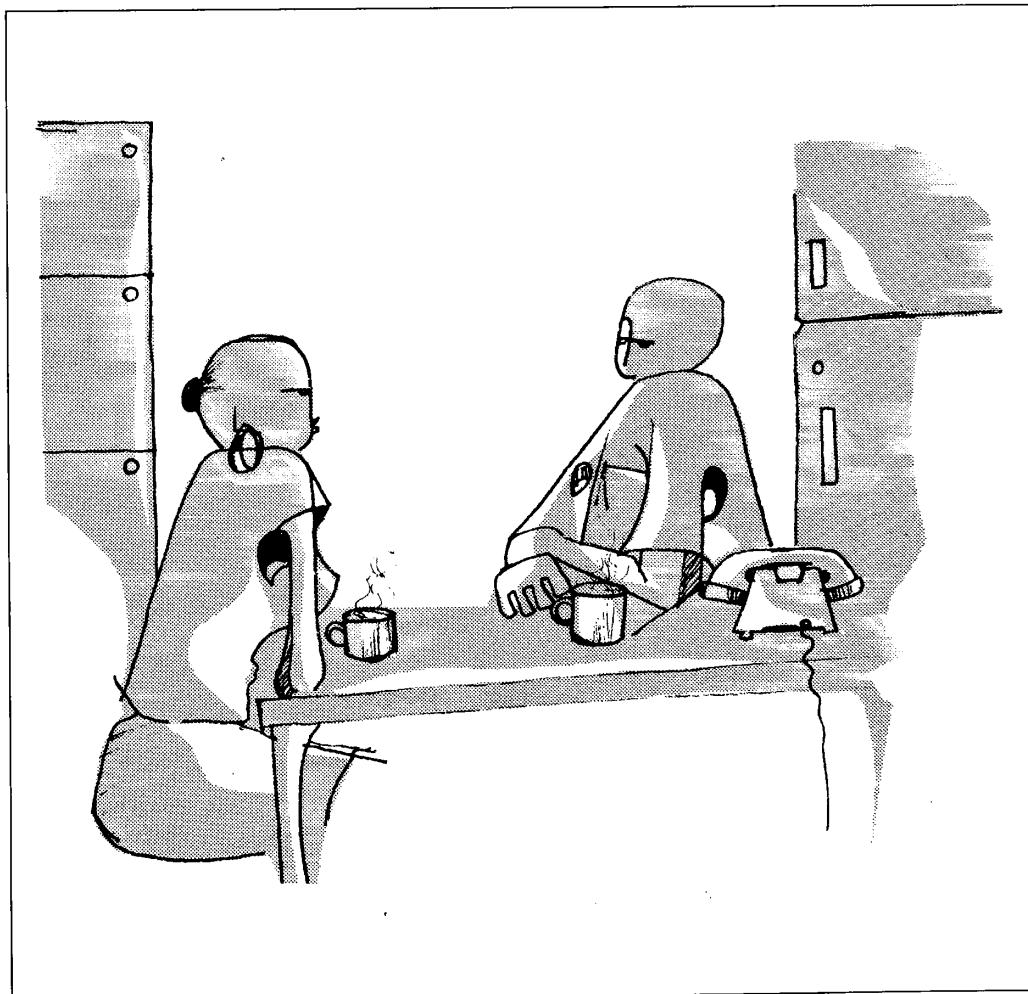
Helpful associations

You can benefit from being a member of the Disabled Drivers' Association or the Disabled Drivers' Motor Club. (See List of Useful Addresses.) There is a yearly membership fee of £5 required for each of these organisations.

CHAPTER



Financial and Legal Help



1. Health costs

As a carer, it is as important to look after your own health as it is to be concerned about the health of the person you care for.

This section gives you some useful information about what is available to you from the National Health Service (NHS). Check this section carefully. You may feel that you are entitled to benefits which you did not know about or thought you were unable to claim.

Which NHS services may be free to you?

- free NHS prescription;
- free NHS dental treatment;
- free NHS sight tests and vouchers for glasses;
- free hospital travel costs;
- free NHS wigs and fabric support;
- free NHS hearing aids.

Can the NHS help me with medical costs?

Services provided by GPs and hospitals are free under the NHS.

The NHS can help you or the person you care for if you come under any of the following categories:

- you are 60 or over (women) or 65 or over (men);
- you or your partner receive Income Support or Family Credit;
- you receive a War or Ministry of Defence Disablement Pension and you need prescriptions for your accepted disability;
- you suffer from certain medical conditions and disorders and essential regular medication or therapy is necessary;
- the person you care for always needs a permanent companion because of their disability or medical condition.

For more information see leaflets:

- * AB11 'Help with NHS costs'
- * D11 'NHS Dental Treatment'
- * G11 'NHS Sight Test and Voucher for Glasses'
- * P11 'NHS Prescriptions'
- * WF11 'NHS Wigs and Fabric Support'
- * MOL 153 'Guide for the War Disabled'

You could get advice on this from your local community centre, GP or Social Services Office.

2. Housing costs

Adaptations to your home

You may find that the accommodation you live in may need to have some special adaptations to make it suitable for your needs. Some of these are listed below:

- widening doors for a wheelchair;
- a ramp for wheelchair access;
- handrails on stairs or next to the bath, toilet etc.;
- a lavatory and/or shower downstairs;
- a hoist over the bath;
- a stairgate;
- a stairlift or lift that can accommodate a wheelchair;
- an extra room.

If you share accommodation with the person you care for, this accommodation and your financial circumstances will be assessed to check on how best to help with the cost of adaptations.

Your rent and community charge (Poll Tax)

You can obtain assistance from the local authority for housing benefit if you are ill, disabled, on low income support and find it difficult to pay full rent or community charge. If you are a council tenant then you can apply for a rent rebate. If you are a private tenant then you can claim for a rent allowance.

Is this claim dependent on NI contributions?

No, but it is assessed independently of any National Insurance contributions.

How much help is available?

- your rent can be paid in full;
- 80 per cent of your poll tax can be paid.

You can get extra help

Extra rebates are given in exceptional circumstances if you are able to show any special reasons which make it difficult for you to pay even part of your community charge. For instance, if the person you care for is homeless or mentally ill, they may be entitled to this.

How to claim

You can get a claim form at the same time as you get a claim form for Income Support. If you are already on Income Support and think you might be eligible for housing benefit or community charge benefit then you need to get a form.

NB: At the time of going to print, the Government intends to change the community charge system. Details are not known yet of what the new system will be.

3. Benefits

Benefits are your entitlements provided by the government to help you cope with financial difficulties. Benefits are usually assessed on the individual circumstances of the person who is claiming or sometimes this is done on joint circumstances if you are part of a couple. You will need to find out more about some of these benefits yourself, but this booklet will give you a general picture of what you can claim.

Benefits are either means-tested or non-means tested. So some may take into account your savings, income and so on. Income Support, Social Fund, Housing Benefit, and Community Charge Benefit do take account of your savings or income, whilst others like Attendance Allowance, Invalid Care Allowance and Mobility Allowance do not. Remember, some of these benefits are your right and it is important that you keep asking for them by talking to the people who provide them.

How do I find out what are my entitlements?

If you have any doubts about what your benefits are then talk about it with someone in your local social services, your social worker, your GP, district nurse or health visitor. You might also want to talk to relatives or friends who maybe able to help you. For further information about your benefits read leaflet FB2 'Which Benefit?', which is a guide to the social security and NHS benefits you can claim. Your local Citizens' Advice Bureau, Advice Centre and Community Centre will also be able to provide you with information.

Which benefits should I consider?

Listing all the available benefits is beyond the scope of this booklet, however below is a list of main benefits, some of which do not conflict with other claims:

- pension;
- attendance allowance;
- mobility allowance;

- sickness benefit'
- Income Support;
- Housing Benefit;
- widows' and widowers' benefit;
- community care grants.

Three of these benefits are particularly important to carers and the people they care for.

Attendance Allowance

Attendance Allowance is a weekly benefit which can be paid to someone with a disability who requires considerable care from another person. The claimant does not need to have a carer to get Attendance Allowance, but merely to show the need for attention. You should know that there is also a six month waiting period, now waived in the case of terminally ill people. There is no appeal for this benefit, but there is a higher success rate on reviews so, if you fail, it is worth re-applying.

This benefit is not taxable and does not conflict with other payments or benefits your relative may be entitled to. Attendance Allowance is split into day and night rates.

Day rate is a lower rate for daytime attendance only.

Night rate is a higher rate for those who require both day and night attendance.

You can apply for either the day or the night rate separately or you can apply for both of these rates combined.

What is the day attendance allowance?

This is the money the person you care for can receive for the help carers provide during the day with things like washing, dressing, eating, going to the toilet, etc.

What is night attendance allowance?

This is the money the person you care for can receive for the regular help carers provide during the night such as helping the person you care for go to the toilet, turning in bed, taking a cup of tea or medication

OR

The money you can receive for regularly attending the person you care for during the night to prevent any harm coming to them or to others.

How can I make a claim?

To claim, ask for leaflet NI205 from your Social Security Office, Post Office or local Advice Centre.

Invalid Care Allowance (ICA)

ICA is available to those who are performing the role of a carer. Basically, ICA is available to you if you are spending more than 35 hours a week looking after or supervising someone receiving Attendance Allowance. You can qualify for this allowance if you are:

- 16 or over, but under 65;
- giving regular care for at least 35 hours a week;
- not earning or earning less than £20 a week;
- not in full time education.

The award of this benefit does not require you to live with the person you care for — you may be a relative, a neighbour or a friend.

From October 1990 there will be a £10.00 weekly premium provided for carers. To be eligible for this premium you must be receiving the Invalid Care Allowance. You can also claim Income Support for your mortgage interest repayments.

How can I claim?

To claim for Invalid Care Allowance ask for leaflet N1212 at your local Social Security Office, Post office or Advice Centre.

3. Mobility Allowance

The person you care for can claim Mobility Allowance if he or she is unable to walk, virtually unable to walk or the exertion required to walk would be a danger to their health. The person must however be able to appreciate mobility (eg: not be in a coma).

Allowance is made for a set period or for life (which ends at 80).

How does he/she qualify?

He/she can qualify for this benefit if:

- he/she is unable, or virtually unable, to walk;
- the effort of walking may seriously affect his/her breath, eg. if he/she has a heart or breathing problem;
- he/she can only walk very slowly or for a short time, or walking causes great discomfort;
- he/she is deaf and/or blind and needs to be accompanied when travelling.

How can he/she claim?

To claim, ask for the leaflet N1211 from your Social Security Office, Post Office or Advice Centre.

4. Income Support (IS)

Income Support used to be called supplementary benefit. This benefit is paid on top of, or instead of, any other income or benefits.

Do I qualify for Income Support?

You qualify if:

- you have less than £6,000 in savings;
- you are 16 or over and are not in full time employment;
- you are in full employment, but getting less money because of your disability.

Premiums

Premiums, of which the disability premium is one, are supplements paid to people on Income Support who qualify.

You are eligible for a disability premium if:

- you are receiving an attendance allowance;
- you are receiving invalidity benefit or severe disablement allowance;
- you are registered blind;
- you have been unable to work for 28 weeks or more. In this instance proof and sick notes will be required.

How can I claim Income Support?

To claim Income Support ask for form A1 at your Social Security Office. Get someone from the local Community Centre or Advice Centre to help if you are unsure how to fill in the forms.

5. Community Care Grants

A community care grant is for a lump sum payment you can receive from the Social Fund.

How do I qualify for a Community Care Grant?

You qualify for a community care grant:

- if you receive income support;
- if you are sick;
- if you or the person you care for are disabled.

How a Community Care Grant can help you

The payment from this grant may assist in various areas. It can:

- help the person you care for to return to live in the community after hospitalisation, staying in a residential home or other institution;
- prevent the person you care for from going into care;
- help the person you care for move to a better house more suitable for his/her disability;
- help the person you care for to pay for the things he/she will require for his/her disability and thereby ease any financial hardship which your family may be suffering.
- help you meet travel expenses required to visit a sick relative you care for.

Things you can obtain through a Community Care Grant

- furniture
- bedding
- washing machines
- clothing
- ground floor bath/toilet, etc.

How can I claim?

To claim for a community care grant ask for Form SF300, which covers both grants and loans, at your local Social Security Office, Advice Centre or Social Services.

NOTE: * Community Care Grant payments are discretionary.

You should know that there are priority items (which vary from region to region) and priority groups, but there is also a monthly budget. So, if an application is made after all the month's monies have been allocated, it will be turned down however worthy it is.

- When you apply for a grant you may be offered a loan if the grant is refused. Grants do not have to be paid back but are quite hard to get.
- Loans are interest free and are repaid by direct deductions from the person's Income Support. If the DSS think you cannot afford the repayments, for example because of other loans, they will not award a loan.
- There is a system of review but no appeal now against a decision by the DSS.

6. Legal Aid

If you, or the person you care for, need help or advice on any legal matters, eg. racial harassment, immigration, property, etc., then you can get support in the form of legal aid. This means that the

Government can pay part, sometimes all, of your solicitor's bill for him/her to advise you on things like making a will, immigration advice, or prepare your case and represent you in court.

What kind of problems can I use Legal Aid for?

- divorce
- family and children
- credit, consumer debt
- accidents
- repairs, rent, eviction
- housing, mortgage arrears
- jobs
- discrimination
- Social Security claims
- criminal cases
- Most other legal problems.

Do I qualify for legal aid?

There are two grounds to qualify for legal aid.

1. Legal Grounds

You may qualify for legal aid if your case qualifies on legal grounds. A solicitor or advice centre will be able to advise you whether your case has legal merit.

2. Financial Grounds

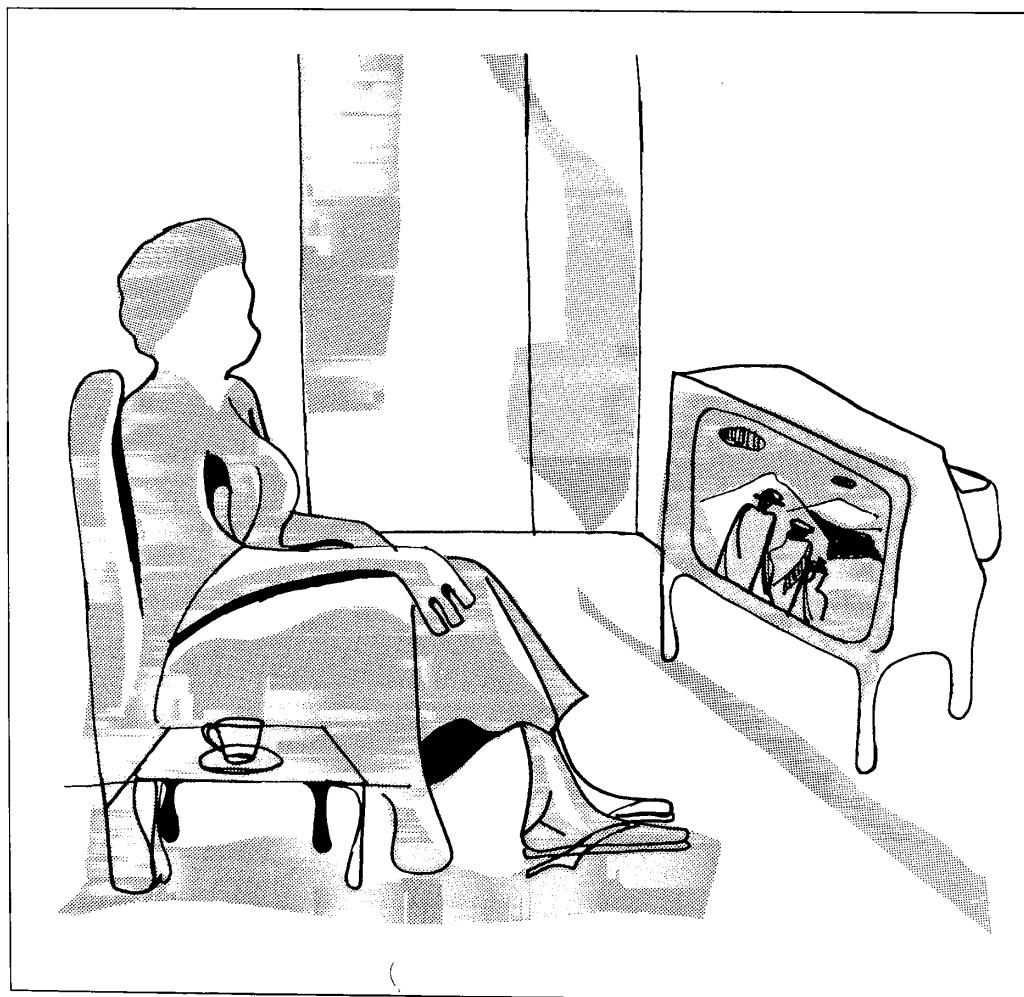
You may qualify if your income and savings fall below a certain limit. You can have up to £6000 in savings and still qualify.

If you are not sure whether you qualify for legal aid you can ask a solicitor for a £5 fixed fee interview. This will give you up to half an hour's advice for £5 or less. Most solicitors who do legal aid work will give you a fixed fee interview. It is advisable to try an advice centre or Citizens' Advice Bureau first as they are likely to advise you free of charge.

For more details ask for 'Legal Aid Guide' and 'Legal Aid — Getting Legal Help' from your local Citizens' Advice Bureau, Law Centre or library.

CHAPTER

Taking a Break



Do you feel isolated in your caring role?

"I have no time to socialise, I do not know what going out is like these days. When he has gone to the Centre all I have time to do is clean the house, do the laundry, rush to the shops, to the Post Office to collect our pensions and pay bills, etc. Before I know it I have to be back home to receive him from the Centre. Once he is back home I have to keep a constant watch over him."

How often do you feel that your whole life is centred around the task of caring and nothing is left over for yourself? Caring is something which you may live with all the time without any end in sight. It is very important both for you and for the person you care for that you can feel good about the role you perform, that it doesn't become an unbearable load and a source of resentment.

"I would love to take a break, but what do I do with him? Who will look after him the way I do?"

Depending on the amount of care you must provide, home caring without a break for the carer can become very difficult, both physically and emotionally. Carers' worries and anxieties about taking a break can sometimes be justified because services and standards of care for the people they care for can be inadequate. However, it is worthwhile checking what is available as various forms of short term relief facilities can be offered to the person you provide care for. This will give you a break. By caring for yourself you are ultimately providing better care for the person you look after.

What kind of break do you need?

What sort of break do you need? It may be simply an hour or two to sit down and watch the television, it may be a few hours on a regular basis to allow you to have a social life. Perhaps you might want to join a community group or organisation — or even start one yourself (see Chapter 3). Or you may want a longer break to take a holiday.

Managing your time may mean getting some extra help in some form or another.

Different kinds of breaks you can have.

There are different types of break available (sometimes called respite care). These breaks come under different names which vary from area to area. The following terms are the most commonly used for Respite Care:

- relief care (temporary care from a few hours to a few days);
- short-term care (for days or a few weeks, not permanent);
- phased care;
- programmed care (care which is planned ahead);
- shared care (care within the family, residential, hospital care);
- holiday care;
- emergency or social admission.

Whatever they are called, they all serve the same purpose, that is, to help the person you look after while you take a break. It is, in practical terms, a two-way break, giving both the elderly person and the carer a change of routine.

Availability and quality of this kind of care varies from area to area. Sometimes this type of care is only available in particular areas, to people with particular disabilities, or to particular carers. It is unlikely that all kinds of relief or respite care will be found in one area. It is important that you find out which ones are accessible to you.

Those who have managed to incorporate a break into their caring have found it to be rewarding:

"Last year I managed to get him into the hospital for two weeks. I was on a convention. When I came back I felt it was like starting a new job."

The various types of respite care cover care both inside the home and outside the home, for short- or long-term periods. Whichever alternative you choose will depend on your individual situation. The various options for each of these alternatives are below.

Place of care for person cared for
a) Care at home

- care attendant schemes
- sitting service
- night service
- live-in help
- domiciliary care
- extended home help schemes
- family support services

b) Care away from home

- day centres
- lunch and social clubs
- day hospital

c) Longer term care away from home

- a short stay in a special home, hostel or unit
- a short stay in a residential home
- a short stay in a hospital
- a short stay with another family
- a stay in a hospice for adults

Statutory

This means services provided by local authority social services departments, the Education Authority and the Health Authority. These services often have a small fee attached.

Voluntary

This means services provided by charities and voluntary organisations which operate on a non-profit making basis. These services may have a small fee attached.

Private

This means services provided by individuals, commercial organisations or companies on a profit making basis and can be very expensive.

For further details of relief care contact:

- your local Department of Social Services;
- your local Advice Centre or community group;
- your GP;
- a local voluntary organisation;
- the hospital specialist in charge of the person you care for.

You can also obtain a free book called *Taking a Break*. The King's Fund Centre Carers Unit offers this book to all carers free of charge. It offers information on the different types of breaks available and where to go to for help. You need to assess all the options and maybe, using these options as a basis, find some of your own. For example, you may wish to take a holiday but for various reasons feel you cannot place the person you care for into the temporary care of someone else. Perhaps you may have to find a compromise, maybe a joint holiday with a companion to offer some relief care could be the

solution. You do not always have to be alone. If you can share your role as carer you will be able to perform it more effectively. Perhaps the new interests and people in your life will have the added benefit of providing some stimulating things to talk about with the person you care for.

CHAPTER

8

Improving Services for Carers



So far this booklet has outlined some of the services and benefits which are available to help you in your caring role. The idea of carers' support groups has also been suggested as a way to share experiences and campaign for changes.

It is important to remember that your role as carer is central to the idea of community care. Community care reduces the responsibility of central and local government to look after sick and elderly people and this, therefore, becomes your responsibility. It means that care in the community is not possible without carers, so the caring role that you perform is vital. It should mean that more help will be given to you and also to the community organisations which provide help for you.

You may not have thought about it this way, but your role as carer is a job. It is a job which has no fixed hours and carries little or no recognition; it is a job which you probably live with 24 hours a day and is unpaid; it is a job which is taken for granted. You may also feel that it is your duty or responsibility to care. Unless you receive adequate financial and physical support, it is a task which you cannot perform to the best of your ability. One carer said:

"I'm elderly and ill but still struggling to care for my husband whose condition is worse. If I do not get enough support and I break down then the State will have to care for both of us."

Remember that by caring for dependants and elderly people you are keeping them out of institutional care and you are saving the Government money. You have a right to make sure that some of the money that is saved is put back into the community to help you as a carer.

Therefore it is important that you look at the services offered to you and ask three main questions:

- 1) Are the services *appropriate* — are they useful?
- 2) Are the services *accessible* — can you find and obtain them easily?
- 3) Are the services *acceptable* — are they good enough?

If you cannot answer yes to each of these questions then changes need to be made. You need to make your views known. The people who design the services and make the policies need to know what you think of them. They need to be aware of your needs and criticisms. This may be more effective if you are part of a group rather than an individual. As an individual you may not have enough time and energy, but in a group you will have much more bargaining power.

Gaps in services

Some of the gaps in services were highlighted as we talked to carers when preparing this book. All the carers felt that financial support was inadequate. Some mentioned the fact that special diets were often required which put a greater strain on their budgets. Others referred to the fees attached to various services provided by statutory and private agencies, local authorities and voluntary organisations. They felt they were unable to pay these charges.

Many carers felt that the criteria for qualifying for most benefits, services and support are very discriminatory, failing to take account of special needs, a failure which extended into the delivery of those services. Most carers would welcome a more comprehensive package of care and support in the community after hospital discharge. It was felt that when assessing the caring needs of Afro-Caribbean patients it was assumed that extensive family support was readily available.

Some carers who had been given home help mentioned that there was often a clash between their requirements and what the provider was willing to offer. Some carers had a willing relative from their home country to help them but they found it too difficult to obtain entry to Britain for their relative. If they did manage to obtain entry for the relative, they almost always had difficulties with their right to remain in this country. It may be possible to get assistance and representation from organisations which will campaign and help people with immigration problems. These organisations are — the Joint Council for Welfare Immigrants (JCWI) and the United Kingdom Immigration Advisory Service (UKIAS). It is worth following up, and using, all available sources of support. (See Chapter 7.)

Taking action as a carer

Meals on Wheels

The Meals on Wheels service is a service that could be very useful to elderly people and their carers where circumstances do not permit provision of meals by the carer. Unfortunately, most Afro-Caribbean carers do not use this service because they do not like the meals. Private arrangements for Afro-Caribbean meals can be very expensive. This is something which could be solved by urging Meals on Wheels services to employ Afro-Caribbean cooks to prepare Afro-Caribbean meals.

Respite care

Respite or relief care (short-term or long-term care by someone else) is felt by many carers to be unsuitable for their needs. This is an

important service which, if satisfactory, could be of great benefit to carers. It is essential that you have a say in the type of relief care that is available and how it is organised so that it does satisfy your needs. You can do this in a number of ways:

- 1) Make a formal complaint if a service has been unsatisfactory, otherwise it will continue to be unsatisfactory. The procedure is outlined below:
 - a) make the complaint as soon as possible to the person you have dealt with or get someone you trust to help you do this.;
 - b) if you do not receive a satisfactory answer then make the complaint to the manager, the organiser or the owner;
 - c) if the complaint is against the Health Authority then inform your doctor, if it is against the Local Authority then inform your social worker;
 - d) if you do not receive a satisfactory answer then there are a number of officials who are paid to represent your interests:
 - your local councillor;
 - the Community Health Council;
 - your MP;
 - the Licensing Authority (if the matter concerns a private agency);
 - the Registration Officer at the Local Authority (if the matter concerns a private residential home);
 - a Citizens' Advice Bureau, Law Centre or solicitor, if you need to take legal action to obtain compensation, or prosecute for negligence.
- 2) Join a carers' support group or voluntary organisation. These groups may campaign on a local level or on a national level. Choose one which you feel would be more suitable.
- 3) If you cannot join a group then write letters or ask other people to help you to write letters, talk to people. Your local Community Health Council or Council for Voluntary Service will have information available on the plans for relief services in your area.
- 4) Become a representative of a voluntary organisation on a formal planning committee. One example of such a committee is the Joint Consultative Committee which is involved in allocating funds, co-ordinating existing services and discussing proposals for future services. It is not essential to have a professional status or be an employee of a voluntary organisation but you would be representing others rather than yourself as an individual. Find out also if they will help you with sitting costs, if you need it. The above four suggestions of how to

campaign to improve services can also apply to services other than relief care.

If you are a member of a support group or you are thinking of joining one or forming one, then it will be valuable if you can think of possible solutions to the gaps in the services. Authorities and planners may be more responsive if they are given suggestions for improvement as well as criticisms. You need to make others aware of your needs on a continued basis, explain and suggest, think creatively and practically about how others can help you and how you can also help yourself. Some ideas which may be worth pursuing are:

- a telephone help-line for those people who do not have a specific worker and are not able to, or do not wish to, join a group;
- a newsletter or facts sheet which would provide information which is relevant to the needs of Afro-Caribbean carers;
- borrowing — one group has set up a sheet bank to help carers to cope in the short-term with incontinent dependants;

Whether you are part of a group or on your own, it is vital that you remember that if you do not ask for something then no-one knows you want it. Above all, try not to be discouraged if at first you are not successful. Let us briefly consider one such example.

Case study

Mrs Lemon is a young married mother of four children who are all under the age of 8. Mrs Lemon cares for her mother who is disabled by arthritis. She does virtually everything for her mother who shares a top floor room in the family home.

Mrs Lemon was one of the carers interviewed for the booklet. She received no benefits and was easily discouraged by social service red tape. The Project Worker encouraged her to apply for attendance allowance. Her mother's application for care attendance allowance was turned down with no reason, although she was told she could appeal. Mrs Lemon was angry at what she considered to be a waste of effort and regards the whole process of appeal as insulting and just more time wasting.

How can we avoid experiences like this being repeated? It illustrates that trying to obtain services can be a discouraging process. But do not take 'No' for an answer. If Mrs Lemon's mother appeals she stands some chance of receiving what she is entitled to, if she does not then

she will certainly receive nothing. If at first you do not get a satisfactory answer then take the matter further or enlist the help of someone who can take it further for you. Remember, you are not asking to be given something for nothing, you are asking for an entitlement for a service you are providing.

Action for service providers

From this research it is evident that there are gaps between what policy makers consider to be adequate provision for carers and what the Afro-Caribbean carers of the elderly need and want. This gap is likely to remain, if not widen, if there is no effective communication between policy makers, the black communities and the carers themselves. There needs to be both a willingness for carers to try to make changes and let their voices be heard, and a receptive and non-discriminatory hearing from policy makers and a willingness to act on suggestions and recommendations.

Services need to be tailored to meet specific needs of carers in general, irrespective of race, and most particularly to Afro-Caribbean carers who are among some of the most needy. At present there is no statutory obligation towards carers. There are several questions which need to be asked of the new community care legislation and of those who formulate policy.

- 1) Who is the support geared towards? Is Government policy merely providing a package of 'care in the community' at the carer's expense?
- 2) Will care in the community be complete, or even viable, without adequate provision for the minority groups within the community?
- 3) Is adequate consideration being given to the area of staff training in relation to the minority communities for those providing services in the community? Are those people dealing with carers in the statutory sector and some national voluntary organisations being properly trained in the areas of anti-racism and anti-discrimination, to encourage the practice of equal opportunities and fair treatment?
- 4) Isn't it time for recognition of the Afro-Caribbean carer's role in the community by some practical action and support?

The poor uptake of existing services such as Meals on Wheels, day care and home help, can be attributed largely to the design and contents of these services. These services fail to make adequate provision for the specific needs of Afro-Caribbean people, particularly elderly and disabled people and their carers. Thus the views of carers are important and should be included when considering practical support for carers.

The experience of racial discrimination should no longer be ignored. These experiences can have a lasting effect on the recipient and discourage them from seeking assistance. This is a particularly important issue for service providers in both statutory and voluntary organisations, and one which should be borne in mind when they are dealing with members of minority communities. Although they, as individuals, may not be discriminatory, they have no way of knowing what kind of history of racism and discrimination the person they are dealing with may have experienced.

Service providers also need to be aware that a proper and realistic assessment should be made of the needs of carers and the people they care for. They should take into account that Afro-Caribbean carers have specific needs which are a product of their background and history both in this country and in their country of origin. A supplement follows this chapter which provides an outline of the Afro-Caribbean experience and is designed specifically to give service providers greater insight into these special circumstances and requirements.

A further consideration for service providers when assessing the needs of carers should be the often severe financial circumstances of those who have little or no savings, and only a very basic pension. They should also bear in mind the extra costs of certain services they recommend and attempt to find some way of taking these costs into account when assessing needs and allocating resources and funds.

More attention should be given to the provision of information — both to service providers and to the recipients of those services. During the research for this booklet it became obvious that most of the authorities, particularly Social Services, dealing with elderly people and their carers had little or no contact with Afro-Caribbean carers for the elderly, and indeed it was difficult to locate any such carers through these organisations. Although these organisations had a wealth of information for elderly people and their carers from the wider community, they had no available information about the Afro-Caribbean carers themselves and, at best, could only direct enquiries for information and support to black and Afro-Caribbean organisations. The services which were provided by these organisations were not received by the majority of black carers in their localities, which underlines the need for service providers to remember that Afro-Caribbean carers have specific needs and are a minority within a minority.

Specifically targeted publications such as this booklet and publications such as leaflets and pamphlets should be made available, or published if

they do not exist, to cater both to those providing information and to those either receiving it or actively seeking it. The idea of audio visual methods, particularly audio cassettes, is also worthy of consideration. This is also linked with the notion of adequate staff training as previously mentioned.

The role of Government is of prime importance. More support and encouragement should be given to minority ethnic organisations dealing with carers and the people they care for. Financial support is of prime importance here. It is sad to note that many of the Afro-Caribbean voluntary organisations working with elderly people and their carers suffer severely from the consequences of inadequate funding. This, in turn, severely restricts the effectiveness of their functioning. Lack of facilities prevents them from reaching those people most in need of their care, such as elderly disabled people. Poor facilities also mean that the activities and entertainment these organisations are able to provide is often so limited that elderly people and their carers are not stimulated by the groups so they do not attend; thereby further distancing themselves from support and reinforcing their isolation.

A further consequence of inadequate funding is that many of these organisations operate in unsuitable premises and under disgraceful and appalling conditions. Most of their workers are overworked and underpaid, if indeed they are paid at all. Often, extra support is provided by volunteers and self-support from some of the more able members of the organisations.

The voluntary organisations which provide care for these people cannot, particularly in the present economic climate, continue to soldier on alone, existing on meagre handouts and platitudes. It may be feasible that Government agencies should liaise more closely with some of these organisations. As mentioned previously, it is also essential that the new community care legislation should be examined and reviewed to incorporate issues specific to minority ethnic carers and their elderly dependants.

Conclusion

As a final but important note, the carers themselves must find, and be encouraged to find, the courage and the time and energy to articulate their needs and to fight for what they are entitled to, whether as individuals or as a group. If there is no campaign for improvement then none is likely to occur. The future of successful community care rests not solely with those who assist the carers nor solely with those providing the care; the future lies in mutual and honest co-operation to assess any shortcomings and work in harmony to improve the services.

Facts about Afro-Caribbean Elderly People in Britain

History

It is important to understand a little about the historical background of the Caribbean and its people (which has created an individual culture of its own).

“The Caribbean” incorporates the islands (as well as Guyana and Surinam on the mainland of South America) and the sea which contains them. These islands have a long history of colonisation by various European nations who virtually destroyed any indigenous people and set up these colonies on a plantation system to serve their own economic interests. At first Africans were brought as slaves to work on the plantations. Later indentured immigrants from India, China and other countries were employed.

Culture

There are variations of culture between the peoples of the islands relating to individual geography, ethnic, racial and colonial experience. In general, however, the people of the West Indies share a history of ethnic diversity; an education system which bore little relevance to their surroundings; economic dependence; and a social system which was sharply divided into a rich white class and a poor black agricultural class.

Over the years language, in the form of local Patois, developed. A cuisine based largely on African and Indian origins, and adapted to suit the local foodstuffs, evolved, along with a rich diversity of religious and social customs. Over the years music styles such as calypso, reggae and steel band developed along with various festivals such as Carnival. The warm climate meant that social interaction frequently took the form of “gaffeing”, spending hours discussing politics, cricket and life on street corners and in rum shops. Playing dominoes in the rum shop was another social activity frequently enjoyed by Caribbean men.

In contrast to the British concept of a small nuclear family, the concept of family in the West Indies encompasses a wide range of relatives from the immediate parents and children through uncles, aunts, grandparents, cousins, distant cousins, and in some instances also includes the notion of an extended family in the form of intimate friends. Frequently three generations may reside under the same roof or in close proximity. Within this structure elderly people have available to them familial support and attention when they are ill, disabled or infirm and they have a very definite role to play in the family structure — they are respected, noticed and consulted for their wisdom and experience. The role of the elderly Caribbean person became a focal point of family life in which they maintained family links during periods when migration in search of employment occurred — their role was important in holding the family together during these times.

Migration and employment

A period of substantial migration to Britain of Afro-Caribbeans occurred during the First World War when many servicemen remained in Britain, particularly at the seaports of Bristol, Cardiff and Liverpool. It was not until the Second World War that emigration once more emerged as a significant demographic factor.

The majority of the post-war immigrants from the Caribbean were men. One sixth of Caribbean men now in Britain migrated before 1956 and over two thirds of them had arrived by mid-1956 which was also a time when migration for Afro-Caribbean women was at its peak. Over half of the Afro-Caribbean women came from Jamaica. The others came mainly from Guyana, Trinidad, Grenada, Tobago, St Kitts, Montserrat, Barbados, the Bahamas and other English speaking Caribbean islands. The majority of these migrants were young people seeking new work opportunities and skills with intentions of staying a few years, establishing a better life for themselves and their families, and then returning home with their newly acquired skills and wealth.

Today the Afro-Caribbean community is the second largest minority ethnic group in Britain. The areas in which Afro-Caribbeans now live are mainly those in which the original migrants had settled, where there has been a high demand for labour, eg. Greater London, Manchester and the West Midlands. Over half of the Afro-Caribbean population live in Greater London.

The Afro-Caribbean migrants who today are elderly were employed in unskilled jobs in factories, foundries, transport services, the Health Service, etc. These jobs required working long, unsocial hours, often

working shifts for low wages, and frequently did not carry an occupational pension. The result has been that these Afro-Caribbean people now find their pensions to be extremely low, if indeed they are eligible for pensions at all. Many Afro-Caribbean carers are unemployed and therefore unable to support their elderly dependants, and in some instances their caring role has meant that they have had to give up employment.

Research has repeatedly demonstrated that there is a correlation between poor health and low socio-economic status. Black people are more likely to have lower grade employment which means they are more likely to suffer poor health. They are also more likely to suffer racial inequalities in housing, education and access to health and social services. Thus, elderly black people are more likely to suffer worse treatment than the mass of the elderly retired community and yet, ironically, their needs have, to date, been largely disregarded in relation to provision of services and professional advice. They have been left to fend for themselves.

It is within the context of a different cultural and social background and a generally poor, often subsistence-level economic situation, that the needs of the Afro-Caribbean carer must be assessed.

Appendix

The Project

Background of research

In its first three years the King's Fund Centre Carers Unit had produced various information and education packs for carers. It became obvious, however, (through consultation with various professionals, organisations, community groups and carers from the various minority ethnic communities) that there was a general lack of information available addressing the specific needs and circumstances of Afro-Caribbean carers. This project began with funding from the Department of Health.

The Unit consulted various Afro-Caribbean workers from community groups as well as voluntary and statutory workers. An Advisory Group representing these organisations was formed to oversee the project.

The King's Fund Centre Carers Unit recognised that a project like this should be based in, and managed by a black organisation. Thus, the West Indian Women's Association (WIWA) — a black organisation in Brent — was commissioned to undertake the work. WIWA are actively engaged in improving and providing support for Afro-Caribbean elderly people and their families.

The project has been given an invaluable dimension gained from the organisation's grassroots knowledge and experience of the Afro-Caribbean community.

The groups consulted during the project stressed that merely producing the information is not, in itself, enough. They felt that the available existing services are often largely irrelevant and insensitive to the needs of black carers. Many emphasised that past experience of institutional racism and hostility make it difficult for Afro-Caribbean carers to seek support. However, producing material such as this booklet is important because it can clearly outline what services are, or are not available. This booklet can also provide a basis for motivating carers themselves to seek help and press for better services and support.

Aims of research

It became clear during consultation with carers that they were frequently unaware of available information on services for carers. When there was information, this was unhelpful and inappropriate. The absence of adequate information and the personal experience of racism were felt to be the main reasons why Afro-Caribbean carers under-utilised existing services. The overall aim of the project is to provide information which meets the specific needs of Afro-Caribbean carers and elderly Afro-Caribbeans.

In providing this information to the carer, the booklet aims to:

- help Afro-Caribbean carers recognise and understand the nature of their caring role;
- inform the carer about available sources of support;
- provide 'signposts' to where this help and support can be obtained;
- underline the current inadequacies and urge carers to press for changes;
- encourage local workers to gain knowledge and understanding of the needs and requirements of Afro-Caribbean carers of elderly people.

Method of research

Although the information in this booklet is to be used nationally, for practical purposes the research was concentrated in a number of selected London boroughs: Harrow, Haringey, Wandsworth, Brent, Westminster, Croydon, Kensington and Chelsea, and other targeted areas such as Birmingham, Manchester and Dudley.

The most important aspect of the project was consulting carers themselves. It was important for them to establish their knowledge of existing services, identify their needs and articulate their experiences and put forward suggestions.

These consultations were conducted in a friendly and relaxed atmosphere either in the carer's home or at the community centres they visit. Consultation was in the form of open-ended questions and discussion which was geared towards finding out the specific needs of

carers. This two-way approach served the dual purpose of providing material for the booklet and also helping carers to become aware of services and benefits available to them.

Fifty carers were consulted. Voluntary and statutory agencies dealing with Afro-Caribbean elderly people were also consulted and this included input from the Advisory Group. The resulting information describes both good and bad experiences of carers when they seek access to available services.

List of Useful Addresses

Age Concern England
Astral House
1268 London Road
London. SW16 4EJ
Tel: 081 679 8000

Age Concern Scotland
54a Fountainbridge
Edinburgh. EH3 9PT
Tel: 031 225 5656

Age Concern Wales
Fourth Floor
1 Cathedral Road
Cardiff. CF1 9SD
Tel: 0222 371566

Age Concern Northern Ireland
6 Lower Crescent
Belfast. BT7 1NR
Tel: 0232 245729

Age Concern Greater London
54 Knatchbull Road
London. SE5 9AG
Tel: 071 737 3456

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

Arthritis Care
5 Grosvenor Crescent
London. SW1 7ER
Tel: 071 235 0902

Association of Continence Advisers
Disabled Living Foundation
380-384 Harrow Road
London. W9 2HU
Tel: 071 289 6111

British Association For Counselling
37a Sheep Street
Rugby
Warwickshire. CV21 3BX
Tel: 0788 578328

Carematch
286 Camden Road
London. N7 0BJ
Tel: 071 609 9966

Carers National Association
19 Chilworth Mews
London. W2 3RG
Tel: 071 724 7776

Caresearch
162-164 Upper Richmond Road
Putney
London. SW15 2SL
Tel: 081 780 9595

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

Centre Of The Environment For
The Handicapped
35 Great Smith Street
London. SW1P 3BD
Tel: 071 833 2451

Counsel and Care Advice and Help
For Older People
Twyman House
16 Bonny Street
London. NW1 9PG
Tel: 071 485 1550/1566

Chest, Heart and Stroke Association
CHSA House
123-127 White Cross Street
London. EC1Y 8JJ
Tel: 071 490 7999

Family Welfare Association
501-5 Kingsland Road
Dalston
London. E8 4AU
TEL: 071 254 6251

Crossroads Care Attendant Scheme
10 Regent Place
Rugby
Warwickshire. CV1 2PN
Tel: 0788 573 653

**Greater London Association of
Disabled People (GLAD)**
336 Brixton Road
London. SW9 7AA
Tel: 071 274 0107

**Dial UK (Disablement Information
and Advice Lines)**
Park Lodge
St Catherine's Hospital
Tickhill Road
Doncaster
South Yorkshire. DN4 8QN
Tel: 0302 310123

Help the Aged
16-18 St James's Walk
London. EC1R 0BE

Disability Alliance
25 Denmark Street
London. WC2H 8NQ
Tel: 071 240 0806

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

Disabled Drivers' Association
18 Creekside
London. SE8 3DZ
Tel: 071 692 7141

Hospice Information Service
St Christopher's Hospice
51 Cowrie Park Road
Sydenham
London. SE26 6DZ
Tel: 081 778 9252

Disabled Drivers' Motor Club
1A Dudley Gardens
London. W13 9LU
Tel: 081 840 1515

**Headway National Association for
Head Injuries Ltd.**
200 Mansfield Road
Nottingham. NG1 3HX
Tel: 0602 622382

Disabled Living Foundation
Main Headquarters
380-384 Harrow Road
London. W9 2HU
Tel: 071 289 6111

Huntington's Disease Association
108 Battersea High Street
London. SW11 3HP
Tel: 071 223 7000

**London Dial-A-Ride
Users' Association**
St Margaret's
25 Leighton Road
London. NW5 2QD
Tel: 071 482 2325

**Mind, National Association for
Mental Health**
Main Headquarters
22 Harley Street
London. W1N 2ED
Tel: 071 637 0741

**Multiple Sclerosis Society of Great
Britain and Northern Ireland**
25 Effie Road
Fulham
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

**National Association of Disabled
Drivers**
Ashwell Thorpe Hall
Ashwell Thorpe
Norwich.
Tel: 050 841 449

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

**Royal Association For Disability
and Rehabilitation**
25 Mortimer Street
London. W1N 8AB
Tel: 071 637 5400

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

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

VOCAL
336 Brixton Road
London. SW9 7AA
Tel: 071 274 4029

Afro-Caribbean Organisations Contacted

Belvedere House Day Hospital
341 Harlesden Road
London. NW10
Tel: 081 459 3562

Wise Project
(Education Project Club)
31-33 Wood Side Avenue
Alperton
Middx. HA0 1UN
Tel: 081 903 0682

New Testament Church of God
179 Willesden High Road
London. NW10 2FD
Tel: 081 459 5345

West Indian Senior Citizens'
Organisation
8 Wrottesley Road
Harlesden
London. NW10 5YL
Tel: 081 965 3533

Brent Mental Health Project For
Elderly People
Pound Lane Clinic
Pound Lane
London. NW10
Tel: 081 451 6262

Pepper Pot
2nd Floor
39-41 Acklam Road
London. W10
Tel: 081 968 6940

Haringey Black Over 60s
Resource & Information Service
Annex B, Door No 6
Tottenham Town Hall
Town Hall Approach Road
London. N15
Tel: 081 885 3107

The Calabash Centre
24-26 George Lane
London. SE13 6HH
Tel: 081 461 3420

Ethnic Minority Health Care
Forum
Paddington Migrant Unit
439 Harrow Road
London.
Tel: 081 960 5746

West Indian Ex-Servicemen's
Association
165/167 Clapham Manor Street
London. SW4 6DB
Tel: 071 627 0702

Adult Home Finding
Social Service Area 5
St Andrew's Road
London. NW10
Tel: 081 908 7483

Brent Age Concern
Craven Park Road
London. NW10
Tel: 081 965 7711

Paradise Luncheon Club
12 Donovan Court
Exton Crescent
Stonebridge
London. NW10
Tel: 081 453 0663

Brent Triangle
120 Craven Road
Harlesden
London. NW10
Tel: 081 961 3337

Welcome Senior Citizen Club
Arlie Avenue
Willesden
London. NW10
Tel: 081 451 4658

Service Manager
Social Services
Stag Lane
Kingsbury.
Tel: 081 908 7251

Wandsworth Black Elderly
946 Garratt Lane
Tooting
London. SW17 0ND
Tel: 767 842617

Golden Age Club
148 Gideon Road
London. SW11
Tel: 071 223 5802/9608

Standing Conference of Ethnic
Minority Senior Citizens (SCEMSC)
5 Westminster Bridge Road
London. SW1 7XW
Tel: 071 928 0095

Monoworth Community Care
Villa Methodist Church
Birmingham 21.

Afro-Caribbean Self-Help
Organisation
104 Heathfield Rd
Handsworth
Birmingham.
Tel: 021 554 2747

Dominica Association Bradford
10 Worthington Street
Bradford 1.
Tel: 0274 392306

Check Point
45 West Gate
Bradford
West Yorkshire.
Tel: 0274 722996

Coventry West Indian Association
159 Spon Street
Coventry. CV1 3BB
Tel: 0203 552929

Leeds West Indian Centre
10 Laycock Place
Leeds. LS7 3JA
Tel: 0532 629465

West Indian Standing Conference
(WISE)
5A Westminster Bridge Road
London. SE1 7XW
Tel: 071 928 7861

West Indian Senior Citizens'
Project (WISCP)
Caribbean Court
31-35 Lincoln St
Leicester. LE2 0JU
Tel: 0533 512224

Moss Side Group for the Elderly
and Infirm
Barley Education Community Centre
Chichester Road
Hulme
Manchester 15.

Black Carers' Support Group
Annie Wood Resource Centre
129 Almay Way
Lozells
Birmingham.
Tel: 021 554 7137

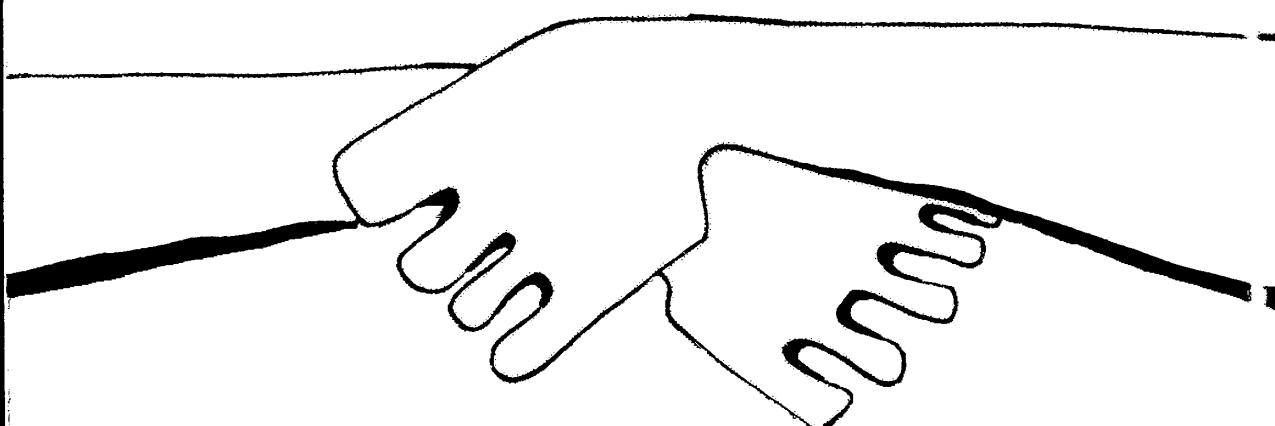
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