

**Older people doing it for themselves**

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# **Older people doing it for themselves**

**Accessing information, advice and advocacy**

**Laurie Kerr and Vivien Kerr**

The **Joseph Rowntree Foundation** has supported this project as part of its programme of research and innovative development projects, which it hopes will be of value to policy makers, practitioners and service users. The facts presented and views expressed in this report are, however, those of the authors and not necessarily those of the Foundation.

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## **SIGNPOST**

The Signpost Project was a part-time development project concerning information, advice and advocacy for older people.

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First published 2003 by the Joseph Rowntree Foundation

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A CIP catalogue record for this report is available from the British Library.

ISBN 1 85935 153 0 (paperback)

ISBN 1 85935 154 9 (pdf: available at [www.jrf.org.uk](http://www.jrf.org.uk))

Cover design by Adkins Design

Prepared and printed by:

York Publishing Services Ltd

64 Hallfield Road

Layerthorpe

York YO31 7ZQ

Tel: 01904 430033; Fax: 01904 430868; Website: [www.yps-publishing.co.uk](http://www.yps-publishing.co.uk)

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# 1 Introduction

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## **Report of the Signpost Project, June 2001 to February 2003**

The Signpost Project was a part-time development project concerning:

Information advice and advocacy for older people.

It was researched, pursued, debated / argued over and the cause of a lot of fun by and for two older people:

Laurie Kerr – Project Director

Vivien Kerr – Project Co-ordinator (and the one whose feet were on the ground – most of the time!)

## **Background to the project**

This report has been written by Laurie Kerr and contributed to by Vivien Kerr. It will describe the research undertaken, look at the provision of information available to older people (with a particular focus on the London Borough of Barnet), identify useful and helpful literature, give some personal reflections and experiences, and draw some conclusions.

I am not an academic, researcher or sociologist and came to this project with a background in marketing and promotion – having run a charity I founded in support of a world-renowned heart research team for 20 years and having been, in the last few years, involved in matters concerning older people. In this latter respect, I made contact with all local authorities to establish what they had in place that encouraged older people (aged 50 plus) to take regular, meaningful exercise that was beneficial to their long-term fitness and health. Having had a very good response, I wrote to Coventry City Council suggesting they organise a ‘Festival for Older People’ and this they did when they became a Better Government for Older People (BGOP) pilot project. I was invited to organise the health and fitness section and was then asked to devise and set up a 24-week pilot project for older people, which would help them to get fitter and realise the benefits

of an ‘active’ life. It would also raise awareness of the benefit of taking on new challenges and ideas to enrich their lives, and encourage them to use their existing or new-found talents to help other older people and to become mentors in Coventry. From this small project emerged the Coventry Older People’s Mentoring Scheme, which was run by the Adult Education Department, under the guidance of Dave Crossan (Advisory Group member) and which is still continuing to thrive. In fact, a recent visit showed that those first mentors, supported by the Adult Education service, were arranging such diverse activities as information and communication technology (ICT) training, healthy lifestyles and Latin-in-Line dancing. The courses allow the students to gain accreditation and, where appropriate, they can qualify for financial support. Part of the ICT scheme enables housebound adults to participate in local affairs and gain direct access to councillors through the council web site. In this way, they were able to increase their access to information and improve their lifestyles. Other ideas I had pioneered had been taken up by some of the voluntary organisations across the city using the Neighbourhood Renewal Fund. This enabled a carers’ group, originally set up for walking, to find out about other support and advice to which they were entitled. The recognition of the continuing work of the mentors demonstrates how valuable a resource older people can be.

In addition to the above, I also worked for the Greater London Forum for the Elderly involving the 32 London boroughs and the City of London. Here, I encouraged and helped the organisation of 33 public meetings of older people whose views were the basis for discussion at an Older People’s Greater London Parliament in 2002. I am currently involved in the Partnership with Older People initiative in the Greater London Borough of Harrow. This arose from the BGOP pilot project and I chair the Information Sub-group.

My wild flights of fancy and sometimes non-politically correct ‘utterings’ were tethered by

Vivien who has worked in the disability field for some years and who became a mature student in her fifties, graduating with a BA Hons in Sociology with Political Economy and an MA in Women's Studies. She is currently working as National Co-ordinator for the Thalidomide Society and is a visiting lecturer with the University of Westminster.

### **What were the aims, what did we hope to achieve and how did we go about it?**

The project brief, accepted and funded by the Joseph Rowntree Foundation (JRF), started with the words:

*The project aims to establish the perceived and actual needs and requirements of two groups of older people:*

- those who are currently pensioners
- those who will become pensioners in the next 15–20 years.

*It will also look at the provision and means of delivery of information, advice and advocacy.*

It was thought that, with better access to information, advice and advocacy, many older people could (if they wished) play a larger part in their community. Hopefully, this would lead to them being seen as 'contributors' to society rather than 'consumers' and as people not as 'pensioners' – a term with which many older people of pensionable age would be happy to dispense.

The project wished to bring to the fore the needs of all older people, regardless of ethnicity or creed, and to identify how they felt such provision would benefit and enhance their quality of life. At the same time, it aimed to demonstrate a range of possible means of delivering information, advice and advocacy, either on an individual or group basis according to their wishes, and including current and future technology.

From the outset, it was recognised that, as bureaucracy does not 'allow for the individual', who nevertheless would require information on an individual basis, a main aim would be to look at:

- enabling people to ask the key questions
- showing people how 'to work the system'.

Little did Vivien and I realise at the time how important this would be on a very personal level when we were both suddenly faced with a totally unforeseen situation, which was to give a new spirit and emphasis to the Signpost Project.

### **So where did it start?**

One of the requirements of the JRF was the formation of an Advisory Committee, which was there to guide and encourage the project. Pooling knowledge and experience, the committee consisted of two academics concerned with older people, two people who were leaders in the older people's movement, one senior supervisor and leader in Adult Education (50+), a disability equality trainer, Alex O'Neil from the JRF and we two authors. The group represented a wide range of knowledge, experience and interests, and, while the discussions were often challenging, they were always stimulating and supportive. Although I knew there was a mass of research papers and briefings on the theme of older people, and it was necessary and illuminating to look thoroughly at these, I felt it would be worthwhile to start with a blank sheet.

During our first meeting with Alex O'Neil, he suggested that we 'KISS'. This was not an invitation, it was an acronym that I readily recognised – 'keep it simple, stupid', the sentiments with which I immediately concurred and have attempted to follow since.

### **Bibliography: a search for the literature on information, advice and advocacy**

I spent many, many hours in the King's Fund Library seeing what had been written on the subject. Many more hours could have been spent continuing the search but there did not seem much to be gained, since quite a lot of what I had tried to read was not very accessible; the language, jargon and phraseology were perhaps aimed at academics, or researchers, or other professionals in the field. From the outset, it had been my intention to conduct this project from the point of view of an older person and, while the content of the research was not totally beyond me, it made for hard work. The amount of literature available on information, advice and advocacy for older people is immense. I give below details of the books, studies and readings that I found to be particularly useful and interesting.

#### ***Getting the Message Across (Social Services Inspectorate, 1991)***

In 1991, the Social Services Inspectorate produced a document – *Getting the Message Across – A Guide to Developing and Communicating Policies, Principles and Procedures on Assessment*. This document was for agencies working with older people. It was commissioned by the Department of Health (DoH) and produced by a small project group drawn from senior officers from social service departments, a health authority and a voluntary agency. The document starts with a quotation made in 1987 by Professor J. Stewart in a paper entitled *Getting Closer to the Public* (Local Government Training Board):

*There are no simple rules; no set of principles that will tell a local authority how to achieve a better public service. It is a search. There is no 'final' discovery. To achieve better public service, an authority must be prepared to learn, to try, to test and to learn some more from the public, from staff, from councillors.*

It would be interesting to reflect from our own personal experiences of coming into contact with a 'public authority' whether the message has indeed come across.

#### ***Age Concern – Action, Help, Advice***

A leaflet describing the work that Age Concern do on behalf of older people and the help and support they provide.

#### ***Age Concern – London Age***

A well produced monthly magazine/newsletter covering issues concerning older people in London.

Age Concern Publications can be accessed by telephoning: 0800 009966.

#### ***Start Here***

An information pack detailing what could be achieved by providing information access on a very wide range of issues through the use of this touch-screen computer system.

Further information from 020 8742 7722; email: [info@starthere.org/](mailto:info@starthere.org/); web site: [www.starthere.org](http://www.starthere.org)

#### ***Living Well in Later Life – a report on a conference supported by Help the Aged, Joseph Rowntree Foundation and Saga (Bowers et al., 2002)***

This is the report of a conference attended by a wide range of representatives of older people from across the country and describes itself as 'An agenda for national and local action to improve the lives of older people in Britain in the 21st century'. Although the report has no direct connection with this project, I would recommend it to all older people. There is so much hope and bubbling encouragement jumping off the page that I will not attempt to highlight any particular aspect, only to suggest that both people who are pensioners now and those approaching retirement would benefit from reading it.

The main aspects identified by older people as crucial to living well in later life are:

- being active, staying healthy and contributing
- continuing to learn
- friends and community
- importance of family and relationships
- valuing diversity
- approachable local services
- having choices, taking risks.

### **Innovations in Information**

This is produced monthly by the National Information Forum. It is clear, concise and carries a fund of information. Its mission statement is to encourage and share innovative ways of making information available to disabled people and others who have difficulty in accessing it. It is also available on CD-ROM. The December 2001 issue included:

- an inspirational Guthrie Memorial lecture from Helen Bamber, OBE, Director of the Medical Foundation for the Care of the Victims of Torture
- information for those going to prison
- information on a web site for asylum seekers or refugees in Gloucestershire
- information on British Red Cross services
- a guide to the NHS
- information on pilot projects with the NHS affecting the general public.

Other editions have carried information on issues that could be of interest to older people.

### ***Speaking Out – Citizen Advocacy and Older People (Wertheimer, 1993)***

This is a readable and readily accessible booklet, which I found useful as background material. The writer is freelance as well as a teacher and trainer in the fields of community care and bereavement. The book places advocacy in context and looks at older people's need for advocacy, citizen advocacy, the development of citizen advocacy with older people and case studies.

### ***Standing by Me – Stories of Citizen Advocacy (Williams, 1998)***

This booklet offers a fascinating insight into how people from varied walks of life benefit and enhance their quality of life through the friendship and advocacy of others who themselves come from a wide and varied background. At times, it seemed to be a little patronising but this does not detract from its useful message.

### ***Citizen Advocacy (Citizen Advocacy Information and Training, 1998)***

If you need to investigate the why and how of setting up and running a citizen advocacy scheme, this is one book that will assist you. Dealing with the subject from A–Z, it provides, in 12 pages, a good idea of what will be involved. It also shows how advocacy can play an important part in the lives of people of all ages.

### ***Citizen Advocacy in Action – Working with Older People (Ives, 1994)***

This is a booklet that is aimed more at the professional but still gives valuable insights into what skills are needed to be an advocate, what works in different situations, why some older people feel the need for an advocate and how professionals view advocates and how they attempt and often succeed in undermining the advocates. The professionals appear to find advocates a challenge to their authority. There is also an extensive bibliography.

## 2 Researching information and advice: meeting people, going places

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### Barnet: mapping the borough

Research was carried out in Barnet in order to map the current provision of information, advice and advocacy. Barnet is one of 32 boroughs which, together with the City of London, make up the Greater London Area and each of the 32 boroughs has a Forum for Older People. Barnet has the second highest population in Greater London, estimated to be 327,100 in 2001. The breakdown of the population indicates that 78,000 of the total population are from minority ethnic communities. There are 48,500 people of pensionable age.

The Barnet Senior Citizens' Forum (BSCF), with an approximate membership of 80, is currently investigating the feasibility and possibility of setting up an information, advice and advocacy resource centre for senior citizens. The Signpost Project has been working in collaboration with the BSCF, which had expressed an interest in the possibility of setting up an older people's 'one-stop shop'.

In July 2001, the BSCF held a conference to discuss the need for such a centre, and the advantages and disadvantages of having a 'one-stop shop' like this for older people in Barnet. After hearing the arguments put forward in the plenary session, there was an opportunity to break into small groups to discuss the points put forward by the speakers. The groups were asked to look at what a resource centre should or could encompass. Not unexpectedly, advice, information and advocacy were high on the list; also included was the chance to have classes on art, information technology, lifelong learning and health facilities including exercise and complementary therapies. There was a strong feeling that the building should be community based, with perhaps a cafe, and that the centre should give older people an opportunity to use their skills. It was also suggested that the location of the centre could be rotated so that older

people living throughout the borough could have access to it. The resource centre should facilitate a two-way process of information – community to the centre and the centre out into the community – and it should be user friendly and have at its core a management/administration system where older people would be the driving force; the age range should be from 55. The aim of the centre would be to facilitate greater independence for older people, an improved quality of life and integration of all members of the community. Other aspects that were considered to be important were outreach health resources, that it should be a venue for other groups of interest to older people and that it should be fully accessible. The groups also discussed funding for the centre, including charging a small fee, and the hiring of rooms and so on.

It is perhaps interesting to note that many of the factors that the groups thought were necessary to have within the centre were already available throughout the borough, both for older people and across the age groups. The older people present, however, were not aware of this and did not always know how to get hold of that information.

A special report entitled *Profiling Poverty, Health and Deprivation in Barnet* (produced by the Corporate Policy Unit of Barnet Council; accessible at [www.barnet.gov.uk](http://www.barnet.gov.uk) – click on 'Local democracy' and then on 'Poverty profile') suggests that many pensioners are facing poverty, even though they might appear at first glance to be affluent, because their capital is tied up in their house. This situation may well be replicated across the country where older people can be asset rich but cash poor and may be exacerbated by enforced early retirement, state pensions linked to prices not inflation, the failure of private pension schemes and the recent falls in the stock market. (It could be argued, then, that the need among the older population for information, advice and advocacy has never been greater than it is currently.)

## Older people doing it for themselves

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In Barnet, there is a wide selection of voluntary, independent and social organisations that can and do provide information, support and help. These include religious centres, minority ethnic social and cultural community organisations, medical and welfare centres, women's centres and specialist organisations such as Help the Aged, Age Concern, Carers' Group, Elderly Day Centres, neighbourhood and community schemes, the Barnet Association of Voluntary Service and the Citizens' Advice Bureau. The local authority provides a large number of notice boards but the main source of information is Action Point (see below for further information) and the council web site.

### Action Point

Action Points are staffed information and advice centres providing a wide range of written material, although not specifically for older people. There are six Action Points throughout the borough, the main one being in the town hall. The trained staff are friendly and welcoming, and are prepared to take the trouble to help. The main library is next to the town hall and includes a wide-ranging reference department. My rather confused queries about population statistics were dealt with efficiently and effectively by the librarian.

In conjunction with the internet, Action Point will have online information on every club, society, social and welfare organisation in the borough. Each organisation will be able to have its own web page, which can be accessed and updated as required. It is also hoped to set up a 'People's Internet Network' through the library system with free internet access for library members.

Another aspect of information and advice provision is for elderly or disabled people who are housebound. This service is carried out by the staff of the mobile libraries, who are increasingly used by people to answer queries, provide leaflets and telephone numbers, and, most importantly, arrange house calls for those in need of specific help. This is seen to be so important that specific training

courses for the staff are being considered.

Barnet Online is the council web site, which, like many other local authority web sites, is being updated to provide easier access and fuller information. I asked if there might be dedicated links for older people but this had not been considered, nor at that time had older people been consulted. I passed this information on to the Barnet Senior Citizens' Forum.

While mapping the Barnet provision for older people, I made contact with a number of organisations whose remit was to help either solely older people or those local community and minority ethnic groups that had a strong connection with older people. I met with the organiser of the Carers' Group but my request to meet with some carers was firmly rebuffed on the grounds that, over the years, 'they [the carers] had been researched to death' and were 'fed up' with it. The carers felt they were an endless source of help and information for researchers from a number of august bodies (e.g. The King's Fund) but never saw anything in return.

There were some frustrating times when a number of attempts were made to set up meetings with local organisations but without success. I also at times had problems making contact with some of the minority ethnic groups in the borough. I approached one group and arranged to meet with the organiser and committee but found, when I arrived at the suggested time, that the committee was not available, another meeting having been arranged. My efforts to rearrange this particular meeting were not successful. This experience was repeated with other community groups, both indigenous and serving minority ethnic communities – meetings were either cancelled without notice or, in one instance, the issues of older people were not considered important. Another group working with older people stated that 'we are well organised and look after ourselves – thank you for contacting us but we have no need to meet with you'.

Although I did have fruitful meetings with other organisations, I think it is useful to make the following points.

- Organisers/committees of some groups seem to control the way things are run and decide what is best for the members even to the extent of 'speaking' for their members, particularly when they (the members) do not speak English.
- Perhaps they were also tired of being researched with no apparent benefit to them.

### **Community Legal Service Partnership**

The Government has decided that measurable standards should be a requirement of all local service provision. In the case of Advice Centres or similar providers, a 'quality mark' will be an indication that the standard of advice provision is of a minimum quality. The Barnet Legal Service Partnership's aim is to 'establish a co-ordinated approach to quality advice based on the needs of the people local to Barnet'. In Barnet, a steering group together with working groups to study needs assessment and provider existence have been set up and have been meeting regularly since 2001. The groups were made up from the Legal Services Commission, Barnet Council and voluntary sector representatives. While the original set-up included the Citizens' Advice Bureau (CAB) and Age Concern, it is noticeable that no actual older people organisations were included.

Initial research showed that those areas where advice was most sought were: consumer affairs, debt, education, employment, family, health and community care, housing and homelessness, immigration, mental health and welfare benefits. These areas were then coded to see how the availability of advice was spread throughout the borough. It was found that many of the providers were 'specialist' in the sense that they restricted their service to ethnicity, religion or some other specific section of the community. This specificity

could in fact limit the sharing of knowledge, experience and expertise to the wider community including older people, leading to lack of co-ordination of information and the possible reinvention of the wheel!

I attended an open meeting of the Partnership to which all likely interest groups had been invited. The response had been lower than anticipated. One of the main points to arise from this was a great concern that the levels set to achieve the overall quality mark (QM) might exclude many small organisations. Where such small organisations relied on the provision of advice to secure their annual funding, the omission of such a quality mark could have devastating effects on their financial resources. In the current financial climate, the ownership of such a quality mark could become one of the funding criteria. At the meeting, the overall feeling seemed to be that the awarding of the QM was based on how the advice was given and the systems involved rather than the actual quality of advice or information. The Community Legal Service (CLS) agreed that this would have to be looked at, as would the objections raised by the various groups to the amount of time and money that would have to be spent on achieving the required standards.

### **Information and advice: what is out there?**

At the outset, it became apparent that, while there is a mass of information available in various forms, there are a number of older people who are not aware of its existence. A meeting with Barnet Seniors underlined this point when, during a workshop session, the question was asked of my group: 'What would you require from a Resource Centre?' The answers included keep-fit sessions, and computer and internet training. The group's astonishment was palpable when they were informed that those activities already existed and were available to them. The question then arose how people found out about those activities. The

provision of information might not be the only answer but rather how to go about finding out what already exists. The issue is complex in that it may be that people simply do not make the effort to find out. But, for some older people, their ability to access information may be severely limited by ill health or disability. However, during the course of the project, I did meet veteran athletes who ranged in age from 60 to 80 years. They were still competing nationally and internationally, and were consequently fitter and healthier than many of their contemporaries.

The problems of accessing information and where to start are not just necessarily confined to older people and can be common to all age groups. If someone has trouble finding something out, this can sometimes be the spur to them setting up a project that would have benefits to people of any age seeking information and not knowing where to start. The following example, I think, illustrates the problems of sourcing information.

### **Start Here**

This project was set up by Sarah Hamilton Fairley, who drew on her own experience of trying to research a serious and unusual health problem in one of her children. She received information and advice from numerous agencies but, even with the benefit of a medical background, found it extremely difficult to obtain facts or knowledge that made sense to her and her family. She felt that her experience was not an isolated one and that many people facing myriad problems could well be asking themselves: 'Where do I start?' After researching the matter further, she discovered that there was a need for a quick and simple method of getting to the starting point and setting off on the 'right path'. The Start Here project was set up to be tailor made to suit any age group or section of the community. The project was demonstrated to the Advisory Committee and works on a simple, computer-based, touch-screen terminal, which anyone can use. The terminals can be sited in any

community-based local building, such as the library, post office or town hall, and trials are currently being undertaken in Scotland and in the London Borough of Newham. Contact details can be found in the bibliography section in Chapter 1 of this report.

### **SeniorLine**

This telephone service is provided by Help the Aged and gives information and advice on welfare and disability benefits, community and residential care, housing, social and personal issues, and other miscellaneous matters. In areas where the staff are not qualified, for example, legal, financial or medical matters, they will refer the caller to someone who can help further. The service covers the whole of the UK but the majority of the calls come from older people living in England and Wales. With a maximum capacity of 125,000 calls per annum, the service is currently receiving 97,000 calls a year. Funding is a critical issue and affects the expansion of the services. Anyone wishing to contact SeniorLine can ring on freephone 0808 800 6565.

### **The Kensington and Chelsea Initiative – Better Government for Older People (BGOP)**

The BGOP programme has given rise to many excellent initiatives, one of which may be of benefit to other local and national authorities in its method of information provision to older people. In the London Borough of Kensington and Chelsea, the Social Services Information Manager became aware that there might be a problem for older people with the differing information offered from council departments. A project was set up under BGOP to research all the information emanating from the various health authority and social services departments that related to older people. This amounted to over 200 pieces of literature. An older people's reading group formed to scrutinise this literature discovered the following.

- Several forms and leaflets duplicated each other and many did not carry a date of publication.
- On some of the duplicated leaflets, the information differed.
- A number of different typefaces were used, some of which were too small and inappropriate.
- There was little or no communication or liaison between departments or agencies.
- There was little or no consultation with older people prior to the production and distribution of information.
- Little was produced in languages of local minority ethnic communities.

The older people's group made the following recommendations, which were accepted:

- 1 The reading group now read and comment on all new literature when in draft form and prior to production.
- 2 Mystery shopping exercises should be carried out involving older people testing information and advice areas.
- 3 More joined-up and community centre information should be commissioned.
- 4 Meeting places for minority groups should be established for the provision of information and advice.

#### Getting information using the internet

I have been regularly advised, throughout the course of the project, that older people do not use the internet because they do not have a computer and are not interested in learning how to use one. Indeed, this was the case with an older friend rapidly approaching 70 years of age who, although still working part time as a chartered accountant, admitted to being a novice concerning the

intricacies of the hard disk. His great hobby is music and, despite being advised that he could use his computer for research, he was not interested. However, he finally succumbed and now expertly orders theatre tickets, buys CDs on line and has 'visited' numerous galleries and museums throughout Europe. My feeling is that he is not unique and many older people are taking up the world wide web to keep in touch with families in other parts of the world. I have been advised that there are a number of schemes throughout the country, some of them government sponsored, whose aim it is to teach all generations how easy it is to access the internet.

Through a government initiative, Learn Direct, an accessible computer is either a walk or bus ride away and free 'how-to-use' training is also available. It should be noted that this is not yet available for people who are housebound. In Harrow, for example, every local library has a number of computers, the reference library having over 30. The council, which had originally been rather lax in addressing information on older people's groups, e.g. Partnership with Older People (an initiative that sprang from the borough being a Better Government for Older People pilot), has now improved and currently gives a breakdown of all Partnership with Older People activities and future projects.

In Barnet, the town hall library has computers as part of the government's Learn Direct scheme. The Learn Direct Centres have trained staff to take people through the course – even how to turn the computer on. Students work at their own pace and personal tutors are provided. As each student has their own account, they can visit any other centre throughout the country and the whole scheme is free. If anyone has their own computer at home, they can access the course at any time providing they have the appropriate software.

Anecdotal evidence suggests that these centres are becoming very popular with older people and, as one 70-year-old woman said to me, 'I can email

## Older people doing it for themselves

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my grandchildren just before I go bed and their  
reply and chat are waiting for me next morning!'.  
Making friends with people across the world is  
another new adventure.

# 3 Advocacy: what it means to older people

---

When older people are asked what the word advocacy means to them, their first thought is usually something to do with solicitors, the law, etc. The word does not seem to be generally recognised. Advocacy has been in existence for a number of years and Citizen Advocacy Information and Training (CAIT) is involved in over 500 advocacy projects.

So, what is advocacy? According to CAIT it is:

*... the process of pleading the cause and/or acting on behalf of another person (or persons) to secure services they require and/or rights to which they and their advocate believe them to be entitled. Advocates owe those they represent a duty of loyalty, confidentiality, and a commitment to be zealous in the promotion of their cause.*

CAIT lists the different types of advocacy as follows.

- *Legal advocacy*: involving lawyers and other legally trained individuals who assist people in exercising or defending their rights.
- *Self-advocacy*: a term used where someone acts on their own behalf to present their case in a fairly formal situation.
- *Collective/class advocacy*: when a group of people unite to campaign on issues affecting more than one person. In the case of class advocacy, it could involve people who are homeless.
- *Citizen advocacy*: involving trained selected volunteers who support those people who may be disadvantaged in some way and not in a position to exercise or defend their rights as citizens. Citizen advocates work on a one-to-one basis and are totally independent of any service providers. They might be involved in expressing the concerns and aspirations of an individual, helping them to obtain services to which they are entitled and providing practical and emotional support.

## Examples of advocacy at work

### Advocacy in Barnet

A recently formed organisation, which is situated on the Grahame Park Estate, has a small permanent staff and relies heavily on the recruitment of volunteers. Its funding is small when compared to the overall need for a larger scheme. It is part of a resource centre, which was developed to serve the needs of the large council estate and which also includes a Citizens' Advice Bureau.

### Westminster Advocacy Service for Senior Residents (WASSR)

This is an organisation where older people help other older people. WASSR also provides training/awareness courses for professionals in the medical and social welfare fields. Fifty per cent of the trained advocates are older people and the trustees and management committee are all older people. The projects that WASSR is involved with concern dementia, housing, residential care, older people and the health service, Independent Complaints Advocacy Service (ICAS) pilot projects, minority ethnic outreach and people with challenging behaviours. WASSR recruits and trains all the volunteer advocates. In any one year, it is working on between 150 and 175 cases and accepts approximately 100 new cases a year. Of the people it works with, 95 per cent are over 60 years old and the remaining 5 per cent are over 55. The latter group are included on merit according to the urgency or seriousness of their need. When WASSR's Director, Irene Kohler, was asked how the organisation viewed what it does, she remarked, 'we help older people resolve their problems so they can lead a less worried and more healthy and contented life'. An advocate with WASSR emphasised that the individual older person seeking help welcomed the fact that the advocate was themselves an older person sharing similar life experiences and knowledge. The added value of the work carried out by WASSR was that it

complemented the services provided by the council and local health authority. It may come as no surprise that WASSR's biggest problem is the lack of ongoing core funding. The amount of hours spent in seeking finance to support its work is disproportionate to the number of 'client-centred' hours. It is a sad comment that all of the advocacy projects that I met have the same funding problems. This is not a new argument and has been rehearsed by many voluntary groups in the past decades but I feel that some way should be found to provide a meaningful basic core funding that would allow such advocacy services to operate freely and independently.

### **The Nubian Life Centre, Hammersmith and Fulham**

The Centre provides a meeting place five days a week with computer classes, a luncheon club, a gardening club, outreach and a positive philosophy of involving older people from African-Caribbean backgrounds. The Centre applied for and received funding to set up a project, Black Ethnic Minority Elders (BEME) – Doing it for Themselves – a project that specifically addressed issues of concern to the members of the Centre. With the guidance and leadership of Jazz Browne, the project started in 2002 with the slogan 'many voices, one goal'. Its aims and objectives are to:

- empower individuals to advise and assist voluntary and statutory agencies to develop services that are relevant and accountable to black and minority ethnic elders, and to enable them to address their specific needs
- respect the experience, knowledge and skills of our elders by creating opportunities for those skills to be used in shaping and developing our communities
- ensure older people themselves are able to influence and have a say in developing local policies and planning services

- reduce social isolation at all levels and address discrimination against elders, particularly black and minority ethnic elders
- build partnerships with other community groups and local councils on issues affecting older people.

I attended one of the BEME meetings to talk about the Signpost project and, prior to my talk, I listened to two specific reports from individual BEME members about meetings they had attended, one as an official representative of the Nubian Life Centre. During one of the meetings, the representative raised a query; his first attempt was ignored and, when he addressed the meeting through the chair, he was not allowed to voice his concern. The issue he wished to raise was not alluded to or addressed, even though other questions were dealt with. This man did not know why he was ignored but felt he was not important. The other report concerned attendance at a council departmental meeting to discuss a local issue. However, it became apparent that the decision had already been made before the meeting was convened and that the council representatives were merely following the 'consultation' protocol. Both representatives then met with Jazz Browne to check whether there had been any misunderstandings and, if not, to follow this up with the respective chairs of both meetings.

After I had introduced the Signpost project, the meeting was asked if anyone had any issues to raise. At this point, it became apparent that there was a need to make sure that the reason and focus for any meeting should be made very clear – particularly as, in this instance, it was assumed that I was a local police superintendent talking about the patrolling of the local streets. However, a further problem encountered by another BEME member was partially solved by sharing the issues with the rest of the group. The member concerned was also a little unsettled by the responses and, in this case, the opportunity to talk separately and

privately was offered and gratefully accepted. BEME is now looking at going into partnership with CAIT to do a project on advocacy for black elders and ethnic minorities in London. I have recently learnt that, subject to further clarification, the project will go ahead.

In the future, the BEME project will continue to

develop and extend its strategy of empowerment through the development of good practice, networking within the borough and training sessions in committee work and public speaking, as well as the setting up of a forum for Caribbean black elders throughout London by networking using email and meetings.

## 4 Talking to older people: finding out their views and sharing their experiences

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Some of the issues and concerns I came across during the research process were checked out and discussed with several small reference groups. This was suggested by the Advisory Group. It was also intended that these small groups could be used to find out whether there was a practical and effective recipe for finding, absorbing and managing information. I followed this up by approaching small groups of older people in Barnet, Harrow and Hammersmith and Fulham. I also continued to meet with a number of individual older people during this time.

### Barnet

I approached Barnet Senior Citizens' Forum (BSCF) and the Partnership with Older People (POP) groups in Harrow to set up several meetings. At each meeting, the group consisted of a mixture of older people from a range of different backgrounds with different experiences. All of them were pensioners and retired from employment.

Through BSCF, a meeting was set up to discuss the range of information available to older people and its accessibility. When the subject of the Barnet Action Points was discussed, apart from the Chair, no one else in the group knew about them. When I explained what the Action Points (APs) were, the group felt that, even though they were in six locations across the borough, the APs were still not accessible to everyone and 'probably cost a lot of money which could have been better spent elsewhere'. Another member of the group had in fact used the facility but had not realised what it was called – perhaps a point for the council to consider.

Possibly the most interesting point to come out of the meeting was when I asked the group if they had experienced any difficulty in seeking information on a problem that had had a bearing on their life and that they were prepared to share

with the group for their possible advice and support. An elderly woman (Mrs C) stated that she had had a problem getting information about a transport issue. It transpired that she and her husband lived in a block of flats with a number of other elderly people. The flats were situated on a major roundabout junction where the A1 met the A41. The junction was undergoing major reconstruction, which included the installation of phased traffic lights, resurfacing, road widening and the introduction of directional lanes. The bus stops that Mrs C and other pensioners used, particularly when going to and from the shops, while not on the junction but nearby, had been moved 100 yards down the road without warning. As Mrs C said, having to walk the extra distance to the shops with empty bags and baskets, although difficult, was not impossible, but returning with full bags/baskets, etc. was exhausting and required a number of rests. She was determined to find out how long the situation was likely to continue and asked an official. The official did not know and referred her to someone else. Her enquiry as to when the bus stop would be returning to its original position was met with the comment that it probably would not be. Mrs C was then referred to the local authority and London Transport, neither of whom responded helpfully. At this point, I put the problem to the group to test out a theory I had been considering. One of the group, having ascertained that Mrs C would be happy to answer some questions, suggested that she contact particular persons within the local authority, giving names and contact numbers and also the names of two of her local councillors. This man then promised that, if Mrs C had no success with the council and councillors, he would be happy to help personally. Mrs C was delighted that at last she could find out some practical information.

If this situation were to be extrapolated to the wider community, I think it would be very likely

that within any grouping – faith, sports, hobby, women’s groups, etc. – there would be someone with the knowledge and experience to provide an answer to many problems. A short telephone survey of faith groups in Barnet indicated that several held advice sessions both informally and formally, and a certain number of them encouraged their members to form social groups.

The main issues that arose from these group meetings included an initial lack of knowledge about advocacy. However, when examples were suggested of helping friends or neighbours with specific problems, many of the group had in fact acted as informal advocates for both themselves and others. At each meeting, a short questionnaire was put to the group asking each of the members to consider what involvement they had had recently where information or advice was needed and how they had tackled this. There was some discussion on the ways of solving a problem by posing it to someone else who, standing back, could suggest a possible solution, or by trying to look at the problem from a different angle. The short questionnaire and answer session proved to be quite successful in getting the group to ‘think outside the box’ and then relate the ‘recipe’ to their own problems or concerns.

### **How some older people have negotiated the information pathway**

During the course of the project, I have met a number of individual older people and discussed with them where and how information can be accessed, and any problems that they had encountered. One very active older woman, who took up long-distance walking in her forties and now takes part in national and international events, is also profoundly deaf and she has experienced considerable difficulty in getting information about her condition from her consultant and in being treated as an individual. This echoes my own experience when trying to elicit information from an ear, nose and throat specialist about my increasing

loss of hearing. The consultant made a number of assumptions when he saw my age and grey hair, and commented that a hearing aid would improve my social life. When I responded that it was not my social life that concerned me but my ability to hear when chairing meetings or in committees, his attitude changed and he began to listen and to provide me with the information I needed to hear.

I discussed the experiences of information gathering with another older woman who had to find home care services for her elderly mother living in the North of England. It had proved very difficult when seeking medical and social services support, and the daughter had made numerous visits to the North to find out the information she needed. In fact, the local social services had been very helpful and the required home care services were put in place. The mother, however, refused or cancelled the services, which caused the daughter a great deal of concern. What became clear from the discussion we had was that the daughter had been successful in finding the information she needed and in managing it. She had never thought of this process as a pathway to follow, but agreed the experiences of bringing up a family, dealing with problems as they arose and finding solutions might act as a model for tackling future situations. She commented that she had to remind herself that, when other problems arose, she had the knowledge and experience and could therefore follow the information pathway again.

Based on what others had told me and using our own experience, Vivien and I devised an exercise for ourselves, which we hoped could provide a basis for negotiating the information pathway, even though it was not in any way rigorously scientific.

#### **Starting point**

- Start by recalling a past problem where information was needed.
- How was the problem approached?

## Older people doing it for themselves

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- Was the information easy to find?
- If not, what were the next steps taken?
- Would it have been helpful to talk to a friend or relative?

### Looking further afield

- Would it be useful to approach the following for information: council, internet, library, home help, neighbour, doctor, social club, church/faith group?

### Stumbling blocks

- Was sufficient information available to resolve the problem?
- Was it useful?
- If not, would it have helped if a friend/ supporter or advocate had been available to help in sorting out what information was needed and what was available?

### Managing the information

- Having acquired the pertinent information, was the process easy to manage?
- Was any help offered by the information provider to manage that information/advice?
- If yes, was that help useful?
- Did acquiring and managing the information give a sense of being in control of the situation?
- What might have helped if no assistance had been offered or was available in managing the information?
- Many people have already acquired a lot of experience and knowledge during their lifetime – could past examples of ‘problem solving’ be used in a current similar situation?

This last suggestion has aroused a lot of interest with both the groups and individuals, as it reminds people that, in many cases, they have the skills to find out what they need.

One other example illustrates the time-consuming task that information gathering can be. A neighbour, when asking about the project, said that he and his wife were trying to find a care or nursing home for his very elderly mother-in-law. Her eyesight was failing and she was no longer able to stay in her warden-controlled flat. Did I have any advice? They had been involved in the information-gathering process for some two to three months and had approached the GP and social services and made a number of enquiries of various organisations. I was able to give this man a list of further possible organisations using the Government’s web site Care Direct. After a few weeks, I enquired how the couple were getting on and was told that the man’s mother-in-law was now happy and living in a care home a few miles away. When I asked him what problems he had encountered in the whole process, he replied, ‘throughout, it would have been much easier if we had known what questions to ask’. He went on to warn, ‘do not assume that you understand all that you see and hear’. He explained that, in three of the homes that he and his wife had visited, they were told that certain areas of the home were the EMI areas or wings. It was only on his third visit that he asked what EMI meant and was told elderly, mentally infirm. He then realised that such places were not suitable for his 85-year-old, sight-impaired mother-in-law. He had thought it meant that those wings of the home were sponsored by EMI (Electrical Mechanical Industries) and how generous the company was to do this!

## 5 Personal experiences: finding information, advice and advocacy

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I became aware a short while ago that it was the 106th anniversary of the birth of my father. Being disowned at birth, fostered and leaving school at 14 did not amount to the best start in life. In addition, my father was blinded at Ypres in the Great War before he reached his majority. He could have been forgiven for thinking 'why bother?'. But, with the help and support of St Dunstan's, his indefatigable spirit and his foster family in Bermondsey, he did bother and made a success of his life. He taught me many things when I was a lad, one of which was that, while you might be disadvantaged, with your own effort you could find ways around problems. I once asked him how it was that, having moved house to a totally new area, he was, within a matter of weeks, able to find his own way to the station, know where the zebra crossing was and go to specific shops. To answer this, he took me for a walk and told me to close my eyes. As we went along, he asked me questions about where we were and what was around me. After a short period of time, although I knew I had walked this route many times before, I had no idea where I was.

He then told me that I was not thinking; we stopped and he asked me how many side roads we had crossed – he had counted and I had not. He asked me how many different types of surfaces we had walked on, what I could hear and, most importantly, what I could smell. Buildings, garages, workshops, restaurants all give different sounds and smells and surfaces can change. The zebra crossing turned out to be 'so many paces' past Smith's the Greengrocers and, as he said, 'if I get lost or am not sure, if I stand still, someone will usually ask if I'm OK or, when I hear people nearby, I've got a tongue in my head and I ask'. He was not unique but he was quite happy to travel to and from London from wherever we lived in England, on his own, using his ears, nose, feet, tongue and brain and, of course, his fingers. At an early age, I learned never to assume but to ask; for

example, when I put his meal in front of him, I would ask him if he wanted mustard and he would reply, 'thanks, at 12 o'clock'. He then knew he had got his mustard and where it was on his plate.

This all comes back to information and how it is received, and how we need to ask these key questions. This leads me to the reference I made earlier about how Vivien and I suddenly found ourselves in a situation where finding the right kind of information and asking the pertinent questions became paramount, and how I found myself in the role of adviser and advocate.

### Vivien's experience

*I was diagnosed with the early stages of breast cancer in February 2002. The news was all the more shocking because we (Laurie and I) had just returned from a fantastic family holiday in New Zealand. Following a routine check-up/mammogram, I was recalled for a further examination which showed the likelihood of pre-cancerous cells being present. At this stage, it was extremely difficult to take the news on board and at the same time consider what information I needed, what the next step would be and whether I was going to die. The knowledge that our eldest son's first wife had died at the age of 34 of breast cancer gave the news heightened impact. Further tests had to be undertaken and I had to return to the clinic the following week for the results and arrangements for possible treatment.*

*The first experience of receiving information and attempting to process it was in talking to the very experienced Breast Cancer Specialist Nurse at the Assessment Clinic. We were presented with the opportunity to discuss the possibilities, try to absorb the diagnosis and set ourselves a personal agenda for dealing with the news and the possible outcome of the further results over the next few days. My initial feeling was to gather as much information as*

possible about the possible diagnosis. After the diagnosis of DCIS [ductal carcinoma in situ] was confirmed, I was given an appointment to see a consultant and the X-rays to take with me. The advice proffered was not to search too deeply, for example on the internet, but wait until I had seen the consultant. I could look at the X-rays if I wished but I would probably not understand the medical terminology. This was not exactly 'a red rag to a bull' but something akin. I did look at the X-rays and I did go to the internet and research it thoroughly.

At each stage of the treatment, including meetings with the consultant and specialist nursing staff, I sought and was given further information. I also spent a considerable amount of time, researching breast cancers and their various stages and the likely survival rates. My own prognosis was good, even though a small invasive section of the DCIS had been found during the first operation. This information necessitated a great deal more discussion with the specialists and ourselves concerning the debate on whether to have another operation to find out whether the cancer had spread to the lymph nodes. I found an American web site run by the National Institute for Cancer, which gave a number of abstracts on research carried out into breast cancer. This site was aimed at the medical profession and required considerable patience and persistence in order to decipher which sections of the information were relevant. Having discussed with Laurie whether to have a further operation, I decided to go ahead. It was first thought that the cancer had spread and over a dozen lymph nodes were removed. However, happily, after further tests proved negative, I had only to undergo three-and-a-half weeks of daily radiotherapy in July and August 2002.

The impact of the initial diagnosis was so great that it took time to assimilate the information given. Despite the fact that I already had research experience and a good idea of where to go for information, it took time and a great deal of discussion, reassurance and almost constant revisiting of the diagnosis before I

could objectively attempt to embark on the 'information journey'. I must here pay tribute to Laurie whose unstinted love, advice and support throughout has been invaluable. I could not have wished for a more loyal, committed and zealous advocate.

The experience of finding our way through a maze of information has crystallised our thinking that there are several stages to negotiate and that, at these various stages, advice, support and/or advocacy are likely to be needed. Courage, tenacity, persistence and energy are required in order to find the information, take it in, make use of it and know when sufficient information has been gathered to make a decision.

Achieving all the above can help to make an individual feel they have some control over a similar situation and give them confidence to manage any ensuing information and advice given or offered. However, it is likely that some other formal or informal support will also be needed. It is possible that the experience gained from managing this process could be used again and again in the future.

### Laurie's perspective

We had had a wonderful holiday in New Zealand with our eldest son and his family, and were completely unaware of what lay ahead of us. The news of Vivien's diagnosis struck like a torpedo below the water line; the reverberating shock came in waves and we were all visibly shaken. One of our immediate concerns was how we would break the news to our eldest son whose first wife had died some six years previously of breast cancer. Once Vivien had jumped that initial hurdle, the situation became a little easier.

During the 34 years of our marriage, we had retained our individual interests and at the same time supported each other. Over the years, I had had a number of stays in hospital and that experience I put to good use and practice during the next few months.

*We discussed the diagnosis and prognosis and all the several possibilities in great depth. We knew that 'information is knowledge' and to that I added 'and with knowledge you can have control', and that is what we aimed for – control. Vivien's fears of going into hospital were somewhat allayed by my own (numerous) experiences – while certain things such as medical issues were not within her control, she was able to control how she responded to the situation. I recognised that, in certain personal areas, she had complete control if she wished to exercise it. I made it clear that I would not intrude where not wanted but would always be there when wanted, regardless. In this way I became her advocate.*

*I accompanied Vivien to all the appointments and visits until she indicated that it was not necessary. My main advocate role came when she had appointments with the consultant, doctors, oncologists, Macmillan nurses and radiologist. For the initial consultation with the surgeon, Vivien had done a great deal of preliminary research and had a clear idea of her diagnosis, which both surprised and pleased the surgeon. Having noticed that Vivien came with a number of notes, he was happy to answer any questions both she and I had. This is where my role as advocate became crucial. At times in such a situation, you will listen to what is being said but not actually hear it. Vivien was taking notes and listening to what was being said and at times missed the subtle inflection in the surgeon's tone or did not pick up the fact that the 'door had been left ajar' to be pushed further open if wished. I then stepped in and asked what was meant and let Vivien pursue the matter if she wished to. We were with the consultant for nearly an hour and he said that, while it had been a pleasure to meet Vivien, he would have rather it had not been necessary. He then thanked me for playing the part I had. We saw him four times altogether, twice at our request.*

*As has already been stated, a second operation was required to ensure the invasive cells had not spread to the lymph glands. And, when it was shown that cells were healthy, the relief was tremendous.*

Why have we included these personal experiences? Because they are about information, how it is gathered, how it is heard and what is done with it. They also explain a different but vital role of the advocate – how a relative or trusted friend can help.

### **'Home thoughts from abroad': the New Zealand experience**

While visiting family in New Zealand in early 2002, we thought it might be useful to find out how older people in New Zealand were involved in working with their Government. I had made contact with the Minister for Senior Citizens before we left the UK and had received an invitation to meet with her Senior Policy Adviser and the manager of the departmental unit for senior citizens.

New Zealand has a population of approximately 3.5 million of which 446,000 were over the age of 65 (1999 figures). It is estimated that, by 2031, the figure will have doubled. Allied with this is the realisation that future generations are expected to be healthier, better educated and more skilled, and more active, particularly in the workforce. The ratio of older people in the general population is similar to that of the UK. The New Zealand Government has an Advisory Council for senior citizens, which meets every two months and which the Minister attends for part of the day. It develops a work programme for the consideration of the Minister. The Council is made up of a panel of five to seven community members, who provide independent advice on issues affecting the well-being of senior citizens. Members are appointed according to their knowledge and experience of the issues involved, and are not drawn from any interest or pressure groups. The following are the main points that emerged from our meeting.

- Eventually, economic imperatives would drive the recognition of older people.

## Older people doing it for themselves

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- Older people are part of the whole population and their position in the population should be part of an organic movement starting within the family – older people as grandparents could be strong role models for the younger generation and could be seen as worthy of respect and valued for their experience.
  - Language is important in either valuing or denigrating older people – for example, the use of phrases such as ‘burden of pensions’ or ‘the increasing older population are a drain on resources’ is to be avoided.
  - Policy makers and politicians need to be aware of their own use of terminology.
- There is a danger of creating services specifically for older people, who may then be seen as needing ‘extra’ – older people can therefore be seen as a problem and not as a resource.
  - Information should be accessible to all ages – people have information needs at all stages of their lives, not just in old age.
  - Older people can use the facilities/clubs/services/classes that already exist in the community and therefore do not always need ‘specialist’ services.
  - It should be recognised that there may be a generation gap within the grouping of older people and there are likely to be different issues around the information needs of those under 60 years of age.

# 6 Comments, conclusions and afterthoughts

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The project wanted to highlight the information needs of all older people and to see how the provision of such information could benefit older people. We feel that there are key messages for older people and for policy makers and professionals working in the field.

## Key messages

### The information is out there

- There is a vast array of information and advice provided by both statutory and voluntary agencies. However, it is often on all aspects of community life and is not just for older people. Barnet, for example, has a rich source of organisations providing information, with well trained staff offering assistance if needed. Action Points in the borough are a good resource but are not recognised as such by older people. A major problem is the lack of knowledge that such advice and information exists.
- Older people do not always know how to ask the questions that will elicit the answers they are looking for. Councils and other information providers need to look again at differing ways of collating and disseminating the value of the information resources they have. Local authorities could benefit by sharing the good practice that they may have developed in their own constituency with other boroughs, local authorities, etc. – an element of cross-fertilisation that would be both cost-effective and efficient. Information should be accessible to all ages – people have information needs throughout their lives, not just in old age.

### Been there, done that, got the tee shirt!

- Older people are a resource and should be used as such.
- Older people have a vast amount of experience and knowledge gained through employment,

bringing up a family, surviving to an older age, etc.

### Advocacy – personal and professional

- Many older people will have used their life skills to sort out past problems – sometimes on their own but often with the support of family, friends, neighbours or by using any network or club (social or religious, etc.) they know.
- Older people can be and are effective advocates for their peers.
- Groups, both organised and informal or social, can often provide the information and advice sought by an individual.
- Advocacy organisations need to be appropriately funded in order to serve their community. They also need to train older members of the community to become effective advocates for their peers and themselves.

### Challenging discrimination

- It should be remembered that older people are part of the whole population and should be seen as worthy of respect and be valued for their experience, not only within the family but also within the wider community.
- Language is important in either valuing or denigrating older people – for example, the use of phrases such as ‘burden of pensions’ or ‘the increasing older population are a drain on resources’ should be avoided.
- Policy makers and politicians need to be aware of their own use of terminology.
- There is a danger of creating services specifically for older people, who may then be seen as needing ‘extra’ – older people can therefore be seen as a problem rather than as a resource.

## Older people doing it for themselves

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- It should be recognised that stereotypical images of and attitudes about older people are discriminatory.
- Older people can use the facilities/clubs/services/classes that already exist in the community and therefore do not always need 'specialist' services.
- It should be recognised that there may be a generation gap within the grouping of older people and there are likely to be different issues around information needs for those under 60 years of age.
- Some of the groups and agencies serving both the older population and elders from minority ethnic communities appear to be protective of the service they provide, and are at times unwilling to share their knowledge, or experience, or expertise with other groups. This may be because of the number of groups with similar aims and objectives, or because they wish to restrict and preserve their specialism.

### Individual strategies for finding out what you need to know

- Be courageous, tenacious, persistent, energetic – have:
  - 1 *courage* to ask and to listen to the responses
  - 2 *tenacity* to continue to ask when unsure whether the reply might include unpalatable news
  - 3 *persistence* to continue to research and ask questions until satisfied
  - 4 *energy*, not just to absorb the situation but also to continually adapt to new information.
- Let people know that information is being sought.
- Share the knowledge with others.
- Acknowledge that no one has control over everything, but how a person responds to situations may be within one's control.

- Information needs to be absorbed, distilled and made use of. There should be a willingness to be involved in the management of that process; acknowledgement that older people seeking information can be their own resource; active encouragement in allowing people the space to share knowledge and experience; and support for the older person in:
  - 1 knowing when enough information has been gathered to give *knowledge*
  - 2 knowing how and when to use that knowledge
  - 3 making decisions on that knowledge
  - 4 adapting to new information and acting on that information.

### Models of good practice – information, advice and advocacy

- The mobile library staff in Barnet are a valuable resource for those elderly and/or disabled people who are restricted to their homes, and provide a good access point for information and advice.
- Kensington and Chelsea's project under the Better Government for Older People programme shows the value of involving older people in monitoring the communications produced by the local authority.
- Westminster Advocacy Service for Senior Residents uses older people to help their peers and provides training/awareness courses for professionals in the medical and social welfare fields. Fifty per cent of the trained advocates are older people and the trustees and management committee are all older people.
- The Nubian Life Centre, Hammersmith and Fulham works with minority ethnic elders and is providing training in both self and citizen advocacy for the members of the organisation.

## Final reflections, acknowledgements and thanks

At the beginning, I set out the project brief and what I hoped would be achieved. All too often in life, we try to bite off more than we can chew! The project was no exception. As time passed, it began to change and evolve. Dirk Bogarde once said that he felt sorry for anyone who went down the 'corridor of life' seeing only the door at the end. I may have deviated but those originally unforeseen avenues have, for me, added an extra quality to the experience of conducting the research.

I would like to give recognition and thanks to the myriad of people I have met and spoken with without whom there would have been no project. Particular reference must be made to the members of the Advisory Group who have always been available for meetings and telephone conversations, and whose knowledge and experience of their field has provided much guidance and food for thought. I would like to thank the Joseph Rowntree Foundation, which funded the project and in particular Alex O'Neil whose kindness, judgement and consideration have

been of great comfort and encouragement. Also thanks are due to Louise in York and Geraldine in London, who have both given great help and support.

To Vivien, I would say, regardless of her own problems, she has always been there in support and partnership, sometimes very challenging but always encouraging. Thank you. I would also like to acknowledge the part played by others, some long dead, others now older people themselves. Their legacy to life, playing away in the background, has in its own way been inspirational: Duke Ellington, Count Basie, Stan Kenton, Benny Goodman, Dave Brubeck, Oscar Peterson, Ella Fitzgerald, The Band, Pink Floyd, Genesis, Tom Waite, Kirsty McColl and others.

From my perspective, I have thoroughly enjoyed the experience, the laughs, the serious discussion and the hard thinking. I would like to leave with you this thought:

*As we grow older, we do more things for the last time and fewer for the first. If we reverse that, we might find an antidote to growing old.*

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