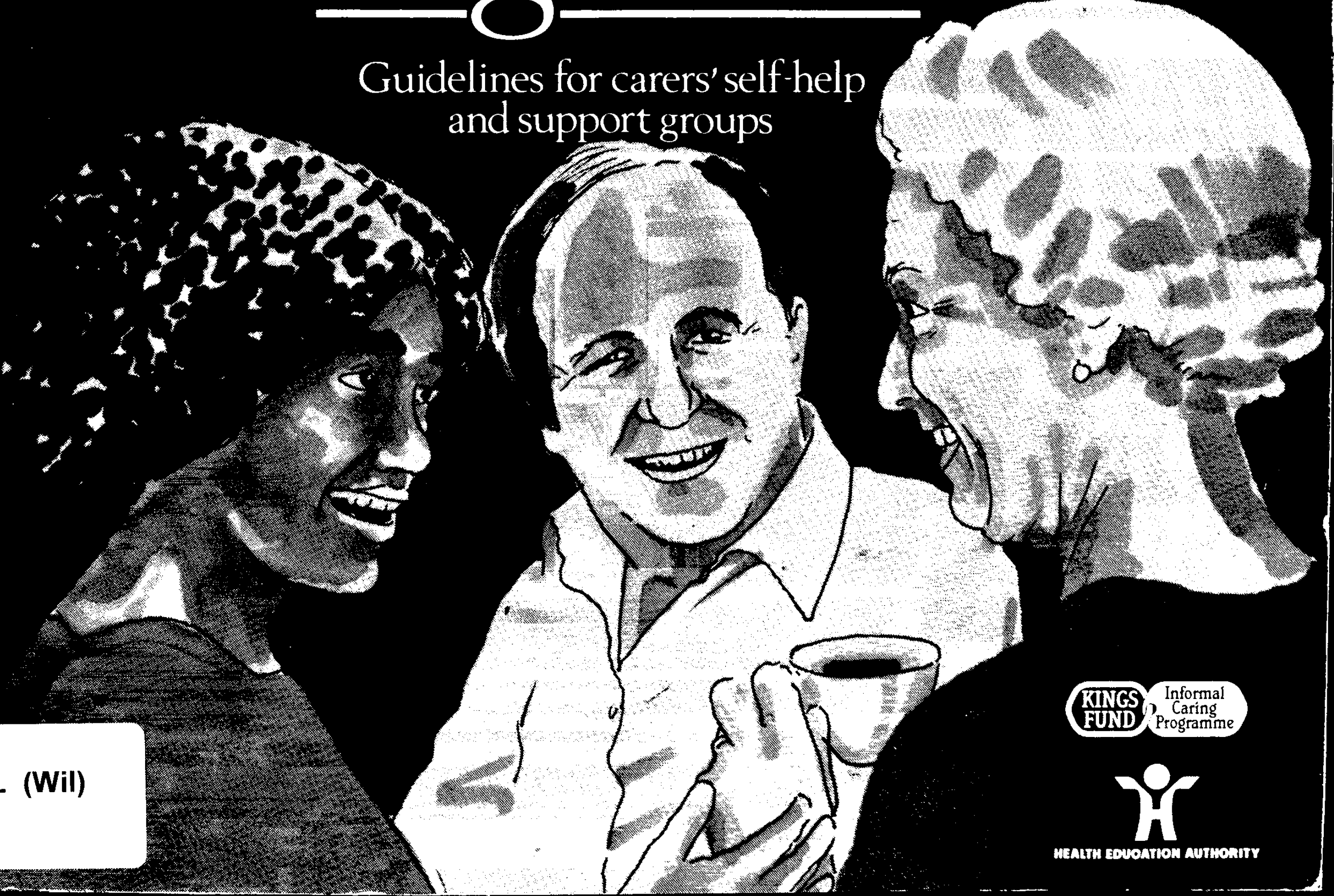
Judy Wilson

Together

Guidelines for carers' self-help and support groups



KINGS FUND Informal Caring Programme

HEALTH EDUCATION AUTHORITY

CARING TOGETHER

GUIDELINES FOR CARERS' SELF-HELP AND SUPPORT GROUPS

Judy Wilson

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Extra sheets

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Note: Throughout the book we have used the shorthand form 'ethnic minority' to describe all black and ethnic minority communities.

Dear carer,

This book is for you. You're caring for someone at home — someone frail and elderly; someone suffering from a serious physical or mental illness; or someone with a disability, who may be young or old. You yourself may be young, middle-aged or elderly; black or white; a woman or a man. Whoever you are, you're a 'carer'. And there are over a million people like you, all looking after someone at home.

You probably have mixed feelings about the life you're leading. You very likely feel love and concern for the person you care for. But there are bound to be times when you feel angry, confused, and taken for granted — that you have lost part of your own life. Maybe you're wishing you could cope better and had more information. Maybe you're worrying about your own health. Or perhaps you're lonely and feel there's no one else around with this sort of life.

But you're not alone. There are lots of people in the same situation, living in your area. And you could find it helpful — a lifeline even — to meet some of them in a support group. A group won't solve all your problems, of course — but people who join one do feel it helps. Groups have different names — self-help groups, carers' groups, support groups, parents' groups. Some take the name of a national society or organisation.

Whatever they are called, they all exist to meet the needs of carers — people like you. They are a group of people caring together — caring for your needs, which are different from the needs of the person you are caring for. You might find that joining or starting a group helps you.

This book will try to help you think through the idea of joining or starting a group, or making changes in one that has got going. It will ask questions, and give you ideas to discuss with other people. Some questions may be flashing through your mind already:

☐ How can I cope with a group and caring as well?
☐ How do groups get started?
☐ What do they actually do?
☐ Do they have to depend on one person?
☐ Can anyone start a group with no experience?
☐ What is the right way to do it?

There aren't any magic answers, and there is no one right way to start and run a group. You'll read about different sorts of groups in Chapter 1. If you decide to go ahead, you'll want a group that's right for you — that helps you and the other members. It doesn't have to have any great aims, and it doesn't have to be highly organised. Most people find it's best to start with a simple group, where they can talk together about their feelings, and sometimes this is how the group stays.

This book will give information, ideas and advice on what seems to work, and you'll find lots of helpful stories and opinions from people already in groups. But don't try to read straight through the book. You'll probably find it's best to read the first three chapters, and then to just dip in to the parts that specially interest you. Use the chapter headings and summaries, and the index at the back, to find the subjects that you want to know more about. There are some extra sheets at the back in case you want to read more about some topics. If you're in a group, it might be a good idea to work through part of the book together: choose a subject you're interested in, and decide how long to spend on it.

Whatever you do, feel hopeful, not afraid or discouraged. Lots of people have found it tremendously helpful to start or join a carers' group — you might too. In any case, you have nothing to lose by reading this book and thinking it through. See it as a first step in exploring what you could do.

With best wishes

Judy Wilson

Judy Wilson

PART 1
SETTING THE SCENE

1: WHAT ARE CARERS' SELF-HELP AND SUPPORT GROUPS?

HOW OTHER PEOPLE SEE THEIR GROUPS ■ WHAT'S SPECIAL ABOUT CARERS' GROUPS? ■ HOW CARERS' SITUATIONS SET LIMITS ■ THE LIMITS TO GROUPS

For me, the group is like the sun coming out from behind the clouds on a dull day."

This is how Liz saw her group. But it's not easy to say exactly what self-help and support groups are — each one is different. Looking at some other people's experiences will help you see the variety.

How other people see their groups

> *"My own problems as a carer, backed by a locally acknowledged need, launched our group. Funding from local charity trusts covered the cost of posters which together*

> *with a story for the local paper, gave us initial publicity. Early discussions revealed anxiety about commenting adversely on services for fear of retaliation. Carers' low public image also emerged, being seen as depressed and inadequate. So meetings were planned to provide not only advice and support but a programme of action. Professionals were barred from early meetings. Three years on, we now have a Crossroads Care Attendant Scheme, which we campaigned for, a strong membership, and a good working relationship with Health and Social Services. Recognising that many carers would not be able to attend meetings, it was decided that a regular Newsletter was essential. So it has proved, not only linking members together but also putting our message across to others."*

The next story is from a parents' group. These parents have handicapped children, and their first language is Punjabi.

> *"We help each other a lot with benefits. One of us finds out about something and then is able to tell all the others. The problem is that all the books are in English, and so few of the professionals are from our culture, even though we represent the majority local population. It's getting better, but we still only get referrals from Education and not from Health and Social Services. So we get these families whose handicapped children are 5 or 6 years old before they learn we exist. It should be for the families to decide whether they want to be part of a support group, not the professional who only sees them briefly anyway. We heard recently that one mum, who should have been able to apply for a washing machine from the Family Fund, hadn't been told about it because 'she would need training to use it'. We were furious, it's her child that's mentally handicapped not her, she just doesn't speak English, that's all."*

If the members of a group all live in the same neighbourhood, it helps get over transport problems, and people can see each other more easily between meetings. This story is a good example.

> *"All the members of our group live quite near each other. We didn't know each other before but found we were all caring for elderly relatives. We began as a group introduced to each other by a health visitor and an Age Concern worker. They'd felt there was a need*

> *for a support group and contacted us to see what we thought. We'd all agreed and really enjoyed the meetings in a comfortable room in the new health centre. We shared out the jobs and the health visitor and the worker from Age Concern helped us sort out some of the problems. After a year, one changed jobs and the other had to do a clinic, but we all wanted to go on meeting. So we do, running the group ourselves. We still keep in touch with the health visitor as she drops in at the end of her clinic."*

Professional workers also took the lead in bringing together this group of parents.

> *"We were brought together — all parents of children with Down's syndrome — as an informal group at a child development centre. Transport was provided. Sharing problems made us realise how much we had to learn. Talking about bad experiences led us to think about what we would like to change. We knew what to do, but who was going to do it? We tried to get other people to take a lead but they had the good sense to leave us to our own devices. In the end we realised we were on our own. This was difficult to accept but had the good result that we set ourselves up as a parents' group and as a genuine voice of parents' interests."*

In some places Social Services departments or carers' projects put on courses for carers. These provide a welcome chance to learn about benefits and services to which people are entitled. Often the courses are for all sorts of carers — this one was for people caring for someone with a disability.

> *"Most of our group look after someone in the family who's disabled and a lot of them go to the day centre. We met each other on a course put on by Social Services. It was very helpful — lots of information on services we could get, with speakers and leaflets. There was always time to talk over a cup of tea and when the course ended we didn't want to lose touch with each other. We'd all found it marvellous to let out some of our feelings and I think it was good for the professionals to hear what we thought. So we went on meeting and invited the people who'd put on the course to come occasionally."*

The last story is from a group member who tells what he gets out of it.

> *"The very fact of meeting together, of physically making the effort of leaving home, even for a couple of hours, is important, bearing in mind that one's social life may be almost non-existent. Within the group, in an atmosphere of what I call 'loving sympathy', we share our problems, talk over our difficulties, pass on tips and ideas we have learned from our experience as a carer, and, of course, give each other support. Information is given and exchanged to try to make life easier for both carer and cared for. It is also important for past carers to be part of a self-help group for they have much know-how and understanding to contribute. Several members of my group have passed from the category of carer to past carer. We are indeed fortunate that this is so, as they are more givers to the group than receivers."*

What's special about carers' groups?

There are lots of groups based on particular conditions — strokes, multiple sclerosis, or cancer, for example. You may already belong to a group like this. If so you will value the information and support you get from belonging. If you are caring for an adult with a condition like these, it's quite likely that both of you go to the group together. That can be enormously helpful, and the importance of these specialist groups is not being questioned. Even if you start or join a carers' group, you may want to go on belonging to a specialist group as well.

One of the differences between the two sorts of groups is that a carers' group focuses on the person doing the caring, not on the person being cared for.

> ***"The first question most people ask when they meet you in the street is how's your mum, or your auntie or your husband. They don't ask after you."***

At carers' groups, they'll ask after the carer first, and then the person being cared for.

What can a carers' group do for me?

It's worth thinking a bit more about the special strengths of carers' groups, and why you might join or start one.

- ☐ *You probably feel angry about the lack of help and understanding.* Many groups are a voice for carers — speaking out, or campaigning, for people whose hard work is often taken for granted. This is a constructive way of directing anger.
- ☐ *You may be desperate for information.* Groups can give you the information you need — or work to get someone else to do so.

  It may be harder to get information if you belong to an ethnic minority community and if you have not used the health and social services before. Information may not be in a language you can understand. The services may not even be what you need. A group can campaign for better services.
- ☐ *You probably feel lonely, under stress, or not very confident.* At carers' groups you can let off steam, laugh, say things that would seem disloyal anywhere else, and have some fun.
- ☐ *You may feel rather useless.* In a carers' group you can be useful, and you may develop skills. You'll be surprised how good you feel when you can help someone else in the same situation as yourself. You may find you can do jobs, take part in activities, and discover talents you didn't know you had!

Carers' situations set limits

Carers' own situations limit what they can get out of a group.

> ***"'I don't see myself as a carer', said Inderjit, 'I see myself as my mother's daughter — she needs me, and I look after her.'"***

Many people don't think of themselves as carers, and don't want the label. And lots who accept that they are carers will choose not to come to a group. Or, if they come, they only attend for a short time.

Here are some of the practical reasons why people may not take part, even if they want to:

☐ they may not be able to leave the person they are caring for, who may be very unhappy about being left
☐ they may not have transport
☐ the group may be too far away
☐ it may be too expensive to get to meetings
☐ they may just be too tired to want to go out
☐ they may have no time.

Emotional reasons may hold people back too, including loss of confidence. When carers do come to a group, at first they may find it difficult to talk to other people about very private situations, involving members of their family. They may even feel guilty over seeming to be disloyal. Some people may feel they are failing in some way, by talking to others about their problems. Many people from ethnic minority communities who expected to be able to turn to the extended family for support, often find that it no longer exists. For them, it may be even more difficult to talk to people outside the family. Some carers will just find it too painful to hear about other members' distress and suffering.

The limits to groups

In spite of such problems, groups do start and succeed. Later on, you'll read how longer established ones have achieved a great deal, and how those that settle for modest objectives can feel proud of simply existing. But what are some of the limits to groups?

Groups can't change the world overnight. It's best to start by realising how long it can take to get your voice heard and changes made. Most people want and need more and better professional care and services. Group activities don't really replace professional help and public resources.

Some carers may just not be comfortable in groups, or they may come from a cultural or home background where there is no tradition of joining one. They might want the personal understanding of another carer, but not in a group. One-to-one friendship, or informal cups of tea together might suit their needs better than a group.

IN SHORT

There are many kinds of carers' groups, and they run in different ways. Value their strengths but appreciate their limits, and the limits set by the situations of people who might like to become members.

2: HOW DO GROUPS START?

STARTING OFF POINTS ■ SOME BASIC PRINCIPLES

Carers' groups begin in different ways, as we saw in the stories in Chapter 1. There's no one best way to start. But it's worth identifying your starting point, because the things you have to think about are not quite the same.

Starting off points

Starting alone

Lots of well established groups began with one person who had the idea *and* the determination to see it through. If that is where you are starting from, feel confident you can do it. But begin by asking yourself a few questions:

☐ Why do I want to start a group?
☐ How might it meet my needs?
☐ Have I got enough time to do it now?
☐ What can I bring to it?
☐ Where else might I go for help?

Try to find out if there is a similar group already.

☐ *Locally*, ask at the library, the Council for Voluntary service (page 68), the Social Services Department, the Citizens' Advice Bureau, or a Council information department.
☐ *Nationally*, ask national carers' organisations (pages 68 and 69).

If there is an existing local group, and it matches your needs, then you may decide to join in, rather than start a new one. Or you may feel it's best just to become a member of one or more national organisations. Explore and check out what's on offer already. It's all right to change your mind and decide against starting a group.

If you still want to start a group, first find a few other people who could help you. Look for other carers first. It's easy for other concerned people, who are not carers, to be too involved at this stage. (There's more on outsiders' involvement in Chapter 8. In later chapters, and on Sheet 1 there are more ideas on how to find the first few people. Be careful not to go too public too quickly at this stage, and don't let the group be seen as yours alone.

When you have found your first few people, get together — maybe several times — and talk over what you want to do and how to do it. Then you can choose if you just want to

☐ stay as a few friends
☐ slowly grow into a group
☐ organise a public meeting (Sheet 2)

If you decide that you want to stay as a very informal group, that's fine. Then you won't need to bother with a lot of the information in the later chapters in this book. Choose what feels right for you.

Being a member of a national organisation

Some of the national carers' organisations have a system of membership. Perhaps you are an individual member — you may have been one for some time — and are now thinking of starting up a local branch. If that's the case, you can get help and guidance from the national office (pages 68 and 69). And remember, there may be other local branches in your part of the country. It could be really worthwhile linking up with them.

A lot of other things you have to decide will be much the same as for the person just described, who is starting alone.

Developing from a carers' course

In Chapter 1 (page 9) there was a story about a group which began when members met on a course put on by professional workers. This can be a good short cut — but don't assume that a support group can be run in the same way as a course. You'll need time to think, so people can choose whether to go on meeting or not — it's important to give people choice. Here are some questions you could discuss:

☐ What was good that we'd like to keep?
☐ What would we like to change?
☐ What relationship should there be with the people who put on the course?
☐ Do we need to recruit new members or stay as we are?
☐ How might we find them?
☐ How are we going to manage practically?
☐ What help do we need, and who from?

Becoming a group run by carers

A last starting off point is where a group changes from being led by a professional to being run by its members. Many groups were started by a professional worker — a social worker, or health visitor perhaps — who gave hours of time and energy to running a carers' group. Often this time is voluntary, outside paid working hours. Professionally-led groups can be very helpful, but this book is concerned with groups led by carers themselves.

Changing the leadership of a group from a professional to its members can have lots of advantages:

☐ the group can gear what they do to what they feel members need
☐ members learn new skills
☐ members grow in confidence
☐ the group can more easily criticise services and put forward proposals for change.

But there are also difficulties to get over:

☐ the professional may find it difficult to change roles, and perhaps won't know how to 'let go'

☐ passing on responsibilities too quickly may be too much for some members: you need a planned period of handover, over quite a time, with continuing background support
☐ at least some of the members of the group must be willing to take on some of the jobs.

As one group put it:

> *"You need to have some members coming forward with a bit of go."*

Sheet 9 is a discussion paper for professionals and group members to use, to help think through all the changes. Pages 51 to 53 will be useful too.

Some basic principles

Whatever your starting off point is, there'll be some things that everyone can consider. Getting these sorted out early on could make your group much stronger.

Carers' situations

A carers' group is not like any other voluntary group. You'll need to think about — and review — your members' situations, feelings and needs, and plan your group to build on these. These are some of the things people in carers' groups have said:

> *"We find attendance at meetings is erratic and worried about this at first. But then we came to realise this was simply because of our situation as carers."*
> *"We find it difficult to delegate the task of caring and feel guilty about focussing on ourselves."*
> *"Your social skills all waste away, like muscles waste away."*

The need to share out jobs

Sharing out the jobs is a much more difficult approach than it is to run a group where a few people are the doers and the others are the receivers. But try to share them out from the beginning — it will be easier, and it will pay off in the end. Look at it as something to aim for; don't expect it will work out entirely.

> *"If you're not careful you may end up running the group, whilst the others just turn up for the Christmas party."*
> *"We wrote down the jobs on slips of paper and each took one or two."*
> *"Doers become mothers to the group if you're not careful."*

Numbers — large or small?

Don't worry too much about numbers — you can either stay small, or grow in time. It's quality not quantity you're aiming for. Showing feelings, often a great need when groups begin, is easier in small groups.

> *"The group is to some extent like Alice in Wonderland — growing in turn to large or small."*
> *"Our group consists of five couples so far."*
> *"Three of us meet at the Afro-Caribbean Centre for a cup of tea once a week."*

Confidentiality
People won't talk if there's a risk of what they say being discussed elsewhere. It's important to work out group rules on this right from the beginning, and tell new members what you decide.

> *"What we say here is just for us and we make that clear to new members."*
> *"There seems to be an instinctive feeling of privacy in our group."*

IN SHORT

Grow gradually from where you and other carers are. Be confident that in time your group will work. Establish some basic principles:

☐ remember carers' situations
☐ share out jobs
☐ be happy with small numbers
☐ make sure confidentiality is the rule.

3: WHAT CAN GROUPS DO?

EVERYDAY ACTIVITIES ■ LARGER SCHEMES

The best way to find out what carers' groups can do is to learn from established groups. You could:

- visit a neighbouring carers' group
- talk on the phone to people active in groups
- read newsletters

You could find out about other groups through national organisations (pages 68 and 69), or from a local Self-Help Centre, or Council for Voluntary Service (page 68).

This chapter will give you a glimpse of what different groups do. We will look at a big variety of activities, because lots of people with different needs will read this book. But remember, you don't have to do all of them. Only some will be right for you, especially when you start. You'll probably find it's best not to be too ambitious at the beginning.

You also need to remember it's important to agree aims for your group (pages 23 to 25). What you decide to do will depend a lot on what your aims are. Make sure that the whole group chooses the activities, and that they are not just what one or two members are keen on. As the group grows, small sub-groups may take on special events, or organise a particular activity, but to start with, everyone should be behind your work.

When you organise an activity, you may find you achieve more than you set out to do. For example, you might arrange an outing just to have fun. But you'll probably get new members involved, give people the chance to talk together, and improve their health.

What ideas for action are there? You can look at them in two ways:

- everyday activities which you'll do because members want them now, or to keep the group going
- larger schemes — things you can do for other carers, as well as the group, or projects for your members which take more time and resources.

Everyday activities

These are some of the things groups often do:

- ☐ give each other support
- ☐ provide information
- ☐ promote members' health
- ☐ have fun together
- ☐ produce a newsletter
- ☐ raise funds
- ☐ simple campaigning.

Giving each other support

However you do it, members will have a real need to talk, and they will want to be helpful to each other as listeners.

> *"Everyone's problems came tumbling out."*
> *"I lock it up inside till the meeting."*
> *"I want to give other parents hope."*
> *"So many carers are desperate for personal support and uplift. Groups can do much to respond to their needs."*
> *"I think I prattled on a bit at the first meeting."*
> *"When new members come in, they need to spend a lot of time just talking about the caring situation. It's remarkable how members of longer standing can listen, understand and wrap new members up in their care and concern."*

Groups often make it an important part of the meeting to share their experiences by talking about them. In small groups this will probably come naturally. Bigger groups must make sure it happens. Here are some ways to help it work well:

- ☐ agree a time to start and finish the 'sharing' part of the meeting
- ☐ choose a room that helps people feel comfortable and welcome
- ☐ decide if non-members can come to that part
- ☐ make sure the person in the chair allows everyone time to talk
- ☐ if anyone seems distressed, offer one-to-one talks at or after the meeting.

Supporting each other also happens over cups of tea, and by doing things together. It comes from visits and phone calls between members outside meetings. You may want to organise activities and provide services to make sure people get support outside meetings, as well as in them. (See Sheet 7 on setting up a telephone service.) Or exchanging addresses and telephone numbers may be all that's needed.

Providing information

Lots of groups find members are desperate for information.

> *"Often parents come to our group who have completely slipped through the authorities' nets and have never received information telling them where to go for help and advice."*

They want to know how to cope — emotionally, financially and practically — and they need more information on local and national services. They may ask to be taught simple home nursing skills. And they will want to learn about the disability or illness of the person they are caring for. As one group said:

> *"We're a group of black people, all with relatives or friends with mental illness. We feel a real need to understand more about their illness."*

There are a number of ways of providing information. Two common ones that work are inviting speakers and sharing information among members.

> *"Over the past year we've had various people coming in and speaking to us: a dietitian, dentist, continence nurse and so on. We've really valued their talks. But members can contribute a lot to these sessions too, and we also share information amongst ourselves."*

Speakers don't mind coming to a small gathering as long as they know that's what it will be beforehand. Brief them clearly on the length of their talk, especially the finishing time: agree on how to raise questions, and find out before they come if they need any expenses. And note the experience of the group above: don't let the 'experts' crowd out the expertise in your members.

These ways of sharing information among members seem to work:

- ☐ making sure there is time in the group for people to ask and answer questions on particular problems
- ☐ putting information in a members' newsletter (Sheet 3)
- ☐ organising visits — for example to a display of aids for disabled people
- ☐ making a simple local information booklet
- ☐ setting up a group library, with books on long loan from the public library
- ☐ affiliating to national organisations and circulating their literature.

Promoting members' health

It's very common for carers to have, or risk, ill health themselves. But if you are a carer it's often difficult to pay proper attention to your own health needs. Carers' groups can help a lot by giving people a chance to talk about their own health problems, without feeling guilty about it, and to share ideas on what to do about them. Some groups, particularly the ones with members looking after adults, find it useful to have activities that are to do with carers' health. You could consider:

- ☐ lending publications (see above)
- ☐ talks on stress, lifting techniques, and so on
- ☐ cookery demonstrations
- ☐ outings
- ☐ yoga
- ☐ relaxation sessions
- ☐ a 'health care' day.

Having fun

Carers' groups also need to get some enjoyment out of what they do. People don't want to be thinking about their problems all the time. Getting some fun at a carers' group could fill a gap in members' lives.

> *"You just have to accept a completely different life style."*
> *"It's hopeless. My own life has gone to pot."*
> *"We told friends a couple of years ago to forget about our social life."*

There are two different approaches groups can take. One is to make sure that quite a lot of activities are fun. The other is to put on special events. Some groups make these special occasions for everyone — for carers, the people they care for, and other members of the family all together.

"Large social gatherings for all the family — the pantomine, the Christmas party and seaside outings — are very popular in our group."

Others prefer a carers' treat.

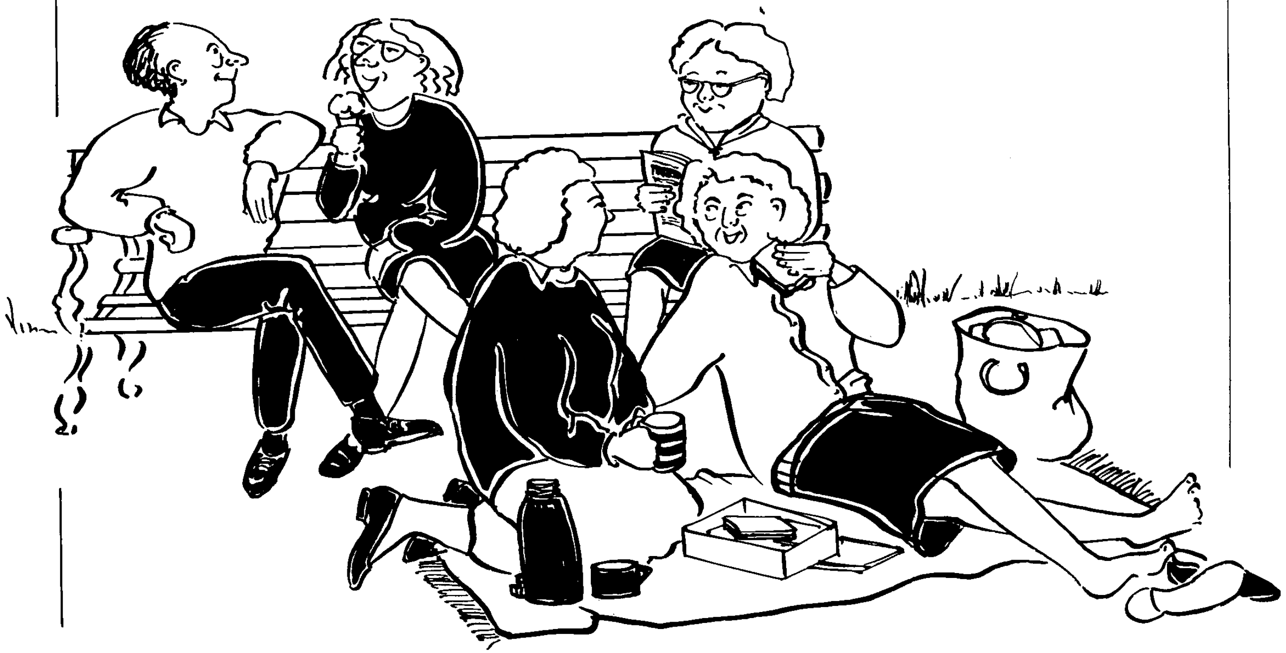
"We went out to the park in the summer. It was the first time Pam had been out without her elderly father for ten years, except to do the shopping and other chores."

Producing a newsletter

If you are a small group who like to keep in touch by word of mouth — calling at each other's homes, meeting at a school, and so on — then a newsletter may not be for you. However, many groups do find it a very successful and worthwhile activity. (See Sheet 3 for details on how to produce one.)

A newsletter helps pass on useful information, and makes sure everyone knows where and when meetings and activities are. You can welcome new members, give news of old ones, and keep professionals in touch. A newsletter is also an easy way to help people who can't get to meetings.

"Your newsletter was a great help and support — and a comfort when I was tied night and day in the house."



Raising funds

In some groups members contribute a bit each time they come, to cover the group's small expenses. Other groups have close relationships with community centres or other organisations who meet their costs. But most groups find they want to raise money, so that eventually they can be independent. There's more on fundraising in Chapter 8 (pages 49 to 56). And helpful publications are listed on page 65.

> *"Make it fun-raising as well as fund-raising."*

Raising money can be an enjoyable activity — don't let it be too much of a chore, or a burden on people who are already overworked. And look at it as another way of getting together. Some people who don't find it easy to talk may get support from doing an activity with other members. And house-bound members may want to help too.

Simple campaigning

Carers know what it's like. They know their own needs and what can meet them. It's important for people to hear their voice, but it's not always easy for individuals to make themselves heard. Carers' groups who choose to do some campaigning — even quite small things like letter-writing — are choosing to do something very important.

Campaigning doesn't always mean large-scale activity or long petitions, and even quite new groups can have their say. If a group does it regularly, it can help people not to get too inward looking, and give some hope, You'll find some useful books on page 65. Here's what some groups have said about campaigning.

> *"We were fired up by what we heard at a conference, and are thinking about how to be involved in campaigning for change. But we had to focus on ourselves first in the group — our lives and values had to come first. Concern for wider issues comes later."*
> *"We're too tired to fight."*
> *"We don't take on campaigning as such, but most of us have time at home to write letters. We've had several published in the local paper, and regular correspondence now with our M.P."*
> *"We invite people as speakers, and then it gives them the chance to hear what we think of the services their organisation provides."*

Larger schemes

Some groups' activities are more ambitious. In fact the activities may be the reason why the group exists in the first place, like this group:

> *"Eight families got involved in setting up a local holiday complex. We don't have regular meetings, but we've become friends and all keep in touch by telephone."*

Or the activities can grow out of smaller groups which began meeting so that members could support each other.

> *"Our group has stopped meeting formally, but we have a swimming club (weekly), a youth club (weekly), a social skills class (weekly), and an informal communications system."*

Big schemes don't always mean that the

support side of the group stops. In fact, it may be very important to make sure this does not happen. Some groups run both sorts of activities side by side.

If members have useful skills and experience, it's probably a good idea to put them to use, in some activity. And a larger scheme can channel anger constructively, and provide more services for the people being cared for.

But beware. Before you launch a scheme, think about the consequences for your group. You need to think about:

☐ *giving each other support*. Are the activities likely to stop this happening — either for existing members who need it, or for new members who join expecting it?
☐ *the structure of the group*. Will you need to form sub-groups, and if so how would they relate to the group or to a committee?
☐ *working with other organisations*. This can be an effective and natural step to take. But it needs time; you must really believe in it, and you must be willing to work in partnership
☐ *management*. You could end up responsible for staff, a building, minibus and a large budget. (See publications, page 65.)

What other groups have done

It may be best to start with a one-off event, or a single campaign, instead of taking on a long-term responsibility too soon. In fact you may not want to tackle a larger scheme at all.

But some carers' groups have done a lot of creative and worthwhile work. National organisations (page 68) could probably link you with groups who have done particular projects. This list will give you an idea of the range of peoples' schemes and achievements:

☐ one-to-one befriending schemes
☐ sitting services
☐ Crossroads care attendant schemes
☐ holiday play schemes
☐ local handbooks for carers
☐ training courses
☐ holidays
☐ large-scale campaigning
☐ carers' fair (see publications, page 64)
☐ publications
☐ phone service (Sheet 7)
☐ drop-in centre
☐ involvement in community health councils and other consultative bodies
☐ conferences or study days.

Small groups may choose not to do any of these. But now you know the range of things that can be done, and that have been done by carers, in spite of the demands of their everyday lives.

What makes them work

We've already looked at the possible disadvantages of large schemes, but if you do feel like tackling one it may be useful to have a list of what seems to make them work:

☐ recognising that they can be hard work, and take a long time
☐ joining forces with other organisations
☐ getting advice and help from elsewhere
☐ making sure they don't stop people giving each other support
☐ forming small sub-groups for particular activities
☐ reviewing what you do as you go along, and making changes if necessary

☐ involving former carers who would like to help
☐ being determined to succeed
☐ finding and using your members' talents
☐ accepting that voluntary groups can't do all that's needed
☐ learning from people who've done it already
☐ getting training, if that's what's needed
☐ feeling confident that you can get there in the end.

IN SHORT

What you do is up to you — there's no one set pattern of activities for carers' groups. Whatever you choose, take on manageable activities, and get the right balance between members supporting each other and bigger projects. And don't spend your time worrying about what you can't do — feel proud of your achievements.

PART 2

GETTING GOING

4: DECIDING WHAT'S RIGHT FOR YOUR GROUP

THREE THINGS TO KEEP IN MIND ■ WHO DECIDES ■ HOW TO DECIDE ■ END RESULTS

It's fine to have very simple aims for your group — they don't have to be anything grand. But if you have some idea of your purpose, it will strengthen your group. One group, which ended before it had really got going, never really decided what it wanted to achieve.

> ***"We started our group with high hopes, but little idea of the direction we wanted to take."***

Three things to keep in mind

Think again about carers' situations. Most groups have found it's best to be realistic, and not too ambitious, especially at first. It's all right to set limits on what you do — in fact, it's a constructive thing to do.

> ***"Setting limits to a group's activities is one of the cornerstones of a support group. And telling someone about other sources of help, is not failure — it's another cornerstone."***
> ***"If you don't want to do it, don't start it."***

Find out what aims other similar groups have. Not all carer's groups are the same. See Sheet 4 for examples of what some groups have produced. National organisations (page 68) could suggest a nearby group, or you might find one through a local Self-Help Centre or Council for Voluntary Service (page 68).

> ***"We were talking about forming our group and decided we wanted to talk it over with someone who already belonged to a group, to find out what they aimed to do. Pat came over and it was really helpful."***

Make sure your aims are group aims, not personal ones. This may take time and will probably be a bit untidy at first. But it will be worth it. You'll

probably find you have to make some short-term decisions, and then review them. The group won't decide on its aims quickly.

Who decides?

In some groups there are a few strong-minded people who take the lead. In others, there may be a professional worker who's inclined to tell members what they want, though a sensitive professional worker can help a group in its early stages. And often when you ask people what they want, you get no response. Even so, it's worth persevering so that the whole group makes the decision.

How to decide

This depends on the size of your group when it starts. If there are just a few of you, your aims may come out quite naturally in informal discussion. If there are, say, twenty people present, you'll need to plan it a bit more. One of these methods might work:

☐ Go round the circle, at the meeting, and ask people why they have come to the group
☐ Look at other groups' aims and see if you can adapt them to suit you
☐ Ask in a sympathetic outsider to help you come to some decisions. An uninvolved person who can ask questions and see gaps may be helpful (Chapter 8)
☐ Split up the group into twos and threes and spend some time in different corners of the room, discussing what you want. Write up all the suggestions on a large sheet of paper, or ask each small group to say what they think
☐ Phone round members before a meeting and come with a list of ideas

Don't worry about getting it perfect. Most groups find they need to review what they are doing from time to time (pages 57 to 59). This can be a time to take another look at your aims too.

End results

By the end of the process, you could have three sorts of aims agreed:

☐ broad aims — general aims of your group
☐ specific objectives — targets you'd like to achieve in time
☐ priorities — some things you feel you can do in a fairly short time, say over the first year.

When you've got your aims agreed, write them down. If you produce a leaflet or a newsletter, put your aims in it. (See Sheet 3). You don't have to put anything complicated, and if your group is very informal, you may not need leaflets. But it's important to have some common understanding and a way of having a record of what's been achieved.

Finally, how you organise yourselves (see Chapter 6) will depend partly on your aims, so think about this too.

IN SHORT

As a group, work out some simple, realistic aims together. Write them down, and make sure people know them. Concentrate on things which you can achieve, not on changing the world.

5: MEMBERSHIP

WHO CAN JOIN? ■ PEOPLE WHO DON'T COME TO MEETINGS ■ SIZE

f you turn back to the stories of groups in Chapter 1, you'll see that although they were all carers' support groups, their membership varied. Some aimed to meet the needs of a broad range of people, others were for a narrow group. You'll probably want to decide early on about your group's membership.

Many groups are open to any carer, others are for particular carers, or a particular area or neighbourhood. It's all right to set some limits, and the group may be much stronger as a result. But remember that all carers have something in common, and a general group may work well.

Some groups are based on a neighbourhood, a school, a day centre or hospital; other groups welcome anyone, even if they have to travel. Carers can get so desperate for support that they'll get there somehow.

There's a checklist at the end of this section (page 30) which you might like to use to help you think through some of these points, and the points we'll look at now.

Who can join?

Members of groups which grew out of a course, or a professionally run group, may value the friendship they have found. If you feel you want to stay with those same members, for a time anyway, that's fine. But people do leave groups and it can be sad if only a small number remain, perhaps feeling abandoned. It may be healthier to make new friends too. So think about reaching out to new members, and aiming to grow.

Most groups won't be starting with a core of members. You'll probably have some idea already who the group could be for. But don't feel you have to limit it to carers looking after people with one particular disability or illness. Groups open to any carers work well too, in towns and in the country.

"Our group was formed 9 years ago on a very

> ***casual basis of various mothers who had a handicapped child getting together to enjoy one another's company. The ages and types of handicap are varied, our common denominator being the small town we live in rather than any particular handicap."***
>
> ***"We started as a group of relatives of stroke victims — my husband had had a stroke — but quite soon we changed to a group caring for people with a wide range of disabilities and illnesses. Our needs were the same."***

If you live in an area where there are a lot of people from one ethnic minority, you may find you'd like just to have members from that community. You may have many things in common as well as caring: for example, language, not knowing how to get services, and cultural needs. Once your group has got going you can make links with other carers' groups later. Other groups in multiracial communities will want to be multiracial too, and let people know they are open to members from all races.

When you have agreed who can be members, you must make sure that everyone who qualifies does feel welcome. Watch out for the little barriers that can creep in — class, sex, race, age, length of membership, and so on. These are some particular points to look out for:

☐ ways of welcoming newcomers
☐ involving new members in the group quickly
☐ being sensitive to the feelings and needs of people from ethnic minorities
☐ choosing a meeting place that everyone can get to, and likes
☐ the danger of little groups of old members
☐ timing meetings to suit as many members as possible
☐ welcoming men as well as women.

Each group will find its own pattern of membership. All groups need to welcome and involve everyone who comes.

Helpers as members?

Many groups have people involved who are not themselves carers — professional workers, play-leaders, sitters, drivers, fundraisers, and so on. (There's more about professional workers on pages 51 to 53.) Are helpers members?

A lot depends on the way the group started, what its aims are, and what members who are carers feel they need. As a general rule, groups decide that helpers are not members, they are warmly appreciated helpers. But there may be reasons why you decide not to have this rule.

> *"In our group, mums are encouraged to bring a friend and hope in this way to bring together the 'normal' and handicapped child in play."*

There are ways round the situation. Some groups welcome anyone who's interested at bigger events — parties, outings, formal talks — but keep the meetings for 'carers only', so they can share problems.

What you decide will depend on what your members need. It's all right to make a decision that might seem unfriendly. Too many outsiders can easily thin a group down, and divert it from its main purpose.

Whatever you decide, make it clear, and let everyone know. Then other people will respect this.

Former carers

This is a sensitive area, and requires careful thought. There is more about it in Chapter 10. People who stop being carers are likely to be full of emotions — they'll be feeling bereaved, exhausted, perhaps guilty, lost, and without routine. No-one would want to ask them to leave straightaway. In fact most groups will want to share members' feelings, and help them face the change in their lives.

In some groups, like the one quoted on page 9, former carers are seen as members. Other groups have a custom that after two or three years, people who are no longer actively caring stop being formal members, but they can stay involved as helpers. There is a good reason for this: to help the former carer pick up old contacts and develop new interests. Some people decide to leave themselves, but on other grounds.

> *"We find some people leave when they are beginning to recover from their grief and find other people's suffering painful."*

It's important to let people choose if they want to go on being involved or not. Former carers can be a great help to the group, and they may find it helps them to be useful.

> *"Some people want to stay on. They find helping others who are going through what they have experienced makes them feel useful and wanted and they want to use their painful experiences constructively."*

Each group will need to make its own decision on this. The following points may guide you:

☐ have a clear agreement, and let it be known
☐ make sure there is a place in the group for former carers, and that everyone understands it
☐ encourage ways for former carers to keep in touch with each other outside the group
☐ make sure the group is filling the needs of people who are carers now, but remember one of its objects could be to keep members' social life going.

The people you care for

Think again about carers' own situations. Their lives are very bound up with the people they care for. It may be too much to go alone to a group where only carers are welcome.

> *"What is my relative going to think if I say I'm going to a group to talk about* **them?**"

But if relatives are present you may not be able to speak freely, and many people need to. Many carers' groups feel strongly they must be by themselves for regular meetings, and they organise other get-togethers for whole families or couples.

> ***"The group is the only place we can go to let off steam."***
>
> ***"We have a rule that it's carers only at the meetings but everyone is welcome at social events."***

What you decide will depend a lot on carers' situations, and the age of the people they care for. Let's look at what other people have to say about it.

> ***"This meeting is the only place where stroke victims and the relatives can come together, and we find we*** **all** ***need the information and support."***
>
> ***"Different parents are taking it in turns to look after the young children so that the other parents can take part in the meetings without too many distractions."***
>
> ***"We meet in a separate room at the day centre which our relatives attend, and get a lift on the minibus which picks them up if we need."***
>
> ***"The only way some members can get here is to bring their mentally confused partner with them. It seems to work."***
>
> ***"Our group found that dads and people at work wanted to be involved, so we meet in a pub in the evening."***
>
> ***"Don't deceive yourself that carers will be getting the support they need, if people who are cared for are also present."***

Joining a national carers' organisation might help you decide what to do about this. Whatever you decide, make it right for you, and make it clear to outsiders and new members what you usually do. It could be very distressing for someone to come with their relative and find they were not welcome.

There is more about care and sitting arrangements on page 45.

People who don't come to meetings

It's very common to have people connected with a group who don't come to meetings. They express interest, and then don't come often, or at all. What do you do?

☐ *Take a relaxed attitude.* Remember how common this is, and remember carers' home situations.

☐ *Agree in the group some rule of thumb.* Some groups ask for some sort of involvement in return for being a member — just small ways of taking part could be enough. If you think of everyone who has made an enquiry as a member from the start, you may end up providing a service for everyone in need. That may be what's wanted, but it could be too much for you to take on.

☐ *Think about where and what time you meet.* Is your choice of place and time of day preventing some people from coming? Some groups like to offer other looser ways of being in touch than membership implies. One way is to send a newsletter. People really do like to have news of a group when they can't come to meetings. (See page 19 and Sheet 3.)

But in the early days it's probably best to concentrate on the carers you actually see face to face, and to work out ways for them to get to meetings (Chapter 7). Then if some people still never come, you can think of them as people in the newsletter network, rather than active members.

Established groups may decide to set up services which offer more than this loose contact (pages 20 to 21), but don't rush to do this.

Size

Large numbers don't guarantee success, and there's no set size for a support group. Many groups actually find it helpful to be quite small. A lot depends on where you live, and what exactly your group is based on. Ten to fifteen people seems to work, but smaller and larger groups can work too.

Some groups get too large, and then discuss ways of splitting, or having informal groups in people's houses. How your group organises itself (Chapter 6) will depend a lot on its size. Aim for a size that suits you and fits in with your aims.

This checklist may help you make some decisions about membership.

CHECKLIST 1

- Will the group be open to anyone who wants to come?
- If not, what limits are you going to set?
  — people concerned with a particular disability or illness?
  — living in a particular area?
  — for women only?
  — from one ethnic minority group?
  — people in a particular age range?
  — a set number?
- Can professionals be members?
- What about former carers?
- If volunteers are helping, are they members?
- Is the whole family a member?
- What part do people you care for play in the group?
- Can people who are interested, but don't come to meetings, be members?
- Do you have to pay a subscription to be a member, or be a member of a national organisation?

IN SHORT

Early on in the life of your group, decide who is a member and who isn't. Work out ways of involving other people. Feel you can make decisions to meet members' needs, but make sure everyone knows what's been agreed.

6: ORGANISING YOURSELVES

PRINCIPLES TO THINK ABOUT ■ GIVING THE GROUP A STRUCTURE ■ BEING ORGANISED AS YOU GROW

Perhaps your group got going informally, and you all feel happy about the way it works. Small groups like this need not think of taking on all the ideas in this chapter. Larger groups will also want to avoid too much bureaucracy, but they might usefully think about at least some of these suggestions.

Some groups follow a pattern of organisation suggested by a national organisation, but many sort out what is right for them as they go along, and this can take time to get right. If your group is changing from being professionally run to doing it yourselves, you might like to discuss the points on Sheet 9.

There is no one perfect way of organising carers' groups, but there are some things which seem to work. You could begin by thinking about what principles to adopt.

Principles to think about

Other groups have found that following these principles seems to help them run smoothly:

☐ sharing out the jobs
☐ asking people to do a job, perhaps in pairs
☐ expecting newcomers to take part in time
☐ taking it in turns to hold positions of responsibility
☐ avoiding a committee appearing remote from the whole group
☐ building in ways of covering for each other in emergencies
☐ appreciating and using individual members with special skills and commitment
☐ making sure not everything depends on one person.

Giving the group a structure

New groups will tackle the question of organising rather differently from established ones. You might remember one group wrote down all the jobs on slips of paper, and each person took one or two.

> ***"For example, one job was 'responsibility for making sure someone makes the coffee at the next six meetings'."***

When groups are new, they often have informal structures. If numbers are small, it's probably fairly simple to do the business at the regular group meeting with everyone present. But be careful it doesn't crowd out sharing experiences or providing information. Some groups divide the meeting into two parts, to make sure there's time for talking and business. As well as timing, you could usefully consider:

- ☐ jobs in the group
- ☐ involving members
- ☐ committees.

Jobs

Secretary and treasurer. There are two jobs which it will probably be useful to identify, and to ask people to take on for a set period of a year or so — *secretary* and *treasurer*. If one person is responsible for each of these jobs, it will help the group structure be much more reliable. (See publications on page 64 and Sheet 5.)

Chairing. Chairing can be done by one member in the traditional way, or it can be taken in turns. Taking it in turns avoids one person becoming the figurehead, and gives several people the chance to increase their confidence.

Chairing need not be very formal if the group is small and new, but it's necessary for meetings to run well. Some groups agree at the beginning of one meeting who is to chair the next one if there is no regular chairperson. Choose a name — chairman, chairperson or chair — that everyone feels comfortable with.

You may not use the word 'leader', but that is

actually what the person chairing the meeting is. It can be quite difficult to lead a full carers' group meeting. You may want to read more about it (page 64 and Sheet 10) or talk to someone outside the group.

The person leading the group needs to think about these points especially, although they may not actually do them all themselves:

☐ welcoming and introductions
☐ good timing
☐ avoiding 'just chatting'
☐ dealing with disagreements, not ignoring them
☐ encouraging people to join in
☐ preventing talkative people dominating the meeting
☐ summarising what's been agreed
☐ drawing attention to achievements
☐ bringing the meeting to an end.

Involving members

Don't assume people will volunteer to take on a job in a new group. It's easy to be sad, or even angry, when people don't come forward, but stop and think what might be holding them back:

☐ they may be very worried about taking on any commitment on top of caring
☐ they may feel they are not totally reliable
☐ they may lack self confidence
☐ they may never have had the chance to do this sort of thing
☐ no one has asked them.

One group felt you should begin by assuming everyone has something to give.

> *"Never assume that because someone is new they don't have any skills."*

Find out what people can offer. Perhaps you could all say, or even write down, something you feel you could do for the group? Or get into twos and threes and talk about it? Large sheets of paper and a felt-tipped pen may be helpful. (See page 25.)

Build in ways of covering for each other right from the beginning. Unexpected hospital visits, delays with transport, and illness can all stop people doing what they said they'd do. If there's a system so they can let other members know, and ask them to help out, they are more likely to agree to do a job in the first place.

Committees

Some people feel more comfortable with more formal organisation, and want to have a committee. It may be a good idea to have one anyway if you have quite a lot of members, or business is taking too long at group meetings. You could think about forming a committee — or call it a steering or working group if that's a better title. (See Sheet 5 on forming a committee, and the publications listed on page 64.)

Being organised as you grow

Once your group is established, you'll probably have made some decisions about what sort of structure you want. If there still aren't many of you and you want to stay informal, then simple ways of getting things done may be right. You may want to read this section, but don't feel you have to follow all the suggestions.

Bigger groups will find they need to think about further points:

- ☐ Annual General Meetings
- ☐ acquiring skills
- ☐ keeping records
- ☐ key members.

Annual General Meetings

AGMs are a chance to review what you have done, for new people to become committee members and officers, and to present the accounts. That may sound daunting, and AGMs may not be right for every group. Some more established groups like to have them, though, and some are required to by their national organisations or funders. See some of the publications on page 64 and Sheet 5 on committees.

If you have some sort of annual review, you can think about your organisation as well as count up your achievements. (See Chapter 9.) You could add on a social event or a speaker, to make the evening lighter and to attract people to come.

Acquiring skills

One group was lucky enough to have links with a national organisation which put on training events for members of local groups.

> *"The training course was a tremendous help, in preparing me to take on a new role as a key member of the group."*

Don't be put off by the word 'training'. If there are courses, day events, or workshops that you can get to, then do so. If there is no national provision, ask your local Council for Voluntary Service (page 68) what might be available locally. Some groups even decide to run their own training.

> *"A basic counselling course, open to all group members who'd be interested, was thought to be a good idea — it might teach us all how to listen to each other."*

But there are other ways of acquiring skills too. We've already suggested doing jobs in pairs. Working alongside someone for a bit can be very fruitful if it's done properly. People may feel happier being asked to do a task with someone else, rather than having to offer.

And be ready to learn from other people's experience. Visit other groups, or read books. Pages 64 and 65 suggest useful reading. Some books can be bought by mail-order, or you could ask your library to get them for you. You can just read the parts that look as if they'll be useful — don't feel you have to go through each one cover to cover.

Keeping records

This may sound daunting too, and informal groups won't need to worry too much about them. But simple record-keeping will help other groups to have continuity and stability. And people are more likely to take on jobs if they know there are records to work on. Choose from these methods that groups have found helpful:

- ☐ a box of membership cards in alphabetical order
- ☐ a minute book
- ☐ a scrapbook for photos and press cuttings

- ☐ an annual report, even if it's one sheet of paper
- ☐ carbon copies of correspondence, kept in files
- ☐ photocopies of grant applications
- ☐ receipt book
- ☐ accounts
- ☐ mailing lists for newsletters
- ☐ dating every piece of paper.

Key members
It's very common for a few committed people, or even just one person in a group with a bit more time in their lives, to do most of the organising. That's fine as long as it lasts, but it won't go on for ever, and it doesn't give other members the chance to grow and learn.

> *"We all like the wonderful warm feeling we get from being in control and 'doing for' others. That's fine for us, but we must ensure that other people too have new experiences and give their skills and gain the enjoyment we ourselves have."*

If a group depends on one special person, the organisation may run smoothly, but other members will probably feel they can't face any change.

> *"She's so good at organising everything, we'll never be able to cope without her."*

But giving some warning of any change means a group can go through a time of thinking it through. In this group the chairperson, the founder member, said she wanted to resign.

> *"An open meeting was held to discuss the necessary changes that had to take place. We had to take stock of the workload and become more aware that this was* our *group and that we must all share the responsibility for its well-being."*

If a key member leaves abruptly, it can be very difficult for the group (see Chapter 10 on endings). Sometimes people are so good at their job, and people make so many demands on them, that they do leave without warning — they feel they can't cope any more.

> *"Key members can often leave a group feeling angry and frustrated — burnt out in fact. It's a common problem for people who don't set limits to their involvement. They feel pressured to take on too much, or just guilty at saying 'No'."*

If this happens, try to be caring, and understand their point of view. But there are ways to avoid such pressures coming in the first place, or to cope if they do.

"Getting support for yourself is vital."

If you're a key member, think if you know someone sympathetic who could give you personal support. (See Chapter 8 for ideas.) You could meet them occasionally, outside group meetings, or arrange to phone them when you need to. Don't feel it's being disloyal to the group — it may be an essential safety valve.

You should also keep watch on how you feel about the group. If your responsibilities there are hindering, not helping your personal life, then it's time to delegate more, or to have some time away from the group. Don't let the stress build up so much that you have to leave suddenly.

You may decide at some point that it is time to let other members take over. Then give plenty of notice, stick to your decision and enjoy being an ordinary member.

This checklist may help you think through some of the ideas on organisation, and sort out what's right for you.

CHECKLIST 2

- How formal an organisation do you want to be?
- Do you want to share out the jobs?
- Is it possible to make decisions in the whole group?
- Is a committee the answer?
- Do you need a chairperson, and does it need to be the same member each time?
- What stops people taking on jobs?
- How could the way you are organised deal with this?
- Do you get help from a professional worker, and how does this affect the way you run?
- Does any national organisation you belong to require you to have a particular form of organisation?
- Do any funders require certain things from you?
- Do you need to agree a permanent way to run the group, or is it better to have a flexible pattern that can change?
- What records do you need to keep?
- Is your structure right for achieving the aims you've set for the group?
- Does your group depend on one person?

IN SHORT

Work out a way of running your group that suits you, but change it when necessary. Involve members as much as possible, and help new people learn skills. Keep simple records, and try to avoid everything depending on one person. But don't feel you have to have a committee when you're small and new.

7: ESSENTIAL INGREDIENTS

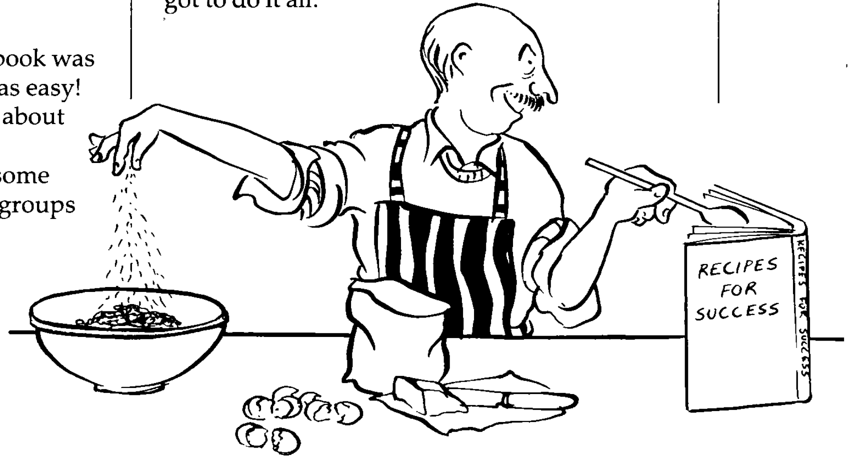
A MEETING PLACE ■ MONEY ■ PUBLICITY AND NEW MEMBERS ■ TRANSPORT ■ CARE ARRANGEMENTS ■ MOTIVATION ■ LINKS WITH OTHER ORGANISATIONS

It's a marvellous cookery book. You follow the instructions to the last letter, use just the ingredients she says and it always comes out perfectly."

This novice cook who found the right book was lucky. Running a self-help group isn't as easy! And this book can't be quite so precise about what works and what doesn't. It offers guidelines, not a recipe. But there are some essential ingredients for most support groups for carers:

☐ a meeting place
☐ money
☐ publicity and new members
☐ transport
☐ care arrangements
☐ motivation
☐ links with other organisations.

If you're a small, informal group, select what you need from this chapter — don't feel you've got to do it all.



A meeting place

Small groups may not find this too much of a problem. You may meet in someone's house, in a corner of a local café or a community centre. It may be easy to meet informally in a community project where a worker can offer help. Groups in some ethnic minority communities may prefer this since a local project may respond better to their language and cultural needs.

If you want to be just a group of friends meeting for a chat, that's fine. Later you may make some changes, taking it in turns to have the meeting at each other's houses, for example.

Groups who are more than a few friends will need to give more thought to where to meet. It's not always easy.

> *"It seemed fine in principle — parking outside, near the shops, and everyone knew it. But the staff got a bit funny about us going into the kitchen to make a drink."*
>
> *"We found the local library gave rooms free to voluntary organisations. It meant we had to carry the children upstairs, but they were all small at the time. And it was a nice room, with folding doors you could pull across — they were at one end with the playleader and we were the other."*
>
> *"The Health Centre made us most welcome and it was in walking distance for most of us. We met on Fridays and decided to call ourselves the Friday Club. It was a nuisance when they asked us to change our day to Thursday!"*

It will probably help to accept that you're unlikely to find the perfect meeting place. But don't feel you have to accept the first one offered. Where you meet will have a big effect on your group. For example, a friendly atmosphere will help people feel welcome, and will encourage them to talk. A place that is easy to find and to get to will help recruit new members. Changing meeting places can make members feel ill at ease, so try to get it right early on. Think through what you need for *your* group. There's a checklist at the end of this section which may help. Here's what other groups have found seems to work.

Paying rent if necessary

It's a dilemma. You're offered free accommodation — it sounds just what you want, and saves all the problem of raising the money for rent. But there's usually some snag, to do with people doing you a favour, or you needing to use a building at what they think are unusual times. So some groups find they have to turn down the offer of a free room, so they can have control over their meeting place. But if the room is free and feels right, accept it — it's one less problem to sort out.

Meeting in a neutral place if needed

> *"We found our members preferred the community centre. They have enough of hospitals and day centres."*
>
> *"We started meeting in my flat, but I found that some weeks it wasn't very convenient."*

It's fine to meet in a school, a hospital or day centre if it suits you, and gets over all the problems of cost, accessibility and transport. But you may find an ordinary sort of building suits your group better. Meeting in houses works for some informal groups; others find it puts pressure on the person who lives there, and perhaps makes other members shy about going.

Groups who want to campaign find a meeting place away from the hospital or social services is best. It's not easy to plan action when you're sitting on the chairs of an organisation you may want to criticise.

Making sure it's easy to get to

For groups where someone has a disability, you've obviously got to be able to get a wheelchair in. But think about it even if there's no disabled member now. For people who have a heart condition or arthritis, for example, it's helpful if they don't have to climb stairs. Groups do find it's easier to recruit new members if the building is easy to get in to, and the meeting room is on the ground floor, or there's a lift.

It also helps to meet near public transport and where there is parking. Neighbourhood-based groups find it's best to meet within walking distance of members' homes. Some people may be able to leave the person they care for for a short time, but that time includes getting to and from the group, as well as being there.

Being comfortable

Most groups find members talk to each other much more easily in a pleasant place. Comfortable chairs in a warm room, homely atmosphere, cups of tea — they'll all help your group to get on well.

Using contacts

It helps to use your contacts — a member of your group may know someone who can ask about a room on your behalf. (See Chapter 8.) Then when you enquire yourself, you're more likely to get a sympathetic response.

This checklist will help you work out what's right for your group.

CHECKLIST 3

- How large a room do you need?
- How will members travel?
- Do you need another room for people you care for?
- Do you want a quiet room?
- Will you need to make tea and coffee?
- Will members smoke?
- What can you afford to pay?
- How good should access be?
- Which day of the week do you want to meet on?
- What time do you want to meet — and end?
- Do you need to split into small groups?
- What might you do as well as talk?
- How could the arrangement of the chairs help discussion?

IN SHORT

Think what's right for your group. Agree on what's essential and what is preferable. Accept that you probably won't get exactly the room you'd like, but don't put up with one which isn't right for you. Look, and ask other people for help if you need it.

Money

Another essential ingredient for a support group is funds. What do groups find their members feel about raising money?

> *"People don't usually go along to their local group with the intention of embarking on fundraising. They go instead for help with their problems, and to talk to others who understand and can share their experiences."*
> *"We've found that many carers at home sew, knit, garden or cook. Lots of them are willing to make something to sell on stalls at other people's events."*
> *"How can* we *do fundraising? We're all so tied down."*

Sometimes groups have got help from outside their membership.

> *"Some time ago I wrote a letter to my local Ladies' Circle, telling them about our group and the desperate need for funds to cover running costs. I was quite overwhelmed on my return from holiday to find a cheque for £75.00 waiting for me!"*
> *"This month there is to be a sponsored beard cut and a marathon snooker game for our benefit."*
> *"Social Services give us £100 each year towards running costs."*
> *"A group at the Indian Community Centre gave us a donation."*
> *"Our 10th anniversary party was held at the Community Centre. We phoned around local firms and got gifts from the Halifax Building Society and the Express Potato Company to mark the occasion."*

This book can't go into a lot of detail on every subject. There are many books and leaflets about money (see page 65). You can get them by post or through your local library, or you may be able to read them at a Council for Voluntary Service. It may be useful to look at them, and then to talk to other people about their experiences.

Here's what some groups find it's useful to have in mind when thinking about money:

- ☐ Have clearly worked out aims for your group. Doing this first will help you and other people see how much money you need, and why.
- ☐ Make sure you look after it when you get it: appoint a treasurer, open a bank account, produce annual accounts.
- ☐ Get advice on looking after money if you need to. One of your members may well know someone who is used to dealing with money, who could advise you.
- ☐ Get members to contribute a little each time they come: aim to make a little profit on the coffee, for example — or have a mini-raffle.
- ☐ Scale your fundraising to your members' situation — don't be too ambitious.
- ☐ Don't be afraid to ask people outside the

group to help. 'Self-help' doesn't necessarily mean being totally self-sufficient.

☐ Don't let fundraising dwarf the other activities of your group.

☐ Try and use any fundraising events you put on to achieve other aims too: having fun, getting to know each other, publicising your group, or making the public aware of a problem.

☐ Think about what you might get sponsored: a leaflet, an event, a member's expenses for a training event.

IN SHORT

Don't ignore money — you can't do without it altogether, and with some you may be able to achieve a lot more. But don't let it take you over, and look for help outside as well as from your members.

Publicity and new members

Sheet 1 gives some suggestions on finding other carers, through organisations and individuals. This section is about word of mouth, media publicity, written publicity and newsletters. What experience have other carers' groups had?

> ***"You need to think of publicity as sowing seeds. You might get one member from an article."***
> ***"The last two families who have come along have heard about us by word of mouth, rather than notices and letters. Maybe this is how our fame will spread."***
> ***"Groups always think they are going to have a queue of members at the door. You aren't going to get flooded out!"***
> ***"It's taken years to achieve, but the specialist health visitor does now tell parents about our group, and gives them one of our cards."***
> ***"I heard Peter talk about his group on local radio — it seemed just what I wanted, so I rang up."***

Publicity comes in all shapes and sizes. There's no one way to go about it, and you can scale it to suit the needs and resources of your group. Working through this checklist might help you think why you might need publicity. Then you can go on to how you can do it.

CHECKLIST 4

- Is your membership likely to stay as it is?
- Do you want to offer your group to new people?
- What steps might you take to tell ethnic minority carers about your group?
- What could new members bring to the group?
- How many new people could you cope with?
- Do you need publicity to promote a cause?
- How might it tie in with fundraising?
- What money have you got available for publicity?
- What useful contacts do you have among your members?
- What sort of image of yourselves and your group do you want to put over?

Publicity, like money, concerns most small voluntary groups, and there are many useful publications (pages 64 and 65) to help you learn from other people's experience. But remember, carers' groups are a bit different from other groups.

Word of mouth

Lots of people caring for dependent relatives don't go out much, and they may have lost confidence. Carers from ethnic minorities may find it easier to go to a group with someone they know already. If you go along to a group because a friend or neighbour's invited you, you're not committed. You can just go along and see how you like it. Word of mouth can work well, so it's worth making a conscious effort. Group members are probably the best messengers, but sympathetic professionals (pages 51 to 53 and Sheet 1) can be helpful too. These things seem to work:

☐ having a tradition that everyone helps recruit new members, not just one committee member

☐ personal visits or phone calls to enquirers before their first group meeting

☐ a card or leaflet that you can leave with a potential member, if they don't feel ready for the group straight away

☐ making sure someone is responsible for welcoming and introducing new members at their first meeting

☐ asking a member from the same ethnic minority community as the new member to visit them before their first meeting, and perhaps come with them to the first few meetings.

It is actually more than 'word of mouth'. It's personal contact, recognising the situation people are in, and meeting their needs. And you'll find people who've been coming for a bit are often very glad to take on such jobs.

Media publicity

A lot of groups find they have a love/hate relationship with the media. 'Love' because a well written article, a good photo, or practical information about the group can bring in new members or put over your message. 'Hate' because things can get distorted so easily.

Remember that the press, in particular, can put over an image of either yourselves or the people you care for which is not what you want. So be cautious in your approach to local papers. These things seem to work:

☐ being clear about the risks you're taking

☐ fostering a personal contact with a journalist you trust

☐ using free local newspapers, and the ethnic minority press

☐ asking for a photographer to come to any event which is a bit different

☐ issuing a press release (see Sheet 6).

Radio publicity is specially well worth exploring. Carers talking about their own situations come over very vividly on local radio. Many potential members are regular listeners, and even those who never join you will feel acknowledged and supported by hearing another carer speak about their situation. Remember:

☐ Local radio stations often like to see themselves as helping the community, and they welcome being approached. But do your homework, listen to the local station, and ask to go on programmes which are particularly relevant to your group — ethnic minority programmes, religious programmes, and any slanted to care in the community — as well as more general spots.

- ☐ Think of a peg to hang your story on — you're unlikely to be interesting to them just because you exist.
- ☐ Don't hold back because you've never done it before — it's not as daunting as it might seem.

Written publicity

Posters, leaflets and small cards have all proved useful to groups. There's more about how to produce them in other publications (see pages 64 to 65). You don't necessarily have to pay out a lot to get them done:

- ☐ many towns have resource centres where you can learn to do it yourself
- ☐ if you can't get out easily, see if a commercial printer will give you a reduced rate
- ☐ someone might sponsor you in return for their name being included
- ☐ Social Services might give you a grant to cover the cost.

Include the cost of translating and printing them in any appropriate minority languages. Don't underestimate the amount of publicity handouts and posters you need, and reckon to get a small response in return for putting out a lot.

There are lots of advantages in producing your own publicity. But in case you don't feel you can manage it the Kings Fund Centre has a standard leaflet you can buy and use locally to tell people about your group. It explains how groups can help carers and has a space for your own address. Details of how to order these leaflets can be found on Sheet 8 (which also gives ideas for posters and leaflets).

Newsletters

Newsletters work. Established groups find they keep the group together, help people who can't get to meetings to still feel involved, and provide a way of passing on information. (See Sheet 3 for detailed suggestions on how to produce them.)

You can send them to people outside the group, too, to keep them in touch and informed. And some groups use them as a way to share out the job of keeping members in touch.

"A link family was chosen for each of eleven small neighbourhoods, and given the responsibility of delivering the newsletter by hand, and collecting items of news for the next one."

IN SHORT

Build publicity into your group. It's specially important for groups who want to go on reaching out to new members, but it's also a tool to weld your group together.

Transport

Many groups have found they need to offer some sort of transport, but it's a daunting task for new groups. It's worth thinking of asking outside organisations for help, though this doesn't always solve the problem (see pages 50 to 55).

Being able to make arrangements for transport will help you get and keep members, but not all groups can manage to take it on themselves. You may just have to hope that members will sort it out individually, and encourage them to ask friends and family to help.

We've already suggested one solution to this problem, in the section on meeting rooms — meet somewhere within walking distance of members' homes, and keep your publicity and recruitment to that small area. What's been other groups' experience?

"Members are often reluctant to ask for lifts, even when really needed."
"People come from a wide rural area, and we find we have to provide transport."
"Have you ever tried using public transport with a handicapped child and a buggy?"
"We do have volunteer drivers, but we find they don't care to be asked to drive more than once a month."
"The transport officer in our group fills an important role as a telephone contact — picking up the latest news and problems."

A lot will depend on the people members are caring for. The choices open to you will vary too. These seem to be ways that work:

☐ meeting at a school or day centre, so members can travel in any transport provided for the people they care for
☐ asking outside organisations (see pages 50 to 54) to arrange transport for you
☐ raising group funds to pay for transport arranged through voluntary transport schemes or shared taxis
☐ asking members with cars to give other members lifts, which lets friendship develop too
☐ appointing a 'transport officer' in the group to plan and coordinate a variety of methods
☐ meeting very near good public transport
☐ buying a minibus (for very well-established groups only) or, better, arranging to borrow one from elsewhere.

IN SHORT

Think carefully about your members' needs, the place and time you meet, and if you need to offer transport. If you do, see it as an expense the group might bear once you've got established. Ask for help outside the group, but be realistic — this can be a difficult problem.

Care arrangements

Many carers will only get to meetings if there is some arrangement for the people they care for. If your group chooses its meeting place well, care arrangements may be simple.

It will probably be helpful to think how you are going to approach care at the same time as you choose where to meet.

You will also need to think if carers are going to meet alone, or with the adults or children they care for (see pages 28 and 29), and what problems this might bring.

If care at home is necessary, be flexible. Don't have one option fixed in your mind and expect members to fit in with you. Offer them choices, and help them towards their own decisions. With some suggestions and a bit of juggling, members may be able to make their own arrangements at home. And they may find this the most comfortable and reliable way. For example, it might be possible to alter a home help's hours.

The group may just help someone think through the choices open to them, and encourage them to ask a relative to sit in. Or you might suggest they could ask a professional worker to arrange this for them. There may not be a local sitting service, so this does not always solve the problem, but asking for help will demonstrate the need.

If people can't make their own arrangements (there may just not be anybody available), then you may need to explore other possibilities. These are some that different groups have found to work:

"We have a playgroup for the children, in the same building, but not in the same room. We get a grant from Social Services to pay the person in charge and volunteers come from the local school. We raised money ourselves for equipment, and a cupboard to store it in. People find it difficult to leave their child at first, but it gets easier once they've been coming a bit."

"We decided that the problem of relief care was not one which just affected members getting to the group. We put enormous effort into a campaign, with the help of other organisations and have just heard that next year a Crossroads Care Attendant Scheme will be started."

"We approached Age Concern. They'd been thinking about a voluntary home sitting service, and eventually one did start. Not all members are entirely happy about a strange volunteer coming into their homes and we find we need to allow some time before they settle down together but it does help."

"Mencap provides a sitting service of experienced people, who get paid for an evening. It means we can both go to the parents' group together. We always tell new members about it."

Different groups find different solutions, many of which need help from outside. Don't feel you have to rely on helping each other out, though former carers will sometimes sit for current members. This is another area where you may need help, but can't always get it.

IN SHORT

When you plan your meetings and activities, take into account the care of the people members look after. Allow plenty of room for choice over this. Ask for outside help if you need it.

Motivation

The ingredients suggested so far have been practical ones. Giving members a reason to keep coming is just as important, but it's not so straight forward. You've found your members, got them to come, welcomed them — how do you make sure they go on coming? If you've got at least some of the practical details right, it should be possible, but even then, groups find that people stop coming.

Perhaps you won't be able to stop this, just because of the situation carers are in. They may not have any energy left to take part, or to think of others. And people must be able to choose if they want to come or not — don't make them feel it's an obligation.

But there are points to think about — don't assume it's always because of carers' commitments.

Seeing it works for others

Members who get a lot out of a group can show it, not just keep it to themselves. It's important for members who have been going longer to let newcomers know why they come and what they get out of it. This can happen quite naturally in conversation, or it may come up in a group discussion. Stories of how people have been helped by the group could be included in a newsletter too. You should encourage members to tell the group what it means to them. Some people can only do this later on.

> ***"It was only after her mother died, that one lady told us just what it meant to her to come to the group."***

Others let you know straight away.

> ***"I've got attendance allowance! I wouldn't have known about it if we hadn't had a talk on benefits at the group."***

You may even feel you can ask people directly how the group has helped them, if they don't say, and talk over what they say with the rest of the group.

Keeping the programme interesting

When you're new it's generally not difficult to organise a programme of activities and talks. But it's not so easy when you've been going a bit. There's probably no easy answer to this, but aim to keep your programme varied and interesting — and you can ask people what they liked. Variety, getting people to do things as well as listen, and visits by other groups or outside people, all help too.

And sometimes pause to think if what you do still suits the needs of members who've been coming some time, as well as new members. Reviewing what you do (Chapter 9) is helpful.

Try to avoid people's pet hates.

> ***"They're playing bingo next week. If it's one thing I can't stand, it's bingo. I'm not going."***

Getting them involved

As we saw in Chapter 6, it helps a group if the jobs can be shared round. You have to be sensitive to the feelings of new people in particular, but getting people involved can be a real incentive to keep on going.

> *"I'm doing the coffee next month, so I've got to go."*

It also helps carers who have to ask relatives and friends to look after the person they care for, if it's clear that the group is depending on them for something.

Getting people involved can help stop a cosy in-group growing. People must feel part of a group, not just on the fringe.

IN SHORT

Give members reasons to go on coming. Let them see it works for other people, review your programme and get people involved.

Links with other organisations

Carers' groups can run things themselves, and you know what's best for you. But the task may be a daunting one, far too much for many carers to handle alone.

A support group might do well to think of how to forge links with other organisations and individuals. These links can strengthen and help what you are trying to achieve, and leave time for the things which only you can do.

Groups which look outward to people and groups in their local community, and to national organisations, are much more likely to thrive than those who only do what they can from their own limited resources. Chapter 8 has ideas and suggestions for different sorts of help you can draw on from outside your group.

IN SHORT

Think about seven essential ingredients for your group: a meeting place; money; publicity and new members; transport; care; reasons for members to go on coming; and links with other organisations. Work out what you need in your group.

PART 3

MAKING IT WORK

8: OUTSIDE HELP

SPECIALIST WORKERS ■ LOCAL ORGANISATIONS ■ NATIONAL ORGANISATIONS

Remember the story of the group who realised they were on their own (page 9)? They saw that it was up to them to get the group going, and to make sure that it met their needs as they saw them.

But running a group by yourselves for yourselves doesn't mean you have to do it entirely alone. You can get help elsewhere if you spend a bit of time at it — searching, then asking for it. As we have seen, looking outward and building links can help give you confidence as a group, and make you stronger and more effective.

Let's think again about some of the stories of groups that got help from outside.

> *"... I was quite overwhelmed to find a cheque for £75.00 ..."*
> *"... the Health Centre made us really welcome ..."*

"... the workers helped us sort out some of the problems ..."
"... the training course was a tremendous help ..."

Where might you get some back-up? There are three main sources:

☐ specialist workers, employed to help groups
☐ local organisations, including local professional workers in the health and social services
☐ national organisations.

Specialist workers

In some parts of the country, people are employed specially to help voluntary groups or carers. Any of these could be very useful to you:

☐ *Ethnic minority community workers* are often useful links between carers' groups and sources of help in the wider community. They can also help with advice, recruiting new members, practical matters, and getting a pattern to your group that feels right for you. They may be based in a community centre for one particular minority group, with a black voluntary project, or a Community Relations Council. In some areas there are specialist workers in Health or Social Services.
☐ *Self-help centres/clearing houses* now exist quite widely, sometimes as part of a Council for Voluntary Service. There's a directory (page 68), giving details of where they are and what services they provide. One advantage of links with them is the chance to meet and learn from other self-help groups. They can also give practical services and support.
☐ *Specialist carers' workers* are employed by voluntary bodies, or by Health and Social Services in a few parts of the country. Ask at your local Social Services if there's one near you. Their expertise and support, and the resources they can draw on have proved invaluable in helping carers' groups get going.
☐ *Liaison officers*, or community social workers who are employed in Social Services Departments, or Health Authorities, to make links with voluntary organisations.

IN SHORT

If you're lucky, there will be someone nearby willing to help you, and whose job it is to give you backing.

Local organisations

Local organisations are another possible source of help. Different organisations and people within them will be able to help in different ways. Most of them would consider giving you a hand if you approach them in the right way.

What sort of help could you ask for? Remember some of the stories you read earlier.

"... meet at the Afro-Caribbean Centre for a cup of tea ..."
"... we had plenty of volunteer helpers ..."
"... Pat came over and it was really helpful."
"... we had gifts from the Halifax Building Society."

There are several key areas you could think about:

- ☐ building up useful links and good relationships with other organisations
- ☐ getting help and support from professional workers
- ☐ drawing on practical resources
- ☐ expanding your group and developing activities
- ☐ getting help with individual members' needs.

Every local area is different, so it might be useful to make a note of outside sources of help as you come across them. You could start by listing local organisations that members already know about. This is again something you could do working in pairs, then writing up ideas on a large sheet of paper.

Useful links and good relationships

What organisations are most useful to you will depend partly on individual members — their enthusiasm and interests — and partly of course, on the sort of group you are, and your needs.

Build up links slowly. It's better to have a close contact with a few helpful, supportive organisations, than lukewarm contact with lots who aren't particularly helpful.

There are lots of simple ways you can link up with other organisations, and build up good relationships:

- ☐ *arrange visits* — for example, to another self-help group, a community centre, a hospital department, or a special school — to see what they do
- ☐ *hold joint events* with other groups and organisations — jumble sales, meetings, and training days, for instance
- ☐ *join in local fairs or exhibitions* where voluntary groups can run fundraising stalls or put up a display
- ☐ *use your members' contacts* — friends, neighbours, workmates, or perhaps another organisation they belong to, or used to belong to. Personal contact with one friendly person in another organisation can be enormously valuable
- ☐ *invite representatives from other organisations* to any special meetings you hold, or to come and speak to your members
- ☐ *think about what you can offer them in return* — send a speaker or your newsletter; keep them up to date with your news and information; mention them, and how they've helped you, in your newsletter or publicity.

Professional workers

Professional workers in the Health and Social Services can be a valuable source of help. If you develop a good relationship with one or two sensitive and friendly professionals, they can often use their own contacts to give you access to all kinds of help.

The most likely people for you to have links with are community nurses and social workers. Others might be physiotherapists, doctors, dietitians, teachers, occupational therapists, hospital nurses and administrators.

Do remember, though — helping groups isn't these people's main job — so the time they have for it will be limited.

Community nurses are employed by the local Health Authority. There are several kinds — district nurses who provide home nursing care;

community psychiatric nurses, who give support to mentally ill people; and health visitors, who work with children under five or with a particular group of people in need.

Your GP can put you in touch with the head of community nursing in your area.

Social workers are usually employed by the Social Services Department of your local council. There are different kinds — field social workers who can help arrange some support; day centre workers; residential social workers; and hospital social workers.

What sort of support might your group get from professional workers like these? They might be able to:

☐ provide a contact address and phone number for the group when it's new
☐ help find new members (see Sheet 1)
☐ arrange speakers on subjects your group wants to know more about
☐ help you find your way round organisations like Health and Social Services, by suggesting the best way to make a request, or how to reach the right person or department
☐ give your members information and specialist knowledge about a particular condition, or tell them what support and services are available to carers
☐ help you solve problems that arise in running your group
☐ give key members personal support

What do groups say about their relationships with professional workers? These groups were all glad of help:

"I was less than hopeful when we wrote to the consultant, but a letter arrived back promptly, saying he had managed to fit us into his busy schedule, and would come and give us a talk as we'd asked."

"Health and Social Services workers are stocking our new business card and give them out for us which helps a lot."

"Although local GPs are interested and supportive we have very few referrals from them. But we do get members through hospital consultants and some social workers."

But be prepared — sometimes the relationship isn't easy, and support is not always readily available:

"Some of us have had bad experiences, individually, with professionals, and would like to use the group to talk about them. But it's difficult with a social worker present."
"I'd really like to help the group more, but the sheer pressure of everyday work makes it so difficult to find the time."
"I thought, well, if I start the self help group, then they can take it over when it gets going."
"Some of them want to get so political! I'm trying to play this down."

What helps to make a relationship with professionals work well? Keep these points in mind:

- ☐ *It takes a long time for a relationship to develop.* And although many professional workers are sympathetic to carers' groups, some of them find it difficult to support a group they're not in control of. Sheet 9 gives some ideas about relationships — they're not always easy. This sheet will be particularly useful to groups changing from being professionally led to being run by members.
- ☐ *Be clear in what you ask.* Even busy people will make time for a clear, definite request, like giving a talk, putting up posters, or arranging a regular meeting room.
- ☐ *You need to remind them about your group's activities.* Keep them up to date. Give them simple literature like business cards that they can give other people, leaflets explaining what you do, or your newsletter. Let them know about any changes in your group.
- ☐ *Get your group listed in any directories that professionals might use.* Councils for Voluntary Service, or local self-help centres might produce this sort of directory.

Practical resources
A number of local organisations can give you access to practical resources. Here are some examples:

Library, school, college, community centre, youth centre, village hall, pub, church, synagogue, mosque or temple. May have meeting rooms or venues for events like concerts and jumble sales. May be willing to display your publicity free of charge.

Council for Voluntary Service, Community Relations Council or Volunteer Bureau. May be able to offer meeting rooms, help with printing/ photocopying, loan of equipment.
Might suggest to someone to audit your accounts.

Community Transport Scheme. Can provide low cost transport.

Health education unit of the local health authority. May be able to provide loan of videos, speakers or information on health matters.

Shops, local businesses, etc. May be willing to donate free or discount materials, sponsor a publication, or give contributions to a social event.

Getting help as you grow
Some local organisations and professional workers can offer your group practical support when you begin to expand. There are three key areas where you may find outside support useful:

- ☐ developing members' skills and practical knowledge, through training events and conferences

☐ campaigning to bring attention to the needs you are trying to meet
☐ fundraising.

These are some of the organisations that may be able to help you as you grow.

Community Health Council (CHC). Patients' watchdog organisation. May be able to help bring your needs to the attention of the right health authority department, or health professionals. May put you in touch, or organise meetings with relevant health staff. Can put you in touch with other local support and self-help groups if you want to join forces to strengthen your campaigning.

Social Services. May be able to provide training for members of your group, or sponsor some of them to attend events. May also be able to help you with running costs. Write to the Director of Social Services for your area.

Community Relations Council or local council Equal Opportunities Unit. May be able to help if you are an ethnic minority carer's group, with advice on sources of funding, for example. May take up a matter on your behalf with the council or Health Authority. Ask for the officer responsible for Health or Social Services.

Council for Voluntary Service (CVS). Can provide advice on fundraising; information about local organisations, and support to voluntary groups. May be able to suggest sources of money, practical services, training, and places for publicity.

Self-Help Centre (or similar name). Can help when you start up; some of the same services as CVS; newsletter, directories and other publicity outlets.

Local offices of national organisations like MIND, Age Concern. Some local branches can offer useful advice on campaigning, and developing projects. They might give practical help, and at least the general support of a nationally-known, respected organisation.

Help with individual members' needs

As your group grows, the most active members may find more of their time is spent giving support of one kind or another to other members. Some will enjoy this; others can find it tiring, and stressful. *Caring at Home* is a new book (see page 66) which you may find very useful, but many local organisations will be able to help individual members in your group. Here are three examples:

Social Services and Health Authority. Can provide information and practical support for individual carers. The local Social Services office, or your GP may be able to put you in touch with someone who can help.

Council for Voluntary Service. Can provide general information about voluntary services available for individual needs.

Citizens Advice Bureau, and Advice Centres. Can provide advice about housing, welfare rights, benefits, etc.

Use the examples and suggestions in this chapter to help you think through your group's needs. You don't have to go to all these organisations, or ask for all this help. And it does take time and effort to build links. It's a good idea to share out the tasks between members.

A final checklist may help you get your thoughts straight:

CHECKLIST 5

- What can we do by ourselves?
- Do we want to stay within those limits?
- What outside organisations might help?
- Which professional workers might help?
- What sort of relationship do we want with them?
- Are there any things we'd particularly like help with?
- What could we do if we joined forces with other organisations?
- Are there things we can offer in return for outside help?

IN SHORT

Get to know who might help your group. Use members' personal contacts with other organisations and professional workers. Work out what you could ask for, and the best way to make an approach. Ask for something in particular. Keep your contacts informed of your activities. Don't be reluctant to ask, but be realistic and remember you may not always get what you need.

National organisations

There's a list of useful national voluntary organisations on page 68. Whilst many are geared to a particular illness or disability, others are for general needs of carers. For example: *the Association of Carers and the National Council for Carers and their Elderly Dependants.* Both provide services and information for carers and carers' groups. They also campaign for better resources and more recognition. They recently decided to form one carers' organisation, so they can do this more effectively. They will be called the Carers' National Association.

Contact a Family aims to bring together families from all over the country with physically or mentally handicapped children.
They bring together families in the same neighbourhood to form local self-help groups, or families across the country to link up particular problems like rare handicaps. They help parents share their experiences, and support and help each other; and they organise activities and services that are needed.

You don't have to have links with these organisations, or any others, to be a carers' group — it's up to you. But many groups find it helpful to keep in touch, and sometimes to become a local branch of a national organisation.

What might you get out of the contact?

Every organisation is different, and so are the kinds of help they can give. Most will advise you on the phone. They also have public information leaflets and a newsletter, and can provide speakers. Many can offer specialised knowledge and expertise on carers' issues.

For example, they might be able to help with:

- ☐ contacts in fundraising — national or local bodies your group might approach about money
- ☐ information (books, leaflets, fact-sheets,

videos) about particular conditions and rare handicaps

- up to date news about issues affecting carers like developments in medical knowledge, changes in Health Service policy, and changes in the law affecting rights or benefits
- expertise in how groups work, such as practical advice and support in getting started, and links with other local groups.

Could your group benefit from joining a national organisation?
There are several advantages:

- Contact with neighbouring groups in the organisation.
- Being part of a wider movement can help make your group stronger — you have more resources and support to draw on than if you're on your own. It can add weight to your group's voice locally if you're part of a national organisation people have already heard of.
- It gives your group a voice at national level. As members of a national organisation, you can influence that organisation's policy and what it does.

There may also be disadvantages:

- Joining a national organisation can restrict your group's independence. Some organisations say members must adopt their constitution, rules and procedures (others are happy for local groups to operate independently).
- Meetings and other procedures required by the organisation can eat up your members' valuable time.

Use national organisations as another source of information which will strengthen what you do, and to help your members.

If you are a small, informal group, you may like just to let them know you exist, and perhaps get their newsletter. If you get larger, and want to tackle bigger issues, it could be a great help to have closer links.

But remember you don't have to get drawn into their structure unless you want to. If you are thinking of joining a national organisation, find out first what it will involve.

They need you too! National organisations want to be kept in touch with issues that concern individual members and groups; they want to be asked to take up new causes. They want you to be involved because this gives them credibility, and strengthens the base from which they campaign.

IN SHORT

Find out about national organisations which might be right for your group and your members. Let contacts grow as you grow. Use any way you can to meet or learn from other similar local groups. And remember that national organisations also need you.

9: REVIEWING AND CHANGING

REVIEWING AS YOU GO ALONG ■ SPECIAL EFFORTS ■ MEASURING ACHIEVEMENTS

From time to time it's a good idea to look at what you're doing, and how, to make sure you're meeting the changing needs of members. If you feel you aren't, don't be afraid of change. This is a useful thing for any group to do — carers' groups especially, because many members' situations will change:

- ☐ the person they care for could go into residential care or hospital
- ☐ the person they care for could die
- ☐ carers themselves could become ill
- ☐ they could regain their confidence, and find a place in the wider community.

If members' situations change, it might alter their feelings about caring, or the amount of time they have, and it might affect how committed to the group they feel.

Why else might you take a look at what you're doing? Groups do it for a number of reasons:

- ☐ to deal with changes in their size and membership
- ☐ to see how well they're involving and welcoming new members
- ☐ to see if the time and place they meet is still right for members and people who might like to join
- ☐ to see if they are meeting the needs of ethnic minorities
- ☐ to look at their resources and see if they need more, or if they could use what they've got more effectively
- ☐ to be able to account to any organisation that gives them money, for example, Social Services
- ☐ to look at their aims and see if they are still right for their members
- ☐ to list what's been achieved and feel good about it.

How might you do it?

Reviewing as you go along

Lots of people have told their stories in this pack. Many found they had to take stock and make changes as they went along.

> *"... We decided to provide a phone number ..."*
> *"... Quite soon we changed to a group caring for people with a wide range of disabilities ..."*
> *"... We joined forces with another group ..."*

They weren't always consciously thinking about it, but in fact they were building in evaluation and change to the way they ran their group. It was part of their structure. These seem to be ways that work:

- ☐ reviewing an event or particular activity soon after it happens, and deciding what changes you might make next time
- ☐ asking all new members how they heard of the group — it's a way of checking painlessly on how good your publicity is
- ☐ encouraging members to go on courses, and to feed back what they learn to the rest of the group
- ☐ visiting neighbouring groups

You may think of other ways which will suit you. Keep them simple, and build them into what you are doing already. Then you'll have an automatic way of evaluating your group.

Special efforts

Sometimes, you'll find you need to make a special effort. We talked about the pros and cons of an Annual General Meeting earlier (page 34). For some groups, AGMs are useful. One group's newsletter editor wrote:

> *"Do try to come to the AGM. This meeting gives us all a chance to assess the past year, and to plan our future together."*

Another group also used their AGM to look forward:

> *"We looked at issues which would need*

attention in the coming year. One was how to give new families — black and white — the opportunity to get involved."

An Annual General Meeting gives a chance to weigh up what's been done and look into the future. It's best if you can make it a social occasion as well, and have a tradition in the group that everyone comes and joins in. There is a real risk that people will make excuses if they think an AGM is just going to be a formality and nothing to do with them.

Sometimes you can't wait for an AGM. Remember the group whose founder member said she wanted to withdraw. They decided to have a special meeting, and gave themselves plenty of time to work through the changes. It wasn't totally comfortable for the new key members, or for the founder member. Change isn't easy.

> ***"The founder sometimes found it difficult to sit back and watch the group begin to move in other directions."***

But facing up to it constructively made the process easier.

Measuring achievements

> ***"Just existing is an achievement for our group."***

As this small group felt, just being there can be something to be proud of. Remember it's actually a very difficult job to run an effective group. Count up your achievements, on whatever scale you operate. This checklist may help:

CHECKLIST 6

- How different do you feel from, say, a year ago?
- How many people has the group been in touch with?
- What changes has it made to your lives?
- How have members been helpful to other people?
- What projects or events have you put on?
- How many organisations now know about you?
- What written material have you produced?
- Have you educated the public about carers' problems?
- What publicity have you had through the media?
- How has the group changed in the last year?

IN SHORT

Accept that your group needs to be flexible and adaptable to meet its members' changing needs. Build review and change into the way you run, as well as making special efforts to check on what you're doing. Be proud of your achievements.

10: ENDINGS

PERSONAL BEREAVEMENT ■ TIME-LIMITED GROUPS ■ WHEN A PROFESSIONAL WORKER LEAVES ■ CLOSING A GROUP

Change sometimes means ending. There's often so much concentration on setting something up or joining a group that we don't give enough attention to closing or leaving one. It's important for carers' groups to think of this aspect of the life of the group and of individuals in it.

It needn't always be sad or negative; sometimes it can be a positive step and a time for growth. What kinds of endings might a group have to face?

Personal bereavement

It's almost inevitable that some members of carers' groups will have to face bereavement. In some groups this could happen quite often.

> *"I'm sorry not to be able to invite you to next week's meeting. The son of one of our members has just died unexpectedly and we're all feeling very upset by it."*
>
> *"Each time someone who a group member is caring for dies, we've all felt it, and been able to feel closely with the person who's had a loss."*

Like the people above, your group will feel deeply for a bereaved member. It can be a very important part of the group's life to share loss together (see page 28). It may help to read more about this, if you feel uncertain about how to deal with it (see page 65).

Members leaving

It's understandable that some people need to leave as part of their recovery.

> *"When she died, I knew I couldn't stay at home all day, so when the offer of a job came up, I took it. It meant I couldn't go to the parents' group any more as it met in the day time."*

One of the jobs of a carers' group could be to help people cope after a death. They may need practical help, and they will certainly need support in coping with the changes in their lives. In some groups, as we've seen, people don't leave completely; they take on a different role, as helpers. It's important to be flexible and understanding. Make it easy for people to vary how they are involved, or to leave the group if they want to.

Time-limited groups

Some groups only ever intend to have a certain number of meetings. They're often called *time-limited* groups. These can be helpful and constructive, and a good way to put over information to carers. Courses for a fixed number of sessions can do the same. This is all that some people may want — they wouldn't have joined an on-going group.

Other people may feel sad and incomplete at the end of a set of meetings. Here are two ideas to help you deal with any difficulties:

- ☐ accept that people will have very mixed feelings when a time-limited group ends — sadness, anger and loss as well as good feelings about the time spent together.
- ☐ find ways of keeping some contact going — make sure everyone has a list of addresses and phone numbers; ask if someone would like to invite a few people for coffee, or perhaps arrange an outing together.

But don't feel you have to keep going in some way. If a group was only meant to come together for a set number of meetings, it's probably better to end tidily than to go on unsatisfactorily. Count up your achievements, and part feeling good about the experience.

When a professional worker leaves

You may remember the group that had a lot of support from a health visitor and an Age Concern worker (page 8). One of them changed their job and left the area, and the other had to run a clinic. It's very common for a group to have a special relationship with workers like these, especially if it was the professional who took the initiative in setting it up. Sometimes the link goes on and becomes a personal one. It's not so much an ending, as a change.

> ***"They come in their own time now, as friends of the group."***
> ***"Chris changed her job, but she still helps on the annual holiday."***

But there can be a sudden end to a relationship when a professional worker changes jobs and can't go on supporting the group. If this happens, some groups feel very hurt and abandoned.

They may find it difficult to make a new relationship with a new worker who takes over, and the group may dwindle sadly. Or if members are suddenly expected to take over the running of the group, they may feel they're not ready to handle all the responsibility.

But it need not always be a bad experience. When the group has worked through its feelings of loss, it's best to be positive and look at the advantages. You can use the change to let people grow and develop, instead of depending on a worker. See Sheet 9.

Closing a group

It's all right for a group to end. It's very easy to expect a group to continue for ever, and to feel inadequate when it doesn't. But groups are fragile, they're there to meet members' needs, and these are likely to change. It may be better to close a struggling group with dignity than to go on in a half-hearted way. There are ways to make it a better experience — these are a few suggestions:

- ☐ meet for the last time, even if it's a handful of you
- ☐ make a group decision on how any money left could be used positively
- ☐ let people know the group has ended — be public about your decision.

There's more about this in my book on self-help groups (see page 64).

IN SHORT

Accept that people will join and leave your group, and make it easy for that to happen. There will be sadness and negative feelings about endings, but try to be positive too. And remember, one of the group's jobs may be to help bereaved members through their loss and on to a new life.

11: OVER TO YOU

You've got to the end of the book. Now it's over to you. You've seen what other carers' groups have done — they've done it, so can you if you choose to.

I hope this book has given you some ideas, but it is not a blueprint. If you do decide to start a group, or to make changes in an established one, do it your way. Just choose the ideas that suit you and your circumstances.

We've mostly looked at support groups. Some people prefer to be in a group based on an activity or campaign, and let support develop from doing something together. That can work well too.

You may decide not to start a group at all, or at least not yet. That's fine too — it's up to you. It's better to start when you're ready than at the wrong time.

If you do start a group, you won't be alone. You can contact other similar local groups, and join a national organisation. It's also possible to have some sort of partnership with professional workers, although this isn't always as easy as we'd like.

You'll also be part of a wider carers' movement. Carers are becoming increasingly determined not to be taken for granted. They want to be seen as partners, and are pressing for change. Carers' groups can help by working to change peoples' attitudes and to get more resources.

Two sorts of changes in attitudes are needed:

☐ changes in how people working with carers — Health and Social Service professionals and the like — see them

☐ changes in how carers see themselves.

Carers' groups are also enormously important in pressing for redirection of resources and better provision of information about them.

Not many carers' groups begin like this, though. Most start by giving and receiving mutual support from each other, and by exchanging information. You can start like this too — it's over to you.

FURTHER READING

GROUP ORGANISATION AND ACTIVITIES

Note: All the prices given here were correct at the time of going to press. If you are sending off for any publications, it is best to check the price list first.

*Indicates address for mail order given on pages 67 and 68.

***Community Start Up**
Caroline Pinder
(National Extension College and National Federation of Community Organisations, 1985)
£6.95 (inc p&p)

Co-operative and Community Group Dynamics
Rosemary Randall and John Southgate
(Barefoot Books, 1980)
£2.55 (inc p&p) from Changes Bookshop, 242 Belsize Road, London NW6 4BT. Tel: 01-328 5161

***Getting Organised: a handbook for non-statutory organisations**
Christine Holloway and Shirley Otto
(Bedford Square Press, 1985)
£5.57 (inc p&p) or £4.95 from bookshops

Giving and Taking Criticism: the self-help way
Bonnie Burstein
(Initiatives, the self-help newsletter of the Canadian Council on Social Development, 1987)
SAE to The Self Help Team, 20 Pelham Road, Nottingham NG5 1AP

Listeners: guidelines for helpful listening
(The Self Help Team, 1987)
80p (inc p&p) from The Self Help Team, 20 Pelham Road, Nottingham NG5 1AP

***Organising a Carers' Information Exhibition**
(King's Fund Informal Caring Support Unit)
£1.75 (inc p&p) from Informal Caring Support Unit, King's Fund Centre

Self-help Groups: getting started, keeping going
Judy Wilson
(Longman, 1986)
£4.95 from bookshops

***Voluntary but not Amateur: a guide to the law for voluntary organisations and community groups**
Duncan Forbes
(London Voluntary Service Council, 1988)
£16.00 (inc p&p)

***Working on a committee**
Steve Clarke
(Community Projects Foundation, 1978)
£2.00 (inc p&p)

PUBLICITY

***Effective Publicity and Design: a do-it-yourself guide to getting your message across**
Jonathan Zeitlyn

(Interchange books, 1987)
£5.95 from bookshops

***How to get the Message Over**
Dilys R. Lewis
(National Federation of Community Organisation, 1981)
£1.00 (inc p&p)

The Alternative Printing Handbook
Chris Treweek and Jonathan Zeitlyn
(Penguin, 1983)
£4.95 from bookshops

***Voluntary Organisations and the Media**
Maggie Jones
(Bedford Square Press, 1984)
£3.94 (inc p&p) or £3.50 from bookshops

MONEY AND RESOURCES

***But is it Legal? — fundraising and the law**
Sally Capper
(Bedford Square Press, June 1988)
£5.57 (inc p&p) or £4.95 from bookshops

***Employing People in Voluntary Organisations**
Sheila Kurowska
(Bedford Square Press, 1985)
£3.32 (inc p&p) or £2.95 from bookshops

***Finding and Running Premises**
Judith Unell and Anne Weyman
(Bedford Square Press, 1985)
£3.32 (inc p&p) or £2.95 from bookshops

Finding the Money: guidelines on raising money for day care and holiday schemes
(National Out of School Alliance)
£2.00 (inc p&p) from National Out of School Alliance, Oxford House, Darbyshire Street, Bethnal Green Road, London, E2 6HG. Tel: 01-739 4787

***How to Manage your Money if You Have Any: an accountancy handbook for community organisations**
(National Federation of Community Organisations, 1983)
£1.50 (inc p&p)

***Organising Your Finances: a guide to good practice**
Maggi Sikking
(Bedford Square Press, 1987)
£4.44 (inc p&p) or £3.95 from bookshops

***The Community Organisations Survival Kit**
(National Federation of Community Organisations, 1982)
£1.50 (inc p&p)

Women's Own Book of Fundraising
Kati Nicholl (editor)
(Collins, 1986)
Now out of print but obtainable from libraries

CAMPAIGNING

Citizen Action
Des Wilson
(Longman, 1986)
£4.95 from bookshops

***Opening the Town Hall Door: an introduction to local government**
Jane Hutt
(Bedford Square Press, April 1988)
£5.57 (inc p&p) or £4.95 from bookshops

Organising Things: a guide to successful political action
Sue Ward
(Pluto Press, 1982)
£4.95 from bookshops

Pressure: the A to Z of campaigning in Britain
(Gower Publishing, 1984)
£6.50 from bookshops

BEREAVEMENT

All in the End is Harvest: an anthology for those who grieve
Ed. Agnes Whitaker
(Darton, Longman & Todd, 1986)
£3.95 from bookshops

Bereavement: studies of grief in adult life
Colin Murray Parkes
(Penguin, 1983)
£2.50 from bookshops

Living with Grief
Tony Lake
(Sheldon Press, 1984)
£3.95 from bookshops

RECENT BOOKS FOR CARERS

***Caring at Home: a handbook for people looking after someone at home**
Nancy Kohner
(National Extension College, 1988)
£2.50 (inc p&p) from Book Sales Department, King's Fund Centre

Taking a Break: a guide for people caring at home
(King's Fund Informal Caring Support Unit, 1987)
1 copy free to carers. Bulk orders: £8.75 (inc p&p) for a local promotion pack of 25 copies with posters and leaflets; £27.80 for a pack of 150 copies. From Taking a Break, Newcastle upon Tyne X, NE85 2AQ

Other publications from the Kings Fund

Training packs

Action for Carers: a guide to multi-disciplinary support at local level. How to improve support for carers by involving different service providers and carers. Price £9.50 (inc p&p).

Carers: a video assisted workshop. To help primary health care professionals improve their response to the problems carers face. Price £95 (inc VAT and p&p). Further information from ESCATA, 6 Pavilion Parade, Brighton BN2 1RA.

Shared Concern. A video on how doctors tell parents their baby has a disability. For health professionals involved in supporting parents both inside and outside the hospital. Price £45.00 (inc VAT p&p), or can be hired from CFL Vision, Chalfont Grove, Bucks SL9 8TN (tel: 02407 4433) for £10.50 (inc VAT and p&p).

Books

Building Community. For people with mental handicaps, their families and friends. By Ann Shearer. Price £9.50 (inc p&p).

Making the Break. Parents' views about adults with a mental handicap leaving the parental home. By Ann Richardson. Price £3.00 (inc p&p).

Further information from: Book Sales, Kings Fund Centre, 126 Albert Street, London NW1 7NF. Tel: 01-267 6111.

Other publications from the National Extension College

Training packs

Counselling: the trainer's handbook. A resource for training courses in counselling skills. By Francesca Inskipp. Price £14.95 (inc p&p).

Counselling Skills. An introductory course in counselling skills. By Francesca Inskipp. Available Summer 1988.

The Trainer's Handbook for Multiracial Healthcare. A training programme in health and race. By Penny Mares *et al.* Price £35.00 (inc p&p).

Books

Caring for Sikhs, Caring for Muslims, Caring for Hindus By A.Henley. Price £5.95 each or £15.00 the set (inc p&p).

Coping With the System: a citizens' manual. A simple guide to your basic rights. By Robert Leach. Price £7.95 (inc p&p).

The Graphics Handbook. How to produce leaflets, posters and teaching materials. By Richard McCann. Price £4.95 (inc p&p).

Health Care in Multiracial Britain. Developing health services to meet the needs of a multiracial population. By Penny Mares *et al.* Price £15.00 (inc p&p).

The Print Book. Describes different printing processes. By Information Transfer. Price £9.95 (inc p&p).

Further information from: National Extension College, 18 Brooklands Avenue, Cambridge CB2 2HN. Tel: 0223 316644.

OTHER SOURCES OF INFORMATION

MAIL ORDER

You can buy the books marked with * in the 'Further reading' section and other useful publications by mail order from the following. Write and ask for a list of their publications.

Bedford Square Press
details from
26 Bedford Square
London WC1B 3HU
Tel: 01-636 4066v
orders to
Harper & Row Distributors Ltd
Estover Road
Plymouth PL6 7PZ

Community Projects Foundation
60 Highbury Grove
London N5 2AG
Tel: 01-226 5375

Directory of Social Change
Radius Walk
Back Lane
London NW3 1HL
Tel: 01-435-8171

(You may find their books and leaflets on fund-raising particularly useful.)

Interchange
15 Wilkin Street
London NW5 3NG
Tel: 01-267 9421

King's Fund Informal Caring Support Unit
King's Fund Centre
126 Albert Street
London NW1 7NF
Tel: 01-267 6111

London Voluntary Service Council
68 Chalton Street
London NW1 1JR
Tel: 01-388 0241

MIND
MIND Publications Mail Order Service
4th Floor
24-32 Stephenson Way
London NW1 2HD
Tel: 01-387 9126

National Extension College
18 Brooklands Avenue
Cambridge CB2 2HN
Tel: 0223 316644

National Federation of Community Organisations
8-9 Upper Street
London N1 0PQ
Tel: 01-226 0189

The Volunteer Centre
29 Lower King's Road
Berkhamsted
Hertfordshire HP4 2AB
Tel: 04427-73311

DIRECTORIES

Libraries usually stock a variety of useful directories about national voluntary organisations and the health and social services. In addition, details of Councils for Voluntary Service and Self-Help Centres can be found in the following:

Directory of Councils for Voluntary Service
£3.00 (inc p&p) from Councils for Voluntary Service National Association,
26 Bedford Square, London WC1B 3HU. Tel: 01-636 4066

Local Self-Help Clearing Houses Directory
(National Self-Help Support Centre, 1987)
SAE to National Self-Help Support Centre, 26 Bedford Square, London WC1B 3HU. Tel: 01-636 4066

USEFUL ORGANISATIONS

Age Concern England
Bernard Sunley House
Pitcairn Road
Mitcham
Surrey CR4 3LL
Tel: 01-640 5431

Alzheimer's Disease Society
158-160 Balham High Road
London SW12 9BN
Tel: 01-675 6557

ARMS (Action for Research into Multiple Sclerosis)
4a Chapel Hill
Stansted
Essex CM23 8AG
Tel: 0279 815553

Arthritis Care
6 Grosvenor Crescent
London SW1X 7ER
Tel: 01-235 0902

ASBAH (Association for Spina Bifida and Hydrocephalus)
22 Upper Woburn Place
London WC1H 0EP
Tel: 01-388 1382

†Association of Carers
1st Floor
21-23 New Road
Chatham
Kent ME4 4QJ
Tel: 0634 813981

Association of Crossroads Care Attendant Schemes Ltd
10 Regent Place
Rugby
Warwickshire CV21 2PN
Tel: 0788 73653

Cancerlink
46a Pentonville Road
London N1 9HE
Tel: 01-833 2451

Chest, Heart and Stroke Association
Tavistock House North
Tavistock Square
London WC1H 9JE
Tel: 01-387 3012

COMBAT (Association to Combat Huntington's Chorea)
34a Station Road
Hinckley
Leicestershire LE10 1AP
Tel: 0455 615558

Contact a Family
16 Strutton Ground
London SW1P 2HP
Tel: 01-222 2695/3969

Down's Syndrome Association
12-13 Clapham Common Southside
London SW4 7AA
Tel: 01-720 0008

Greater London Association for Disabled People (GLAD)
366 Brixton Road
London SW9 7AA
Tel: 01-274 0107

Headway (National Association for Head Injuries)
200 Mansfield Road
Nottingham NG1 3HX
Tel: 0602 622382

MENCAP (Royal Society for Mentally Handicapped Children and Adults)
MENCAP National Centre
123 Golden Lane
London EC1Y 0RT
Tel: 01-253 9433

MIND (National Association for Mental Health)
22 Harley Street
London W1N 2ED
Tel: 01-637 0741

Motor Neurone Disease Association
61 Derngate
Northampton NN1 1UE
Tel: 0604 22269/250505

Multiple Sclerosis Society
25 Effie Road
London SW6 1EE
Tel: 01-736 6267

†National Council for Carers and their Elderly Dependants
29 Chilworth Mews
London W2 3RG
Tel: 01-724 7776

National Schizophrenia Fellowship
78 Victoria Park Road
Surbiton
Surrey KT6 4NS
Tel: 01-390 3651

National Self-Help Support Centre
NCVO
26 Bedford Square
London WC1B 3HU
Tel: 01-636 4066

Parkinson's Disease Society
36 Portland Place
London W1N 3DG
Tel: 01-323 1174

Royal Association for Disablity and Rehabilitation (RADAR)
26 Mortimer Street
London W1N 8AB
Tel: 01-637 5400

SENSE (National Deaf-Blind and Rubella Association)
311 Gray's Inn Road
London WC1X 8PT
Tel: 01-278 1005/1006

The Spastics Society
12 Park Crescent
London W1N 4EQ
Tel: 01-636 5020

Standing Conference of Ethnic Minority Senior Citizens
5 Westminster Bridge Road
London SE1 7XW
Tel: 01-928 0095

Terrence Higgins Trust
BM AIDS
London WC1N 3XX
Tel: 01-242 1010 (3pm-10pm)

† From May 1988, the Association for Carers and the National Council for Carers and their Elderly Dependants will work as one organisation — Carers' National Association, 29 Chilworth Mews, London W2 3RG (Tel: 01-724 7776) or 1st Floor, 21-23 New Road, Chatham, Kent ME4 4QJ (Tel: 0634 813981).

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Note: Page numbers in italic refer to 'Useful organisations' on pages *68-69*

SHEET 1

FINDING OTHER CARERS

Finding other carers will be a job for your group, whatever stage you're at. This sheet suggests ways you could do it, other than by using the media. Of course, local papers and radio are a very useful way to find members — or people to help you get going initially. (See books listed on pages 64 and 65 and Sheet 6 for ideas on this approach.)

Not all the places and people listed below will be right for you and where you live. So pick and choose.

Ask other organisations to be a link

Social Services Department
  area social work teams
  hospital social workers
  home help org
  occupational
  day centres
  day nurse
District He
  district
  healt
  chi
  h

Councils for Voluntary Service (CVS)
Community Health Council (CHC)
Special schools
Community centres
Ethnic minority centres
Age Concern
Specialist carers' workers
Libraries
  local
  central
  Books on Wheels
Citizens Advice Bureaux
Self-Help Centres
General Practitioners
Chemists

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Ask other organisations to be a link

Social Services Department
  area social work teams
  hospital social workers
  home help organisers
  occupational therapists
  day centres
  day nurseries
District Health Authority
  district nurses
  health visitors
  chiropodists
  hospitals
  paediatric assessment centres
  health centres
  community psychiatric nurses
Councils for Voluntary Service (CVS)
Community Health Council (CHC)
Special schools
Community centres
Ethnic minority centres
Age Concern
Specialist carers' workers
Libraries
  local
  central
  Books on Wheels
Citizens Advice Bureaux
Self-Help Centres
General Practitioners
Chemists

Use people to find your way through the maze

Ask people you know already — the district nurse who calls, the teacher at your child's school, and so on — to suggest ways of getting through the maze, or for names of helpful people to contact in the organisations you choose.

Use co-ordinating bodies — like the CHC or CVS — to advise you on how things are organised, and the best way to approach people. If there are carers' workers and self-help centres near you, they will help too.

Look for key people working with the problem that is common to your members — social workers in a stroke ward for example — and concentrate your efforts on them to begin with.

Produce printed material

Many of the methods suggested here need written material. Don't worry — it could be just a handwritten postcard or small poster at first. Later, you'll find your approaches are much more successful if you have simple printed material to give away (page 43).

Use public notice boards

Think where carers — or people who might tell carers about a group — go. You could put up a card or poster at any of the following:

- libraries
- churches and other places of worship
- community centres
- hospital waiting areas
- shop windows

Use directories

You can save yourself time and effort by using directories to find some of these people and places. Try:

- *Yellow Pages* — see under Charitable and benevolent organisations and Social Service and welfare organisations.
- *Phone Book* — look under the name of your council to find council run services, like Social Services; look under Libraries — public (which may be a separate entry); look under the name of your area to find your CVS.
- *Thomson's Directory* — local free directories of organisations and services.
- *Local help directories* — often produced by a CVS.

Use other people's mailings

You can save time and a lot of money by approaching organisations which post information to a large number of people. Think about:

- *Family Practitioner Committees*, who mail to GPs and other professional workers.
- *Health Authority units* (often called a Community unit) who distribute to health centres, health visitors, district nurses and so on.

- *Social Services Departments*, who may send out printed matter to offices and departments, and may also have a central newsletter
- *Councils for Voluntary Service*, who usually produce a newsletter and have a big mailing list to voluntary organisations
- *Self-Help centres*, who may have a newsletter and strong links with other self-help groups.
- *Libraries* — central libraries may distribute to local libraries.

These methods are useful if you want to inform a large number of people and are willing to do a lot of publicity, probably for a small return. You could:

- get them to send out a leaflet or poster
- publicise an event, or your meeting
- include an article about your group in a newsletter.

Place advertisements

If you can afford it, you could think about placing an advertisement in your local paper, in shop windows or in local publications. It could be in a personal column or an events section.

Join in events

Look out for publicity or fundraising events run by other people. It's quite simple to have a display, stall or game, and you don't have to do the publicity. Sometimes you have to pay a contribution, but it's a cheap and easy way to show your face. Look out for:

- *fundraising events* — schools, community centres, Lions Clubs, etc.
- *carers' fairs/information exhibitions*
- *self-help fairs.*

The advantage of this isn't just to find other carers. You'll also meet other organisations and make useful contacts.

Go in directories

When you're established, think about having an entry in a local directory. Most groups find they need to have a good core of people committed to the group, a regular meeting place and time before they do this. Don't do it too early on.

Keep at it

If you want to find other carers, you need to keep at it. Keep your eyes open for new ways, make sure you have enough money for publicity material, and get other people in the group to help.

SHEET 2

ORGANISING A PUBLIC MEETING

Why have a public meeting?

Groups have successfully run public meetings — sometimes called open meetings — for three different reasons:

- to launch a new carers' group
- as a tool in a campaign
- to renew interest in a flagging group.

Exactly what you do, and how you publicise the meeting, depends on why you're having it. But many of the general points to think about are the same.

Who could organise it?

Many new groups get going because of a public meeting called by professional workers. Then it works best if a small group of professionals and carers do it together.

If people involved are not carers, you should make it clear from the start why they are there, and how long they will be involved.

If a carer can chair the meeting, people will know that the topic is being seen from carers' viewpoints, and that it is based on personal experience of caring.

If you, as carers, call the meeting yourselves, remember some professionals may be very helpful allies, so involve them in your plans.

If you are an established group, think about setting up a small sub-group to do the job. If you are aiming to get going again, you'll probably need everyone to help.

Split up the jobs, whoever is involved, and make everyone feel part of the event. But remember one of the jobs should be to coordinate, so someone has an overview.

Have several planning meetings, and a discussion session soon after. Get everyone involved in organizing to wear a badge on the night.

What could happen?

Plan the meeting under four main headings. The detail is up to you.

Welcoming — e.g. several people to say hello at the door; hanging up coats; signing lists; introducing people; handing out information; getting people to sit near the front. Arrive 45 minutes before advertised meeting time.

Main business of meeting — e.g. general welcome; introductions of people organising meeting; speaker(s) or videos; questions; discussion; thank-yous. Allow perhaps 1h. 15 mins.

Looking ahead — e.g. announcement of future meeting(s); decisions on future action; getting new people involved. Allow perhaps 15 mins.

Unwinding — e.g. coffee and tea; donations in a plate; one-to-one chat; personal conversations with anyone in distress; asking individuals to help if it seems right; saying goodbye to your speaker; matching people up for lifts; thanking caretaker. Plan for 45 mins.

Your meeting probably won't follow this pattern exactly — you can never tell quite what's going to happen. But even if you're nervous — and lots of people are — stick to what you've planned. Remember all the time why you've called the meeting, and make sure you keep to that. For example:

- you can gently remind speaker(s) their time is up, if they're going over the agreed length
- don't let one person's personal worries take over; it's a public meeting, not a support meeting
- do stick to a timetable — carers will all need to get home.

Where? What time? When?

Choose a room that's neutral, central, pleasant and easy to find, and has an unlocked, well-lit entrance. It should be near public transport, and have parking if possible. Go and see the room before you book. Make sure you can have coffee and tea in the same room as the meeting. Ask if you can put up a notice and arrows to direct people. Find out what time you have to leave the building.

Most meetings of this sort are in the evening, usually at 7.30p.m. Think about the time of year — avoid holiday periods and winter weather.

Choose a date well in advance and don't leave everything till the last minute. If public meetings fail, it's usually because there wasn't enough planning time. You should allow three months or more.

How could you publicise it?

Use the media. An event like this is news — there's a good chance it'll get a mention. You may even get a journalist to attend, especially if you invite a national speaker. Look back at pages 42 to 43 in the main booklet, and at Sheet 6 on writing a press release.

Make posters. It's a good way to publicise a one-off event. It's best to get them printed, on a bright colour, and circulate them widely. You can often use other people's distribution systems (Sheet 1). But to be absolutely sure, you may prefer to put them up yourselves. Get them put up wherever carers might go (Sheet 1).

Tell allies. Think of people and organisations that might be sympathetic to your aims, and let them know. Allow time for them to put it in their newsletters. Think about doing handouts — reduced versions of posters are effective — and hand them out.

Write personal letters. Write individually to people you'd really like to come, enclosing a handout. Even if they don't come, you'll have let them know of your existence and ideas.

Place advertisements. Consider placing an advertisement in the local paper. You'll have to pay, but it may be worth it.

What results might there be?

Think what you want to happen *after* the meeting, and plan for this *before* it. For example, if you want a committee, speak to one or two suitable people beforehand. If you want to make a public statement, get someone to word a resolution in advance.

What makes a good meeting?

Beforehand — planning it well in advance; sharing out the jobs; professionals and carers working together; plenty of publicity; being scrupulous about detail.

At the meeting — mixing a sense of informality and purpose; having something for everyone present; having equipment that works, and speakers who stick to time; letting everyone who wants to speak do so; time to chat; not worrying about big numbers.

After the meeting — someone to produce notes taken at the meeting; reviewing what's been done, and how well your plans worked; thanking everyone who took part; following up ideas and people who came.

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ORGANISING A PUBLIC MEETING

SHEET 3

GROUP NEWSLETTERS

This sheet is for two sorts of groups:

- those who have decided already they want to produce a newsletter, and want to think it through
- those who haven't got to this stage, but who may have problems in their group that could be solved — partly at least — by a members' newsletter.

There is no one perfect way of doing it. Each newsletter will be an achievement for that group, and its size and style will show the character of the group.

Why have a newsletter?

Think it through with your group. You might decide you want to do it for all or some of these reasons:

- to pass on *useful information* about meetings, services, activities and contact people
- to make members of a big group *feel part of it* and to welcome newcomers
- to *keep in touch* with non-members
- as a means of *stating your aims* and putting over what you're trying to do
- to feed back *opinions* and share *ideas*
- to *lift* carers' spirits.

Who is it for?

When you write anything, first of all you need to think about who is going to read it. In other words, decide on your *target readership*. Then think who else might enjoy it too. How widely you circulate it will depend on style, cost and how much energy you have. You could think of aiming your newsletter at:

- regular members
- carers interested in the group, but not actively involved

You could also think of sending it to:

- interested professionals
- local papers and radio
- councillors or Health Authority members
- people who fund you
- libraries and other local information points
- umbrella organisations like Councils for Voluntary Service.

Is your newsletter only for people who read English? Or do all or some of your members read another language more easily? If so, you'll need to think about translation, and using a typewriter with the right typeface.

What style and how long?

It all depends on your group. When you're starting, especially, you'll want to keep it simple and short. Try to make it attractive, readable and regular. Make it enthusiastic — don't let it seem as if it's a burden to all concerned.

One or two typed and duplicated sheets of A4 paper are fine to start with. Ten sheets of A4 duplicated is probably too long — if you've got that much material, you need to think about better design and production, getting proper funding, or more frequent issues.

Think about the different rates of postage — how many sheets can you send for a particular rate? It would be annoying to find that your last sheet brought you just into the next rate.

What might it cost?

One group found it cost 13p a newsletter plus postage (1987 prices). Work out a budget for an issue *before* you start to produce it. You'll need to think about:

- number of pages
- number of copies
- how you're going to produce it
- translation costs, perhaps
- whether you're using white or coloured paper
- whether you're posting it, or delivering by hand
- whether you're going to put it in envelopes or not.

You'll probably end up with a budget for each issue like this:

Printing or duplicating costs	£
Postage	£
Envelopes	£
Miscellanous	£
X number of issues per year	
= total annual cost	£

How could you find the money?

First, you need to think if people are going to pay for the newsletter — like ordering a magazine from the newsagent, or subscribing to a journal — or if you will largely fund it in other ways.

Most groups find it best *not* to have a subscription system, because it brings more headaches than pounds. (You can, of course, have a membership fee for the group, which includes a copy of the newsletter as part of the benefits, and brings in some money.)

It's worth thinking about other sources too:

- general group funds
- sponsorship by a firm
- grants from Social Services or elsewhere.

And remember help in kind. You might not get money, but you might find you can get:

- printing done free or cheaply
- donations of paper or envelopes
- use of other people's mailings.

It's probably *not* worth trying to fund a simple newsletter with advertising.

When, and how often?

Big groups with lots of activities to publicize may want a *monthly* issue; others may go for *quarterly*. It's best to have some pattern, but choose one to suit your group. Think first if your newsletter is going to be *topical* or *non-topical*. If you are going to use it to publicise events and remember birthdays, then you'll have to work to tight deadlines.

If it's not too topical, take off some of the pressure by having a general name for the edition — *Spring 1989* instead of *April 1989*. Then if you do get a bit delayed, it's not as obvious. Whatever you decide, you'll need a timetable for each edition:

- deadline for contributions (copy date)
- editing (receiving and sorting out contributions, and getting the newsletter right)
- typing, correction and layout
- printing or duplicating, and visiting printer
- addressing envelopes
- packing
- posting and delivery.

People mostly underestimate the time it takes to produce a newsletter. Allow about a month from start to finish.

How could you get it done?

There are three ways to think about:
Photocopying — fairly expensive, but quick and easy for small quantities.
Duplicating — cheapest, but can take a lot of time. If you can use an electronic scanner, you can be more ambitious than if you use traditional wax stencils.
Printing — best for long newsletters and big membership. You could use a local printer (choose one nearby), or you might be able to use a resource centre or arts centre for voluntary groups.

Whichever you choose, think about the following:

- the pros and cons of a printer doing it for you, or doing it yourself
- using letraset for headings, or using someone's headlining machine
- making it look better by putting your material in columns, drawing boxes round items, and so on
- buying paper in bulk.

However you do it, involve several members of your group. It's an activity where jobs can be shared out, and where working as a team can be fun. People will surprise you with unexpected talents; or by being willing to take on routine tasks, as long as the tasks are broken down into manageable amounts.

Remember two key people are essential:

- someone to receive and sort out contributions (editor)
- someone who is the regular typist

Don't feel people have to do these jobs for ever — agree a time limit with them when they start.

What could you include?

The content of your newsletter will probably develop and change with each issue. But these are the sorts of contributions you might include:

Practical information — date, place, time and topic of meetings; new services; new books in your library.

Regular features — children's birthdays, For Sale, etc.

Feedback — summaries of talks at meetings; members' experiences of using services; reports of national conferences.

Personal accounts — members' feelings about things that happen to them; ideas for action.

News of members — births and deaths; welcome to new members; changes of jobs.

You won't want to include all these at once, or even in every issue. But *do* include in every issue:

- date of newsletter
- contact people for the group, including newsletter editor
- information about regular meetings
- a summary of the group's aims
- copy date for the next issue.

You don't have to present every contribution in the same way. Try to get variety. Think about the following:

- illustrations
- poems
- cartoons
- recipes
- jokes
- notice board.

How can you get material?

Getting contributions from your members may well be a problem. It helps to coax your contributors, give them deadlines, and remind them before the copy date.

Think about having conversations on the phone and writing them up, rather than expecting everyone to write an article.

Get a supply of non-topical articles in hand, so you don't have to get them written for a particular issue.

Use other people's information. National and local organisations are usually quite happy to have their material used, as long as you acknowledge the source.

Keep your eyes open for anything you might include, and put it straight away in a file.

Make it a tradition that anyone who does something new, goes on a course, etc., writes a short contribution for the newsletter.

Where could you get advice?

It hasn't got to be perfect. Carers' groups newsletters are best more homely than glossy — but make it as good as you can within the limits you set yourself. If you think you need advice, try the following:

- your members
- places where your members work
- Social Services
- arts and resource centres
- CVS and Rural Community Councils
- looking at helpful books (see pages 64 and 65 of main booklet).

How do you know you've got it right?

It's quite difficult to know this — readers aren't generally very good about telling you what they think. Start by being open to ideas and comments — don't feel hurt by feedback.

Use meetings and visits to ask people what they thought of the last edition. Occasionally spend part of a committee meeting looking at the last few issues and seeing what could be improved. Ask outsiders what they think.

You'll know you've got it right if people get to meetings, and take up services, and outsiders seem informed about what you do.

See it as a tool to keep members friendly and informed, and to welcome and involve new members. It will be hard work, but a job well worth doing.

SHEET 4

GROUPS' AIMS AND OBJECTIVES

These groups have all worked out what they aim to do in their group. Use these to get ideas for your aims and objectives – not necessarily to borrow them exactly.

The Amber Valley Carers' Support Group

A carer is anyone who is leading a restricted life because of the need to look after a person who is mentally or physically handicapped or impaired by old age.

The aims of the group are simple. To meet informally, once a month, so that we can either discuss our problems with others in a similar situation or simply have a chat and a coffee and relax for a couple of hours.

At some meetings speakers will be invited to discuss benefits, aids and adaptations and similar topics, if the group wish this.

New carers in particular may benefit from this type of discussion.

Also we arrange social outings, a trip to the pub or out for a meal on occasions.

The Eye Opportunity Playgroup

The Eye Opportunity Playgroup aims to advance the development of pre-school children in a safe and satisfying environment by:

- enabling handicapped and non-handicapped children to mix socially
- mutual help and co-operation between parents, relatives and friends, as well as those entrusted with the care of these children
- to raise adequate funds

Parents for Parents, Milton Keynes

Parents for Parents is a voluntary group of parents of handicapped children set up in Milton Keynes to help parents of newly diagnosed handicapped babies or children of any age.

Parents for Parents offers a confidential counselling service, and is solely run by volunteers. When parents are told that their child is handicapped they react in different ways — perhaps disbelief, or horror or grief — often they appreciate talking to another parent.

Parents for Parents aims to help families adjust to the strains created by the presence of a child with special needs in family life — whether that child is a new-born baby or an older child, perhaps hurt in a road accident.

Parents for Parents offers an information and advice service of available resources both locally in Milton Keynes and at a national level.

South Glamorgan Branch of the Association of Carers

(extract from annual report)

Locally the aims are to:

- offer support to carers and seek out those who need such support
- find out what is available locally and make this information known
- press for increased local resources
- provide a setting for carers to meet without their dependants.

Helping Hands — Cirencester

Helping Hands is a support and self-help group for parents of handicapped children. Our group is small and informal, and our children have many different types and degrees of handicap. We meet once a month to share problems, pass on information and offer help and advice about bringing up a handicapped child. We also meet regularly for coffee mornings in each other's homes. If you do not wish to attend meetings you can still receive our regular newsletter.

Newham Branch of the Association of Carers

(extract from annual report)
Throughout the year the Newham Branch of the Association of Carers has sought to develop and improve means to help those who give love and care, to those whose physical or mental disabilities would otherwise require them to live in a hospital, home or some other institution.

Hartcliffe Friends of the Handicapped

We are a newly formed group of family and friends of the handicapped.

Our aims are to bring together families in the same locality who have a handicapped child.

We offer play activities, holiday play schemes, outings, parties, coffee mornings, social evenings for parents, and a chance for volunteers to be involved.

Thanks to the groups on this sheet who allowed us to use material.

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GROUPS' AIMS AND OBJECTIVES

SHEET 5

FORMING A COMMITTEE

Why form a committee?

Only form a committee if you need to. It's not essential — many carers' groups run well without one. They do their business at the regular group meeting, and a few key people do most of the jobs.

You may feel you need a committee because:

- your membership has grown too large
- there is so much business that doing it at regular meetings prevents sharing problems
- having a pleasant time has become difficult
- newcomers feel unable to share feelings because business takes so long.

A committee brings other advantages too:

- being able to share out the jobs more
- giving proper time to planning and finding resources for the group
- helping a group which is changing from being professionally led to becoming more self running.

When should you do it?

When it feels right. Don't do it too quickly. Formalising a group too soon, which can really organise its affairs informally, can have a deadening effect.

When you do it, give proper notice to all members, so everyone has a chance to nominate and, if necessary, vote. Plan the formation of a committee, don't make it a snap decision. Some groups decide to do it at an Annual General Meeting. Some simply tell members it's going to be discussed at a particular meeting.

What officers should there be?

Committees normally have three key officers:

- chairperson
- secretary
- treasurer

Many carers' groups like to have a number of other named jobs. Then the three main officers won't seem to have high status; you can share out the jobs out better, and people can get experience in a less responsible job. Groups have chosen a number of posts — you could choose from:

- vice chair
- newsletter editor
- librarian/information person
- membership secretary
- new members' contact person
- social secretary
- publicity person
- minutes secretary
- someone to book speakers

It may work best to elect key officers plus a number of committee members at a group meeting. Then you can decide in detail who does what at the first committee meeting.

It's important for everyone to understand the jobs of the chair, secretary and treasurer. If you're not familiar with these jobs, look at simple books (page 64), or talk to people who are used to committees. Briefly,

- the *chairperson* makes sure that the meeting's business is carried out properly and that decisions are put into practice, and they represent the group elsewhere
- the *secretary* prepares the business of the meeting, tells members where and when it is, keeps minutes, and does correspondence
- the *treasurer* receives money, pays bills and keeps accounts.

How could you link with the main group?

Build it into the way you work from the beginning. You could:

- have a short verbal report at each group meeting after a committee meeting
- do a summary of committee decisions and action in a newsletter
- distribute minutes if people want — but don't deluge them with paper they won't read
- discuss major issues with the whole group, not only in the committee.

Involve non-committee members when you can. Ask someone to help with a particular one-off job, to go with you to a meeting or an event. It bridges the gap and gives other group members a taste of what's involved.

Be clear how long members serve on a committee, and stick to decisions you make. If you agree that someone serves as chairperson for only two years, keep to that, however good they are. It's really the group, not the committee, who is responsible for your future. Keeping committee membership the same for years makes things difficult.

What helps it run well?

It's all right to muddle on a bit, while you're getting used to a committee. A carers' group isn't a high-powered board meeting. But in the long term, aim to make your committee run efficiently. Following these suggestions could all help:

- meet in a pleasant place
- keep meetings a reasonable length
- start and end promptly
- have a plan (an agenda) — handwritten will do
- make decisions clear
- keep minutes
- know how much money you have
- share out the jobs
- keep in touch with the main group
- take big decisions to the main group
- get new people involved.

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FORMING A COMMITTEE

SHEET 6

PRESS RELEASES

A *press release,* or *news release,* is a summary of facts or views, or both. It's an efficient, quick way to communicate with the media. All you need is someone who can type and a list of your local papers and radio.

Benefits

To you

- saves you time
- more control over information
- you can choose when you put it out

To the media

- easy to read
- provides clear summary
- helps them plan
- alerts them to interesting stories

Who to send it to and when

Local newspapers, including free ones, radio stations and, if it's worth it, local television. Address it to friendly reporters or the appropriate person — e.g. News Editor, if the angle is news; Women's Page Editor, if it's a story that could go there.

If it's geared to a particular date, send it out in good time, to arrive one or two weeks before an event. You can put EMBARGOED TILL … at the top right-hand corner, if you don't want it published till a certain date. Or you can put RELEASE DATE — IMMEDIATE, which is probably best.

Points to note

- Keep it short, sharp and to the point — *who, what, when, where, why,* and *how.*
- Date it.
- Find a clear short headline — maximum five words.
- Use headed notepaper, if you have any.
- Type it with double spacing and wide margins.
- If you go to a second page, put 'more' at the end of the first page, and 'end' at the end.
- Summarise important points in the first paragraph.
- Use short quotes to give life to the story.
- Give the name(s) and telephone number(s) of member(s) who can be contacted for further information, and times available.
- Keep a copy.
- Fold it so the letterhead is visible when the envelope is opened.

What is newsworthy?

Journalists don't just want to know that you exist. They're looking for an angle. Think about these as possible subjects of your press release:

- formation of a new group
- a first — something really original
- an anniversary or birthday
- a fundraising event, especially an unusual one
- presentation of a cheque
- visit by a local dignitary
- recruitment drive
- new service/benefit/activity
- a new members event.

Enclosures

It's not essential, but you could enclose:

- a leaflet about the group, if you have one
- a handout about any event you want mentioned.

Don't send photos unless they are very professional.

Follow up

Feel free to follow up your press release with a phone call. Most papers get so many press releases, they find it difficult to attend to them all. A call from you may do the trick, and even get a photographer to cover the event or an invitation to record an interview.

Results

Don't assume it will bring results — there's a lot of luck to it. You may find your story reproduced as you sent it or, more likely, rewritten. And the headline will not be the one you'd choose. Read the papers you have sent your release to, and keep the cuttings if you've been successful.

Aim for several short mentions/radio spots in a year, rather than a big splurge. If you never get your news used, ask a reporter for advice.

Some of the ideas in this sheet were taken from ***Community Start Up*** *by Caroline Pinder (published by the NEC/National Federation of Community Organisations 1985) and from CancerLink's Information Sheet on the same subject.*
Thank you.

SAMPLE PRESS RELEASE
on headed notepaper

Release date: immediate
Address
Date

PRESS RELEASE

LOCAL CARERS' GROUP FIRST BIRTHDAY

Just as we were about to celebrate our first year's existence locally, we had wonderful news nationally. Jackie Drake won her case at the European court and the government agreed to pay married women the Invalidity Care Allowance. This will help many women who have had to give up jobs to look after dependants at home. It also at last recognises that carers fulfil a most essential role in achieving 'Care in the Community'.

The local carers' support group has grown considerably since it started just a year ago on ... 19 ... 80 local newsletters are now sent to carers, volunteers and other contacts. Special thanks are due to the local statutory services, such as Social Services, who have given us much support and from whom so many referrals are received.

For the next year a series of training sessions is planned for carers and volunteers, dealing with both practical and psychological aspects of caring. But more volunteers are needed. Carers are often totally housebound looking after their dependants. They spend night after night with their sleep interrupted and many badly need just a little time to be themselves.

End

For more information contact:
Tel: or
available (*give time*) to (*give time*) Monday to Friday
(*give time*) to (*give time*) evenings and weekends

6

PRESS RELEASES

SHEET 7

SETTING UP A TELEPHONE LINE

Not everyone who contacts your group for support will want or be able to come to group meetings. Some people just don't like being in groups, some people are housebound, or family obligations are too great. Some people will live too far away from the meeting place to be able to get there.

For all these people a telephone line, however limited, can provide the vital link for them to get the support they need. Your group may want to provide this link at some stage. It can be very worthwhile work but it can also become overwhelming if you don't think it out properly from the start. Here are a few points to bear in mind which may help:

Which number do we use?

Not surprisingly,. many group members don't want to publicise their own telephone number in a public place. They're afraid of not being able to cope with the response, and the intrusion in their private life. Even if someone is willing to take on the responsibility, it may not be practical if this person can't be at home all the time.

There are various ways round this problem:

- install a separate group telephone line, and possibly an answerphone
- make a rota
- publicise several numbers on any publicity materials
- get your call to be answered by a local agency such as the Council for Voluntary Service or Volunteer Bureau — at least on a short-term basis.

Separate telephone line and answerphone

Why a separate line? This sounds extravagant, but it can pay dividends. If one person decides to have a line and answerphone in their home, they are able to separate out group work and private life:

- they'll know that any calls on that line will be connected with the group
- from a financial point of view, it is much clearer which calls are group calls and which are personal calls.

If the person moves away or leaves the group, it may be possible to transfer the line to another place. Then you won't need to change the phone number in the group's publicity, and people won't have to remember a new number.

Why an answerphone? Most of us hate being answered by an answerphone. It's often frustrating and offputting, specially for someone who's taken a long time to pluck up courage to make contact with the group.

Nevertheless, an answerphone is better than a phone that's often not answered, or a phone answered by someone who can't give the attention the caller needs at the time.

With a clearly worded, friendly message, the caller can find out exactly when someone will be available to help. Or if the message contains details about the next group meeting, this gives them another way of making contact.

You could try asking a local business to donate money to enable you to buy an answerphone, or persuade a manufacturer to supply one free of charge. There are now very sophisticated machines, so you can change or hear messages by remote control.

Make a telephone rota

Instead of one person answering calls all the time, you can share it out. Members will be much more willing to volunteer to do a stint of telephone work if they know they only have to do it at certain times. It's much better to set aside a few times in the week when you can give someone your undivided attention, instead of having someone phoning you when you are having dinner.

One way to share out the workload is to make a telephone rota. You can work it out a month or more at a time, so members can commit some time to answering the phone.

All you need do is to change the message on the answerphone, so callers get clear details about who they should ring and when. If someone can't do one of their phone duties, then the person coordinating the rota can find a replacement and change the message.

British Telecom also offers a service that may help. It is called *Customer Controlled Forwarding*. Calls to one telephone line can be automatically directed to any one of up to ten pre-programmed telephone numbers, provided they can be directly linked. You need a separate line for the group in someone's house, but at various times calls can be directed to other lines. For more details about this service contact your local British Telecom Sales Office.

Several numbers on publicity material

Some groups decide they are definitely against the idea of an answerphone. Some members may feel they never want to say no to someone in need. For most of us though, this commitment is too much. If the group does not want calls to be answered by a machine, another solution is possible.

You can print several contact numbers on publicity leaflets, stating clearly the best times for people to ring — daytime or evening, for instance. The first on the list will probably be rung first, but the caller can try other numbers if that person is not available. If you put men's and women's names and numbers on the leaflet, then callers have a choice.

Training

It can be a taxing job to answer the phone to people with difficulties. Some groups offer training to members who regularly answer the phone, to help them develop listening skills and to cope with any pressures.

Getting calls answered by a local agency

For a number of reasons, some groups just don't feel able or willing to take one of the options outlined above. Another idea is to get a local agency to act as a switchboard for calls coming to the group. A local professional worker may offer; or organisations such as Volunteer Bureaux, Council for Voluntary Service, or Community Health Councils may be willing to do it on a short-term basis at least. They can either refer callers to a group member, or take the caller's details so that someone from the group can contact them. This system may sound awkward, but it has worked very well for several groups.

Thank you to Sheila Ritchie of CancerLink for permission to use material.

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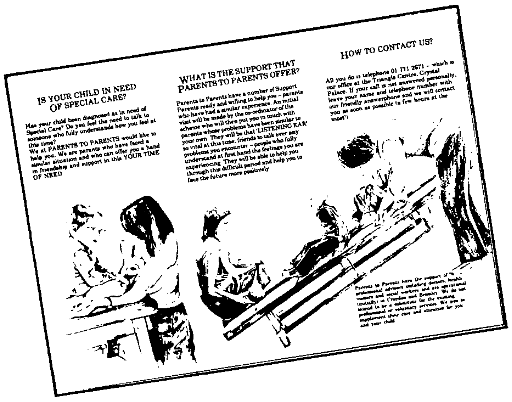
SETTING UP A TELEPHONE LINE

SHEET 8

IDEAS FOR POSTERS AND LEAFLETS



IS YOUR CHILD IN NEED OF SPECIAL CARE?

Has your child been diagnosed as in need of Special Care? Do you feel the need to talk to someone who fully understands how you feel at this time?
We at PARENTS TO PARENTS would like to help you. We are parents who have faced a similar situation and who can offer you a hand in friendship and support in this YOUR TIME OF NEED

WHAT IS THE SUPPORT THAT PARENTS TO PARENTS OFFER?

Parents to Parents have a number of Support Parents ready and willing to help you – parents who have had a similar experience. An initial visit will be made by the co-ordinator of the scheme who will then put you in touch with parents whose problems have been similar to your own. They will be that 'LISTENING EAR' so vital at this time; friends to talk over any problems you encounter – people who fully understand at first hand the feelings you are experiencing. They will be able to help you through this difficult period and help you to face the future more positively

HOW TO CONTACT US?

All you do is telephone 01 771 2671 – which is our office at the Triangle Centre, Crystal Palace. If your call is not answered personally, leave your name and telephone number with our friendly answerphone and we will contact you as soon as possible (a few hours at the most!)

DO YOU HAVE A CHILD WITH SPECIAL NEEDS?

We have over 500 support networks and groups around the country that can put you in touch with a family in a similar situation to yourself.
Telephone:
CONTACT LINE (01) 222 2211
for help, support and information between 10.30am and 2.30pm, or write to us at
16 Strutton Ground,
London SW1P 2HP.

CONTACT A FAMILY

This sheet is to help you design your own publicity material. Overleaf are some illustrations that you may photocopy, cut out and use to liven up your leaflet or poster. Permission is also given to photocopy the other cartoons in the book.

Here are some more tips

- Keep your message short and simple.
- You can make the headings stand out by using a lettering machine (often available at local resource centres and Councils for Voluntary Service) or rub-down lettering such as Letraset (available from stationers).
- There are many ways of producing leaflets and posters. Look at other examples in your area – for example at your local library or Citizen's Advice Bureau. You may also get advice from a local community centre or printer. Think about:
  – size
  – type of paper/card (eg thickness, glossy or non-glossy)
  – the number of colours (remember you can choose a coloured paper/card as well as one or more coloured inks).

If you would like a ready-made leaflet, the King's Fund has produced a local publicity leaflet – *Find Out If There's a Carers' Group Near You*. This explains what a group can offer carers. It has space for you to add your own group's name and address by:

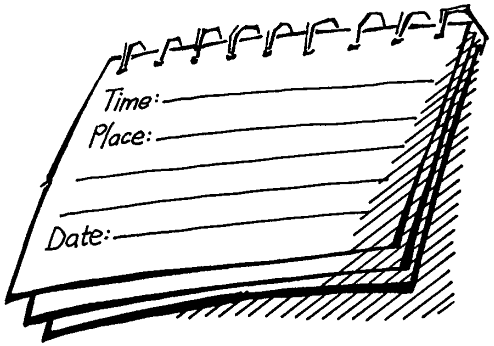
- attaching a printed sticky label – ask an office supplier or contact: Able Label, Steepleprint Ltd, Earls Barton, Northampton NN6 0LS (tel: 0604 810781). Prices start at around £12 per 1000, depending on size.
- using a rubber stamp. Most office suppliers can have a rubber stamp made up for you. Some stamps need an ink pad, others [eg Trodat Printy) are self-inking. Prices are around £10.

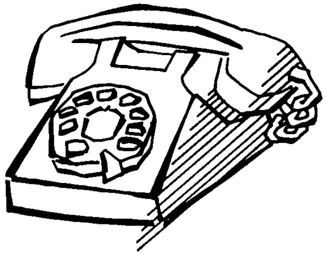
The leaflet, *Find Out If There's a Carers' roup Near You* is available in multiples of 00 only and costs £2.50 per 100 leaflets. vailable from: Book Sales, King's Fund entre, 126 Albert Street, London NW1 NF. Cheques to be made payable to 'King dward's Hospital Fund for London'.

Some ingredients

You are free to reproduce the words and illustrations on the next three pages and to use them on your own publicity material.

you care for someone at home?





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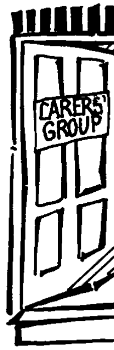

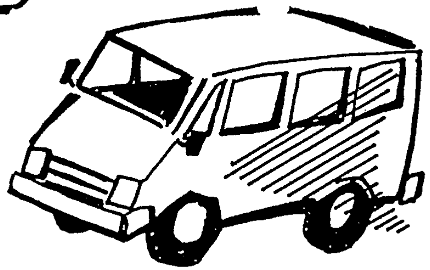

Illustrations by Vicky Squires
Thanks to Contact a Family and P
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leaflets.

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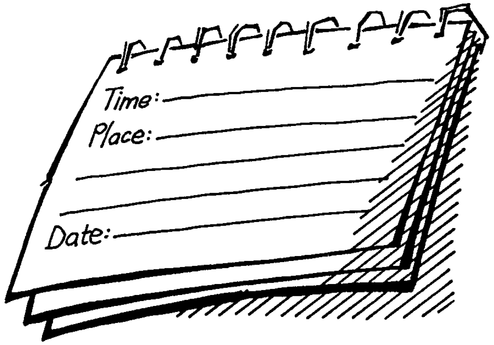

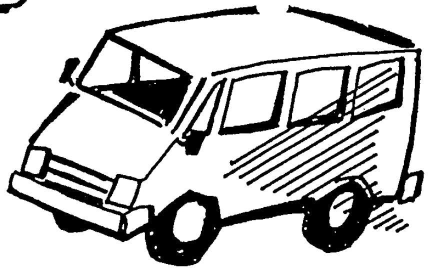

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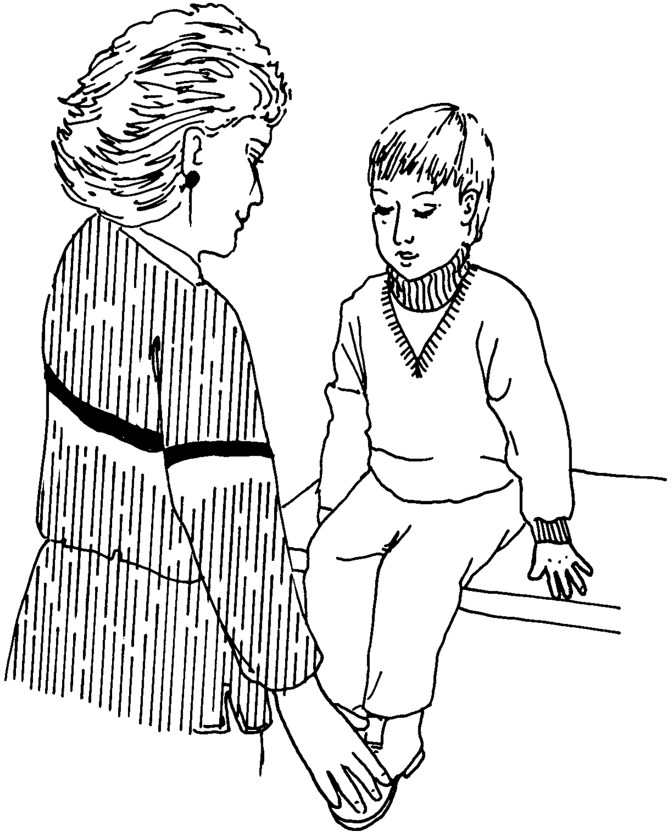

SHEET 9

PROFESSIONAL SUPPORT: MANAGING THE CHANGE

Carers' groups often start on the initiative of a professional worker in the Health or Social Services, or in a voluntary agency. And in many groups the situation changes later, so the group is run by members not led by a professional. This sheet aims to trigger off your thoughts on this change, and to aid discussion between carers and professionals. It doesn't tell you how to do it — each group is different.

"Achieving a workable balance is quite a delicate task."

Members and professionals will have to adjust. Both must be involved in managing the change. You can achieve a workable balance, but it's not easy and it takes time. It will be that bit easier if:
- carers have been involved in running the group from the very beginning
- the professionals have seen their job as making things easier, not directing, from the start
- you have reached some decisions on aims and membership (Chapters 4 and 5)
- you review how you're getting on during the period of change.

Reasons for change

In some groups, there has been an agreement right from the start that the professional will only be closely involved for a limited time. Then it's just a natural development that everyone has known about. Sometimes the professionals change jobs, or have to spend more time on other parts of their work. The organisation they work for may be short-staffed, and they have to make difficult choices on how to spend their time.

Sometimes the initiative comes more from members. They feel ready to take on the running of the group, or they don't get on with a particular individual. They may want to give more consumer feedback, or do more campaigning — both are difficult when a group is professionally led.

Ask yourselves:
- Why are we discussing a change?
- Who wants it?
- What could be the advantages of such a change?
- What could be the disadvantages?

Feelings and attitudes

Any period of change arouses mixed feelings. Everyone concerned will probably feel a variety of emotions, some good, some not so good — it's quite normal. A lot will depend on the attitude of the professional concerned. If a worker has come to see members of the group more as partners than clients, it will be easier for everyone. And if the atmosphere is one of trust, of feeling able to take risks, the change is more likely to work.

These feelings could exist:

Among professionals
- pleasure at progress
- anxiety and nervousness
- temptation to stay on
- responsibility for standards
- protectiveness to 'clients'
- uncertainty about future role

Among members

- eagerness to take responsibility
- dependency on professionals
- anxiety about responsibility and time commitment
- confusion about roles
- anger over departure
- denial of change.

Ask yourselves:

- What feelings do you have?
- Who can you talk to about them?
- What feelings can be talked over openly in the group?

Timing

Expect the process to take longer than you thought, and be flexible about the length of time. A lot depends on whether carers felt involved at the beginning, and whether the professional has always been open about their departure or not. Trying to make the change too soon or too quickly can bring too much anxiety and responsibility before people are ready for it.

Certain things can speed up the process:

- members being responsible for specific parts of the group's activities first
- an unpredictable event, like a worker's illness
- opportunities for training and developing skills
- carers unexpectedly having more time to give.

There will never be a perfect time. Don't expect a group to get running smoothly, so that a worker can leave in a straightforward manner. But see that taking on responsibility gradually, learning skills and letting a group develop to meet members' needs are all part of the process of change. So are setbacks and challenges — it won't be smooth or predictable.

Ask yourselves:

- What timing do you have in mind for a change?
- What do other people think?
- Can you, realistically, set a timetable?
- What stages do you need to go through first?

Practical matters

Practical arrangements for a group may mean that it is closely involved with a professional service. It may meet in a school, hospital or day centre. Letters may be written on Social Services notepaper and typed in their office. Money may be channelled through a hospital. Managing the change successfully means giving attention to these practical matters, and others, in an open, constructive way.

The central issue is not so much *where* you meet or *who* types the newsletter. It's more who controls the situation. Groups may decide to go on meeting on official premises, for example, but make their own booking or take on responsibility for locking up. Some money may still come from Social Services, but go into a bank account for the group. Some things may need doing before a professional can leave easily. You may need to:

- buy your own coffee
- get headed notepaper printed for the group
- open a bank account
- renegotiate room bookings, or find somewhere else
- do some fundraising.

Groups can still go on receiving practical help, and probably need it, but they, not the professional, need to be in charge.

Ask yourselves:

- What practical help does the group receive now?
- Might this change?
- Could such change weaken the group or strengthen it?

Leadership

An important decision to make is about leadership. Even if professionals have not taken named or obvious leadership roles, they will have become key people in the group. A gradual process of change will help to share leadership.

Some groups find this comes from a subgroup taking on responsibility for a specific project first. Others decide to form a committee (Sheet 5). In some cases, two or three members work alongside the professional for some time. You need to be aware of how leaders will emerge in your group — appointed? elected? volunteer? just happen? — and of the need to avoid a few members taking over.

However the leadership changes, there may well be a job for the professional to give ongoing support to people taking over. It can be a worrying time — having someone in the background to turn to, regularly or when you need it, can be very helpful. Even if there are no major problems, it will greatly benefit the group to have an objective view from someone who knows it.

Ask yourselves:

- What form of leadership does the group need now?
- How will leaders emerge?
- How formal and organised should it be?
- What could help people take on responsibility gradually?
- What help might new leaders welcome?

Group structure

A house needs a framework before the roof goes on and the inside is complete — so does a group. Most groups need to have at least part of their structure worked out before they face the change brought by a professional's departure. Most groups need to have some agreement on:

- the format of meetings
- how business is conducted
- any essential rules — like only one person speaking at a time
- a system for involving newcomers
- ways of communicating between members
- initial aims and some decisions on membershipYou may not finally resolve some of these points until the group has settled to being run by its members, but you need some structure before a professional leaves.

Ask yourselves:

- How much of a structure do we have?
- What more do we need to decide on at this point?
- How might we reach such decisions?

Contact people

One practical form of help a group has often had from a professional is being a contact point. The professional's office address and phone number may have been given on publicity material for potential members to make a link.

Some groups decide to go on with this arrangement, but make it clear that it's a place to leave messages, not the hub of the group. This can avoid pressures at home, and gives a phone which will be answered in office hours. It provides continuity and gives credibility to the group if professionals in other agencies want to make contact.

But if you continue to do this permanently, the group's public image will be of a group still led by a professional. Also, if a carer phones to talk to another carer, they'll feel let down.

You probably avoid facing up to some of the responsibility of running the group by keeping the professional as the contact point. And he or she may keep some control over membership of the group.

Ask yourselves:
- What are the advantages of a professional as contact point?
- What alternatives could there be?
- How could we publicise any changes?

Future relationships

As you work through these points and others, you should see a pattern of future relationships between the group and the professional emerging. Most groups want to go on having links. It can be enormously useful to have continued support, now at arm's length.

If there have been tension and personality conflicts, a new pattern of contact may develop. The same agency — school, day centre, Social Services and so on — may maintain a link, but with a different worker.

Whatever you agree, the form of relationship must be properly understood, and perhaps even written down by both the group and the professional. You could do this in stages — a plan to work through early on, and an agreement later.

There are several points to cover:
- what aspect of the group the professional remains involved with
- how they do it
- how often they come to meetings
- whether they ask if they can come, or just turn up
- how long the link might last.

Some groups want to run alone for a few meetings, to find their feet. Most feel more confident if there is still background support, with someone who knows the group available for advice at times of change or crisis.

It can also be useful to have someone as a link with fellow professionals, a source of contacts for speakers, and to give advice on individual matters for members as necessary. It's likely that a relationship will remain, and become one of partnership not dependency.

Ask yourselves:
- What existing links do we want to keep?
- Do we want the same people to be involved?
- How can we keep in touch?
- When should we review any agreement?

A final checklist

Give time and thought to how best professional support could continue for your group. Think through:
- reasons for changes
- feelings and attitudes
- timing of changes
- practical matters
- leadership issues
- group structure
- contact people
- future relationships.

SHEET 10

IT OFTEN HAPPENS IN GROUPS

It's quite common for problems to happen in groups – not just carers' groups – despite hard work and great effort to prevent them. This sheet identifies four problem areas which can occur and makes some suggestions about what you might do. But just identifying and understanding a little more about what is happening may be enough to help. Accepting that you may have to live with a problem may be another solution.

It often happens in groups that problems arise:

- because of the stage the groups is at
- from the different stages individual members are at
- because of the behaviour of insensitive members
- from outside pressures.

The stage the group is at

All groups pass through different stages. It may be that the problems you have come because you are just passing through a difficult phase, or wanting to run before you can walk. Four different phases are common and they have been given names for convenience: forming, storming, norming and performing. If you want to know more, look at page 64 for suggestions on additional reading. Briefly, this is what happens at different stages:

Forming. People are still behaving very much as individuals, still unsure about whether they want to be part of the group. They may be looking to a 'leader' and be worried about their role in the group.

Storming. This can be an uncomfortable, but creative, stage as members try to pull the group in different directions or gain power. People may get angry or dissatisfied and some may leave the group.

Norming. Calm comes after the storm. The group settles down, members start to work actively together and mutual support becomes possible. People express their feelings in a more open, constructive way.

Performing. The group gets down to work to achieve its aims. Solutions emerge, jobs are undertaken and achievements enjoyed. People feel involved and comfortable and roles become flexible. The group acquires a strong identity.

Progression from one stage to the next is not always automatic or at a set speed, and some groups, particularly if the membership changes a great deal, may shift back and forth.

What you might do:

- Stick it out. Wait for the storm to pass, and things to settle down.
- Encourage people to talk things out and to express their hopes and anxieties. Allow time and opportunity for this, particularly in the early stages.
- Discuss these ideas with other key members of the group but don't expect everyone to be interested.

The stages members are at

It's very common for members of a group to be at different stages. They may be newly coping with a problem in their family or have lived with it for years. And they may be brand new or long-term members of a group. Both situations will affect how they see the group and what they need. It can be a difficult problem for groups to meet everyone's needs.

These are some of the different needs people have: just to talk; to express their anger and get things changed; to shut off everyday life and enjoy a relaxing activity; to learn and study. These differing needs can lead to conflict, boredom or confusion in a group.

What you might do:

- Identify the different stages and needs your members have.
- Find a common core of activity that everyone enjoys.
- Develop sub-groups and extra activities, short and long-term.
- Encourage people to develop their skills and change their role in the group.
- Come to accept that your group may have to live with this problem.

Insensitive members

It's not unusual for groups to have a member who is insensitive to others and whose behaviour is distressing and disturbing to the group. You can probably make a list yourself of such behaviour – it could include: people who talk too much and try to dominate the group; constant clowns; people who block all initiatives; two or more people who pair up and form an in-group. This can be just mildly annoying, but if such behaviour persists, it can become intolerable. Some groups have actually stopped meeting, others have ended up not doing all they could because of individuals' behaviour.

Carers' groups tend to be tolerant and to accept people as they are. Groups can, though, take this acceptance too far. It may be better sometimes, for both the group and the individual, to stop pretending there is no problem. It may be possible to deal indirectly with it but sometimes there may need to be honest feedback to the person concerned about how you feel. (See page 64 for details of a helpful article.) It can be painful, but better than the group suffering or even disbanding.

What you might do:

- Come to accept that something needs to be done.
- Deal indirectly with the problem, e.g. through firm chairing; having more structure to the meetings; asking people to do a job.
- If this fails, have an open discussion in the group meeting. Choose a day when there is time and plan what you are going to say; say how *you* feel, don't attack them; be specific; say good things about the person too; and be prepared for their reaction.

Outside pressures

Some groups experience problems, not because of what is happening within the group or because of members' behaviour, but because of outside pressures. People who are not members of the group may be expecting action or services which are not reasonable. They may assume that they have the right to say what the group should do. Your problems could come from: professional workers involved in the group; professionals who are referring new members to the group inappropriately; national organisations who are asking too much. You may identify other pressures too from outside.

A number of difficult situations can arise: expectations that a group will work in a particular way when most members don't actually want it; lack of opportunity to grow and change; new members coming to a group with wrong expectations; pressure to conform to a model or to spend time on a particular activity.

What you might do:

- go back to your aims and be sure of what you want to do.
- make sure outsiders know your aims, the scale on which you work and what newcomers can expect.
- feel you can restrict your activity to what you feel is right for you.
- discuss the problem with people concerned.

In short

Don't bemoan your lot. Instead, try to identify and understand the cause of any problems you have. Some may be solved in a practical way by more resources or training or the situation may change in time. But others you may have to learn to accept as part of running a group. In extreme cases, you may need to bring problems out into the open – discussion and feedback may solve the difficulty.

In short

Don't bemoan your lot. Instead, try to identify and understand the cause of any problems you have. Some may be solved in a practical way by more resources or training or the situation may change in time. But others you may have to learn to accept as part of running a group. In extreme cases, you may need to bring problems out into the open – discussion and feedback may solve the difficulty.

Looking after someone frail, ill or disabled at home can be a lonely and stressful job. Many carers, whether caring for children or adults, find that meeting other carers locally can provide invaluable support – at times a lifeline:

'I don't feel isolated any more'
'I lock it up inside till the meeting'
'I have found friends in the same position as myself'

Groups can also offer practical information on day-to-day caring and how to get help.

Caring Together is the first book on support groups for carers. Groups may be small and informal, or well established with lots of members. Judy Wilson offers suggestions, encouragement and inspiration to all carers, whether they are starting a new group or helping their own group grow. Issues covered include:

☐ what carers' self-help and support groups do
☐ deciding on aims and membership
☐ ways of organising groups
☐ how to get outside help
☐ publicity and meeting places

The book contains many examples of groups and quotes from members plus a series of worksheets designed to help groups tackle important tasks like writing a press release, producing a newsletter or organising a public meeting.

About the author: As leader of the Nottingham Self-Help Team, Judy Wilson has worked alongside people starting and running self-help groups for many years. A firm believer in the value of groups run by people who share a common problem, she has written extensively on the subject and contributed to the growth of the self-help movement both in this country and abroad.

Produced in consultation with:
Association of Carers*
National Council for Carers and their Elderly Dependants*
Contact a Family

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Further copies of this book may be purchased from **The Kings Fund Centre, 126 Albert Street, London NW1 7NF** for £3.95 inclusive of post and packing. Please make cheques and postal orders payable to **King**
Edwards Hospital Fund for London.

*From May 1988, the Association of Carers and the National Council for Carers and their Elderly Dependents will work as one organisation – the Carers' National Association.