



KING'S FUND CENTRE

TAKING A
BREAK
GUIDELINES
FOR COMPILING
LOCAL
INFORMATION



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by Martin Bould Development Officer King's Fund Carers Unit

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TAKING A BREAK

GUIDELINES FOR COMPILING LOCAL INFORMATION

CONTENTS

- Introduction
 What are these guidelines for Advice before you start
- 2. Types of break compiling information from statutory services

Social services Health services Education authorities Writing for information

3. Types of break — collecting information from the voluntary and private sectors

4. Compiling local information
Sources of counselling
Holidays
Financial assistance
Transport

Campaigning and planning

- 5. Making the most of your information Exploring all the angles Design considerations
- 6 Worksheets for use in compiling the pack
 Checklists
 Sample format
 Transport and holiday information
 Help from national voluntary organisations

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WHAT ARE THESE GUIDELINES FOR?

These guidelines are to assist anyone who is compiling local information about the types of relief breaks that are available to help carers and the people they look after. An easy-to-use directory of respite services in their own area will be invaluable to individual carers who often have neither the time nor the resources to gather full information about local provision. Professionals and other people who work with carers will also benefit from such a directory.

The King's Fund publication *Taking a Break*, gives a general picture to carers of the sorts of breaks that may be available across the country, and contains much advice about emotional and practical issues. It offers many suggestions as to how individual carers can find out about local services for themselves. But it was never intended to provide details about local services. These guidelines have been produced to help organisations follow up the use of *Taking a Break* with a publication covering their own area.

Who will use them?

The guidelines are intended for use by people in statutory or voluntary organisations who set out to compile local information directories. They are not designed for use by individual carers in search of appropriate respite care.

Gathering information on services for carers is complex whoever does it. These guidelines have been written for people who may not be familiar with health and social services and the way they are organised. These may be members of a carers support group, a voluntary organisation worker, information worker or carers support officer. We are confident, though, that the advice will be just as relevant to professionals in the health service and in local authority departments who compile information as part of their authority's policy for carers. Indeed, we hope the guidelines will make their task easier and quicker.

Uses and benefits

Once you've acquired the material it will have a range of important uses:

- local information sheets for individual carers to supplement Taking a Break
- part of a carers pack covering all aspects of caring
- part of a publication which is produced to give information on services for people with disabilities (as required by section 9 of the Disabled Persons Act 1986)
- a loose leaf directory for professional workers, who work with disabled, ill or elderly people and their carers
- a similar directory to be used for public information points such as town hall, libraries and reference or information centres, and for disability organisations and carers organisations.

Some authorities or organisations have already produced directories or carers packs. Examples are:

Handbook for Carers — produced by North Yorkshire County Council. (Available from; Social Services Dept., County Hall, Northallerton, North Yorkshire DL7 8DD)

Carers Pack — London Borough of Camden (Public Relations Office, Town Hall, Euston Road, London NW1)

Directory for Carers — Coventry Social Services Dept. (Age Concern, 5528 New Council Office, Little Park Street, Coventry CV1 5RS)

Handbook for Carers — Carers National Association, Newham (P O Box 230, London E15 4AS)

Carers Information Pack Leicester Rights Centre, (Alliance House 6 Bishop Street, Leicester, LE1 6AD)

The benefits include:

- A really useful resource for carers and the people they look after, and for the professionals who work with them.
- It may be the first time that information about these services and resources have been collated in your area. Services for respite care may not have been thought about before in a systematic way. Collecting information will help

highlight the importance of these services for carers and may prepare the ground for better co-ordination or new developments.

 In all areas where the material is collected, it should be presented in consistent, easily understood categories (matching those of Taking a Break) so that it will be possible to exchange information and make comparisons across the country.

Contents of the guidelines

The guidelines, are written to be used in conjunction with *Taking a Break* and follow the categories and structure set out in that booklet (They also fit with *Caring at Home*, a handbook for carers published by the National Extension College and available from Bailey Distribution Ltd, Dept KFP, Learoyd Rd, New Romney, Kent TN28 8XU, price £3.50.)

The guidelines tell you:

- full details on how to compile names and addresses of respite services.
- what to include and where to find it.

- ideas about how to tackle problems that arise.
- advice on the information that should be contained in the sections on local transport schemes, counselling and advice schemes, and sources of financial assistance.
- appropriate and accessible ways of presenting the material.
- Sample forms are included which can be used in collecting or presenting information about breaks.

Summary

You will be looking for information about the many different types of relief care available in your area. In order to find that information, you will have to contact health and local authorities, voluntary and private agencies. It will involve a lot of telephoning, letter writing, consultation and even visits. It will be time consuming, but worth it because you will have full details of services, organised in a way that carers can use.

ADVICE BEFORE YOU START

Check whether a local guide has been produced already

When you make contact with each authority or organisation, check whether some, or all, of the information you want has been compiled already — you may save yourself a lot of work. A few local authorities, health authorities and voluntary organisations are beginning to produce information packs for carers. This may have been done or started in your area but may not be well publicised. (Ask whoever you make initial contact with, and ask everyone else subsequently.)

Be persistent

In most cases, it won't be easy to compile the information.

 Statutory organisations such as health authorities and social services departments are often large, complicated, and sometimes unwieldy structures. There are few consistent patterns of organisation across the country.

 Coordination and communication between all the different parts (and between each other) can be difficult even for the people who work in them; it's usually much harder still for 'outsiders' to find their way around.

The effort will be worthwhile. If you show a positive approach and remain patient, you will be successful.

State your purpose clearly

Remember that some service providers will be unused to giving information. Have an explanation ready about what you are doing and why. Sometimes it is a good idea to set out on one sheet of paper your aims, details of who's involved, your timetable, and the information you will be collecting.

Offer reassurance and feedback

Reassure people that there will be a result from your enquiries. You may be able to send them a copy, invite them to a launch, or at least let them know when your publication is completed.

There may be a natural concern amongst organisers that telling carers what is available will result in a sudden rush of extra demand for services which are already hard pressed. Reassure them that it doesn't usually happen that way. Many carers only ask for help with reluctance and then only in small amounts. Like everybody else they will understand the resource constraints that apply, even if — like many others — they don't agree with them. Finally, you may think that not giving information undermines partnership with carers and leaves them without knowledge of services which could help provide better care and minimise the risk of breakdown.

Consult widely

It can be very helpful to set up a small advisory group to help the person who is doing the main work of collecting information. (This group should of course include carers and their organisations). It is very easy to be overwhelmed by detail and to lose sight of what carers really want and can really use. Involving others will help make sure that the information is comprehensive and accurate. Do send out drafts of the final version for consultation (if possible, include artwork for the cover and sample page layouts). Taking a Break itself was written this way.

Throughout the work of compiling information, take every opportunity to ask carers themselves. Attend a carers meeting, or meet users of services, and ask them what things they find important or valuable in a

particular service. That way you are checking that your information is saying the right thing. Sometimes, too, you will be given information that is inaccurate or which doesn't correspond to users' perceptions. That is why direct information from the people who have used a service will give a valuable extra dimension to your directory. Needless to say, don't print derogatory or critical comments without first checking them thoroughly and giving the service a chance to reply.

Black and ethnic minorities

In many cases, knowledge of services and how to use them is lower in minority communities. Your local information must help redress this imbalance. So the first step is to be sure you collect the information about services provided for black and ethnic minorities, and services run by their community organisations.

You should consult with minority organisations directly and through an umbrella community relations organisation, if one exists. Where appropriate, include these organisations in your guide.

Their suggestions to you will be based on well-founded local experience. They may include:

- collecting information about different provisions for people of different cultures, eg. meals in lunch clubs
- including information about languages spoken at particular centres
- producing information in ethnic minority languages.

The sample format for collecting information includes a space 'notes on multicultural care' to remind you to collect this data. But advice from local organisations on what to collect and how to present it will often be more useful.

SOCIAL SERVICES

Below is a simplified and only partial description of a typical Social Services department. It may seem complicated, and it can be difficult to find your way round, especially as an 'outsider' (but sometimes even from the 'inside'!). To start to accumulate information on respite care you need to make contact through one of the tiers of management. It probably won't matter much where you start as eventually, and even if you have to try several routes, one should be productive.

The Structure of Social Services Departments

Social Services Departments vary in their organisation. At the top is the Director of Social Services who has overall responsibility for policy, management and delivery of the services.

At the next level Departments are divided into main sections (about 4 or 5) each headed by an Assistant Director. The particular designation and responsibility of each section varies across the country.

A typical Department may be divided into Residential care, Day Care, Field Work (which may cover a range of services including social workers, home helps and transport), Health Service Liaison, and Training and Administration. It won't always be clear exactly what services are included in each section.

These large sections are again divided into smaller management units. For example, Residential Care may be organised by client group (services for the elderly, mentally disabled, children and so on), each with a manager or senior officer. At the level of service delivery, each individual establishment, such as a day centre or nursery, will also have a senior responsible officer.

Social workers (who are part of a larger Field Work section) may be organised into 'generic' area-based teams situated in local offices. There will probably also be a few specialist social workers who work with mentally ill or deaf and blind people. Each team or area office will have responsibility for the whole range of clients and will have an overall manager or team leader.

In some areas social services are 'decentralised' into neighbourhoods or districts, or else subsumed within a larger department. In these cases you will have to look for the same things, but allow for different structures than those summarised here.

There is a standard directory you could consult: Social Services Yearbook (published annually by Longman)

Telephone contact

Social Services Departments are listed under the Local Authority in the phone book. The number of offices and establishments listed will vary. Telephone contact has only limited success. On the whole, the more senior the level of manager you are trying to contact the less likelihood of doing so on the phone. You may find it more useful to use the phone to establish how your Department is organised and to find out the names and addresses of Assistant Directors, for example, so that you can write to them. On the other hand, in some Departments, a phone call to one of the local area offices may elicit all the information you want from a well-informed social worker.

Points to note:-

- you may have to telephone a general enquiries number, often at the Town Hall. If you have to go through a general number you will have to say what office or section you want as the number is probably the same one for education and housing as well. If you don't know which part or person you need, then ask for a local area office.
- all the separate area offices may be listed, and one of these may be your most useful starting point.
- it is unlikely that the offices of the Assistant Directors will be listed. You will have to ask for those through a general, or local, office number.
- sometimes all the separate establishments such as nurseries, day centres and residential homes will be listed. You can start by ringing, for example, a day centre directly and asking for the name and number of the overall coordinator or manager for day centres.

A phone call to a local office

There are several starting points into Social Services Departments and it's not possible to trace the way through all of them in these guidelines. As all Departments have local area (or district) offices it may be useful to describe a typical contact made in that way. Many of the following points would in fact apply to an initial phone call made to any officer or manager.

Points to remember when telephoning

- wherever you start, don't forget to check whether any of the information has already been compiled (you may then be referred to an information or planning section).
- Ask to speak to the duty officer, who is a social worker. Some social workers have information at their fingertips and can help you straight away, but in any case you need to be very clear about what you want.
- It can be useful to establish straight away that you are not an individual carer seeking support as you're likely to get a different response. Say who you are — a representative of a group or organisation, a professional etc. — and that you want to know about relief care facilities so that you can compile a local directory for carers.
- Remember, that a range of terms are used to describe breaks — relief care, respite care, social admissions etc. You may get a blank response until you hit on the term they use.
- It's often more straightforward to ask for information about each type of break rather than asking about breaks in general. List all of the services you want to find out about (all the various types of service are described in *Taking* a *Break*).
- Have ready a list of the information you want about each type of service. It's unlikely you'll get all your answers on the phone but you may be able to leave the questions with the person so that they can send you a written reply.
- The Department may have information about social services facilities only, or may also know about those provided by the voluntary sector and health and education authorities. They may be able to refer you to people/organisations who can help you if they can't. Try and get information about the

- voluntary and private sector from knowledgeable, helpful individuals you speak to on the phone. It can be hard to come by anywhere else.
- If you want to know about private residential care homes (which are registered and inspected by Social Services Departments) ask to be put through to the registration officer for private residential homes (the name varies). They will be able to give you a list of registered private homes. They should know which will provide day care facilities and short residential breaks. (They are also responsible for dealing with complaints).

You will probably get one or more of the following responses from the local area office:-

- the department may already produce information sheets/guides to facilities covering the whole range of relief care or those for specific groups such as children or elderly people.
- the duty social worker/officer will be able to tell you broadly which types of relief care the department provides, and will be able to send you written details of the different establishments.
- you may be transferred to, or asked to telephone, an officer, adviser or manager who is responsible for a specific age range — such as under 5's, children, adults, or elderly people — or a section — such as residential care, field work, or day care.
- you may be asked to write to the manager of an area office, or any other specified person (see item above) who is more able to help you, detailing what information you want and how you're planning to use it.

In all cases you will probably need to follow up by letter. The information you get at first may not be what you want.

HEALTH SERVICES

Structure of District Health Authorities (DHAs)

District Health Authorities are divided into units (usually 3) each with a unit general manager. The name and responsibility of these units will vary from authority to authority — there is no standard pattern. The units may be divided by client group (services for elderly people, mentally ill people and so on), or by type of service (eg. hospital services or community services, such as district nursing, health visiting, school health, chiropody, physiotherapy). Some districts have a combination such as community services unit, mental illness unit, and acute unit. The responsibilities of each unit may not be completely clear from its title.

Below this level, each district organises its health services in different ways with its own management tiers. General Practitioners (GPs) do not come into this unit structure at all. They have a separate structure altogether, now called Family Health Service Authority (FHSA). (This is one reason why some GPs do not know about all the different services available from the DHA: they are outside it themselves.)

The standard directory for addresses is:

Hospitals and Health Services Yearbook (published annually by the Institute of Health Service Management)

It is sometimes the case that there is little coordination between the different units and tiers, and unless you have some idea of how services are organised in your district you may find yourself going round in circles.

Your first task is to find out the unit structure of your DHA (by telephone — see below). You can then contact the general manager of each unit.

Contact by telephone

The range of DHA numbers in the phone book will vary greatly from authority to authority. It's quite possible that the different units will not be listed at all. The Health Authority central administrative office (which may be under 'Offices' or 'Headquarters' or 'Management Team') should be able to give you the names, phone numbers and addresses of the unit general managers. If the main offices are not listed try to get the information through a hospital or clinic number.

You can also contact your local Community Health Council (CHC). Some CHCs have information about respite care, but it's unlikely that many will have full details about Health Authority schemes unless they have specialised in that area. However, the CHC may be able to save you time and effort by giving you the unit structure and the names of the people to contact.

You can use the phone to identify who you need to contact, but you will be extremely unlikely to get much of the information you want about respite care over the phone. So you will have to follow up your contact by letter.

EDUCATION AUTHORITIES

The Structure of Local Authority Education Departments (LEAs)

As with Social Services Departments, the structure of local Education Departments will vary from area to area. There will be a chief education officer (who may be called director of education), ultimately responsible for what goes on the Authority's schools. Beneath this, there will be several assistant education officers each with a responsibility for a specific area of education, for example, primary or secondary. Most Education Authorities appoint an officer with responsibility for ill and disabled children probably called the education officer for special education. It is this officer that you need to contact to find out about local provision such as nursery schools and classes, special schools and units.

The Social Services Yearbook (Longman) has a list of Education Departments.

Contact by telephone

Education Departments are listed under the Local Authority in the phone book. Usually a general number for the administrative offices will be given. Ask for the office of the special education officer. You will then be put through to a secretary or administrative officer.

 You will need to explain that you are not a parent of a disabled child making a personal enquiry — the procedure is likely to be different if you are.

- Usually, the information you want will be readily available often in a pamphlet intended for individual parents outlining policies, procedures and facilities. This is because Education Departments have a statutory obligation to make educational provision for all school age children, and to provide an assessment of the educational and social needs of disabled children (of any age) if the parents make such a request. This means that the Department will have a policy on the provision available for pre-school age children as well.
- In most cases whoever you speak to will be able to send you this information, or you may be asked to write to the special education officer explaining what you want. You may find the standard information for parents adequate, or you may need to supplement it (sometimes the information is general rather than specific as it assumes the details will be provided as each individual child is assessed and specific recommendations made for her or him). You should then write to the special education officer directly.

Contact by letter

Alternatively, you can write directly to the special education officer (find the name and address by phone) and ask for the information you want. You may also need to write if you have to supplement any standard information which you have previously received.

There is more information about writing letters to Local Authority Departments in the next section.

WRITING FOR INFORMATION

Education:

• Write to the special education officer

Social Services:

- You can write directly to the director of social services and ask him/her to forward your request to the relevant assistant directors and managers.
- You can find out how your Department is organised (by phone) and write directly to a manager, or managers, at any level.
- You can write to the manager of your local area office.

Health Authority:

• Write to each Unit General Manager

The way your letter is written is crucial to the success of your project. Requests for information can be misunderstood. Providers of services often find themselves being assessed and criticised by 'outsiders' and you must make it clear that this is not your intention. You can do this by emphasising:

- that the information is to benefit carers and the people they support
- that the finished directory will benefit the providers of services too; it will cover the resources provided by all the sectors and will be available to each sector (for comment during its production if they so wish, and as a resource when it is completed).

Service providers may also fear that if such information is readily available to carers, it will result in greatly increased demands. Several of the points made in the introduction to these guidelines may be useful in reassuring organisations that producing information will result in greater partnership with carers and better overall use of resources.

Explaining what you are doing and why, stressing the benefits for everyone, may also encourage people to put the information together for you as this could require extra work. Consider the suggestion made in

the introduction for a simple sheet setting out your aims. This could be enclosed with your letter.

In addition, your letter should do the following things:

- Specify all the age ranges and groups you are concerned about, eg. children, adults, elderly people, mentally disabled and mentally ill people, and so on. Remember to include respite care for people with AIDS.
- List the information you require for each type of service or individual establishment. There is a list of points for carers to ask about in *Taking a Break* (page 21). Or you can use a checklist like the one below:

its precise name
address and telephone number
name of manager/senior officer
criteria for eligibility
how individuals apply for admission
number of places and details of waiting lists
service and facilities — eg. therapy, assessment,
recreational activities etc.
charges and sources of financial help
transport arrangements
other

- Alternatively, you could use the sample format provided in this pack. Using a standard form means that you have more chance of getting the information in the form you want. If service managers fill it in themselves, you can be confident that what is written will be accurate (even if you need to go back and supplement it later.) Note that it is always advisable to pilot a standard form first — even ours— to see if respondents misinterpret meanings.
- Enclose a copy of Taking a Break. This will be valuable background for those who haven't thought about respite care, and may even make a positive impression as a well-produced booklet.

What to do next

Whoever you write to, you cannot expect an instant answer, and you may have to wait some time, especially if your letter has to be circulated amongst several people who all need to contribute information for someone else to compile. Some authorities may have much of the information ready to hand, but, for others, your request may be unusual and may require considerable effort on their part. You can always back up your letter with a phone call, especially if you have waited some while for a reply. You can also send a copy to your local elected councillor who may take an interest in what you're doing and make enquiries on your behalf.

In the health service, you may find that the availability of some respite facilities (e.g. shared-care hospital schemes), vary according to the practices and policies of individual consultants and the needs of individual patients, so that the managers are unable to say that these services are always available.

You can also ask your local Community Health Council to support your enquiry or make enquiries on your behalf. The Community Health Council has the statutory right to ask for and receive information from the District Health Authority (which is especially useful if you haven't received an answer).

TYPES OF BREAK - VOLUNTARY AND PRIVATE SECTORS

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For both voluntary and private sectors, word of mouth is a good source of information — so ask statutory workers you talk to about the services they know of.

VOLUNTARY SECTOR

How to compile information

There is no single avenue of approach to finding out about respite provision in the voluntary sector. In many areas there is a directory of local organisations: ask the Council for Voluntary Service (or equivalent) and the local authority. The latter may know which organisations are grant aided to provide respite.

The disablement association or Community Health Council are also likely to be good sources. The volunteer bureau may know of services which have requested its help in finding volunteers.

National voluntary organisations can usually tell you if there is a local branch serving your area. Consult the chart at the end of this pack.

All these services may produce addresses or contacts but you will probably have to follow each one up individually.

You may still be missing out small local groups. Remember to try churches and religious organisations. They may run care groups, day centres or special voluntary projects. Check the library for annual reports by local organisations. The standard directory for voluntary organisations is:

Voluntary Agencies — The 1988 Directory (published by Bedford Square Press, part of the National Council for Voluntary Organisations. £7.95, plus £1 postage. Available from Harper and Row Distributors Ltd, Estover Road, Plymouth, PL6 7PZ — cheques payable to Harper and Row)

The Social Services Yearbook (Longman) lists Community Health Councils, Councils for Voluntary Services and Rural Community Councils

What to include

addresses and contact for

- the council for voluntary service
- the disablement association
- local Age Concern
- main carer organisations
- any good local directories: titles, where they are obtained from, price.
- black and ethnic minority umbrella organisations.

PRIVATE SECTOR

There is no central organisation which keeps information about private sector provision. You will need to find out about each type of service — private sitters and care attendants, nurseries and play groups, residential and nursing homes etc., — in a different way.

Contact by phone

The Yellow Pages phone book is a useful source. You will, of course, have to contact each establishment to find out the precise information you require. Yellow

Pages lists:

Employment agencies (some provide domestic help and 'sitting') — under 'Employment'

Nursing agencies (employ sitters, qualified nurses and care attendants) — under 'Nurses and Nursing Agencies'

Residential homes (do not provide nursing care, many take people for short breaks, some have day centres) — under 'Residential and Retirement Homes'

Nursing homes (provide qualified nursing care, many take people for short breaks) — under "Nursing Homes"

Day nurseries for children — under 'Nurseries — child'

Nursery schools — under 'Nursery Schools'

Contact by registration agency

Employment agencies: These have to be registered with the Regional Employment Licensing Office. Look in your phone book under 'Employment Department of' for the number of your regional office. Alternatively, look in the phone book under Manpower Services Commission for the number of your local Job Centre. Ring them and ask for the number of the Regional Employment Licensing Office. The Licensing Office cannot send you a list of agencies, but the licences of all the agencies are 'open to inspection' in their offices.

Nursing agencies — have to be registered with the Regional Employment Licensing Office (see above).

Residential homes — Those which look after four or more people have to be registered with the registration officer at the Local Authority (usually somewhere in the Social Services Department — try asking at the general enquiries number or a local area office). The list of registered homes is available to the public. You would again need to find out precise details from each home.

Nursing homes — Those that look after four or more people have to be registered with the registration officer at the District Health Authority, who can provide you with a list of inspected homes in the area. It is sometimes difficult to get hold of this person — they are based in different departments according to the structure of the DHA. You may have to ring around.

Alternatively, write to the registration officer for private nursing homes at the district administrative headquarters/offices. A letter will eventually find the correct person.

The Directory of Independent Hospitals and Health Services (Longman) lists registered private nursing homes by Health Authority and registered private and voluntary residential homes by county.

Day nurseries and playgroups — These have to be registered with the Social Services Department. Ask for the manager/officer responsible for under 5's, or for day nurseries. They can let you have a list, but you will have to contact each establishment to find out their admission criteria.

Nursery schools — These have to be registered with Social Services Departments (the section may vary, try the manager/officer responsible for under-5's). Social Services will provide you with a list, but will not necessarily know which schools will take disabled children. You will have to contact each school to find out.

Other sources:

Many private services are advertised in local papers.

There are a few national organisations:

- British Nursing Association
 Head Office: 443 Oxford Street, London W1.
 Tel. 071-629 9030
- National Confederation of Registered Rest Home Associations
 74 LondonRoad, St.Leonard's-on-Sea, East Sussex TN376AS Tel: 0424-712982
- Registered Nursing Homes Association
 Calthorpe House, Hagley Road, Edgbaston,
 Birmingham B16 8Q Tel. 021- 454 2511
- UK Home Care Association
 Secretariat, Premier House
 Watson Mill Lane, Sowerby Bridge
 W. Yorkshire HX6 3BW Tel. 0422-835057

COMPILING LOCAL INFORMATION



SOURCES OF COUNSELLING FOR CARERS

The first section of *Taking a Break* (called 'Your Concerns about Taking a Break') deals with the difficulties carers and people with disabilities experience in deciding to use any kind of respite care service.

Local guides can help by giving information on where carers can talk to someone about their feelings, receive counselling, or find very practical and sensitive advice-giving. Such services are not widely available in an organised way.

Some careful checking will be necessary to see what exists in your area. Always ask whether a service has experience of meeting carers' needs, and whether staff are trained in counselling. Possible agencies are:

- family counselling projects (including marriage guidance councils)
- clinical psychologists sessions in the NHS
- individual counsellors not in the NHS (enquire about costs)
- · bereavement counselling projects

You should also find out what counselling sessions are offered by social workers.

The British Association for Counselling can give enquirers names of counsellors working in their area. Send an sae to 37a Sheep Street, Rugby, Warwickshire CV21 3BX.

Some advice services have information and specialist knowledge, and their help may amount to more than just advice-giving over the telephone, without being seen as counselling. Ask the local organiser:

Disablement Information and Advice Line (DIAL)

Citizens Advice Bureau (CAB)

Some voluntary organisations (especially the disability organisations) have welfare officers or voluntary welfare visitors who can see carers individually. Their workers may or may not have had training in counselling. Local branches will differ widely. Check what is available locally.

Finally, some carers groups offer a supportive environment where users can talk to other carers and get support and information on problems associated with respite. Check this with the group leader or contact. Do not use this section merely to list carers groups.

HOLIDAYS

National organisations

Holiday Care Service, RADAR and the main publications should be mentioned (see holiday and transport publications list). Holiday Care Service has over 300 free information sheets, giving details of provision in various regions and countries. It can also give individuals information in all aspects of taking a holiday. The chart 'Help from voluntary organisations' in this pack shows which run holiday accommodation. Many of these organisations also give advice and know of holiday provision which is specially suitable for the people they are set up to help. However, this list is not comprehensive and it will be worth checking what is relevant for your own area.

Local organisations

Locally you should list any organisations with their own holiday accommodation, or which regularly organise holidays which carers and people with disabilities may be able to take advantage of.

A good source of information is likely to be the local disablement association. If they offer advice on holidays, include their address, phone number etc.

The major local disability organisations are also worth contacting, eg. MENCAP, Age Concern, etc.

Statutory bodies

Local Authority Social Services Departments have the power to give financial help towards the cost of holidays, though not all use it. Some offer holidays at places of their own choice. A statement of the Local

Authority's policy, details of holidays or financial help available, and the name of the person to contact will be essential in this section.

FINANCIAL ASSISTANCE

Financing breaks can be a great obstacle for carers. Your directory should set out key points for advice, and refer to publications which carers can consult. It should describe the main sources of financial help, entering into as much detail about benefits and charities as you feel is appropriate.

Sources of advice

Give the address of the DHSS office, the tax office, and local advice centres such as CAB, mentioning any special services such as money advice, help with appeals, etc. Give the DHSS freefone number (0800 666 555).

Refer to the help given by voluntary organisations. The national offices can often give individual advice on points relating to their area of special concern. The Carers National Association and Counsel and Care for the Elderly should be listed in this respect. Local branches of disability organisations may know about sources of grants or charitable help — but check this before you include them.

Publications

The main source is the *Disability Rights Handbook*. This covers all benefits but reference could be made to the sections on 'respite care and income support' and on 'going abroad'. In the 1990 edition they are on pages 178-79 and 186 respectively. Published annually by the Disability Alliance (25 Denmark Street, London WC2H 8NJ).

Other publications include Your Rights for Pensioners (Age Concern), the National Welfare Benefits Handbook and the Rights Guide to Non-means Tested Social Security Benefits (Child Poverty Action Group 1-5 Bath Street, London EC1V 9PY). Caring at Home

(National Extension College, 1989, 3rd ed) includes a section on money matters. Transport benefits are outlined in *Door to Door* (see Transport publications) as follows:

Mobility Allowance	p 2
Exemption from Road Tax	p 12
Relief from VAT & Car Tax	p 12-13
Fares to Work	p 22
Bus fare concessions	p 26
Railcard	p31
Hospital visiting	p58

Types of help - benefits

The benefit system is very complicated and changed in 1988. Details are in the above publications and can be explained if you wish (though it is wise to get a specialist to check what you write). If you wish to include information on the main benefits relevant to people with disabilities and their carers, you could refer to the appropriate DHSS leaflets (which contain application forms):

Invalid Care Allowance	N1 212
Attendance Allowance	N1 205
Mobility Allowance	N1 211

They do not pay for respite care, but they explain the rules and may help carers be aware of financial help more generally.

Do not forget to include the Independent Living Fund if you are including comprehensive information on finance. Address: P.O. Box 183 Nottingham NG8 3RD.

For London residents only, the Taxicard scheme is administered by London Regional Transport's Disabled Passengers Unit, 55 Broadway, London SE1.

Types of help - charities

Some trusts make small grants to individuals. Some national voluntary organisations can help, too (see chart in this pack). Local voluntary agencies and social workers may know about sources of charitable help. It is worth approaching these sources for grants for respite care. Your local information pack can either include general advice of this nature or specific contacts you discover in your researches.

There are a number of published reference books which can be consulted:

- Directory of Grant Making Trusts 1989
 (Charities Aid Foundations every 2 years)
- A Guide to Grants for Individuals in Need ed.
 Luke Fitzherbert and Helene Bellofatta,

Directory of Social Change 1987.

 Local authorities have the power under section 10 of the Charities Act 1960 to maintain an index of local charities. You can ask the legal or solicitors department if the authority has such an index, and where it is kept. You have a right to see it. This can be a way of tracking down small local charities which give money to individuals — often very small sums.

Types of help - Local Authorities

Local authorities have the power to make grants or provide holidays. But not all exercise it. If grants are made, outline the procedure and timetable.

TRANSPORT

Who to contact and what to include

Transport is a crucial element in arranging respite, but provision for people with disabilities is fragmentary and poorly publicised.

In order to track down what exists, you should find out the name of the officer in the statutory organisation responsible for public transport in your area. This person (the public transport coordinator in shire counties) may have colleagues dealing with transport for elderly or disabled people, community schemes or rural schemes.

In shire counties, contact the county council — usually the planning or highways departments.

In metropolitan districts, contact the public transport authority.

In London, contact the planning department of the local authority and the Disabled Passengers Unit of London Regional Transport.

These officers/departments can give you information for your guide about specific services and operators.

Disablement organisations often have information on local transport. They may not be able to present such a comprehensive picture but can probably give a consumer point of view.

These are the types of provision, the information to include and the people to contact:

- Adapted bus services (with lift access). Give details of routes, timetables, charges, assistance (there are not many such services). Contact public transport coordinator or bus company.
- Community minibus schemes. These are run by voluntary organisations for elderly or disabled people. Many are primarily or only for their own members. Some are more flexible. Community transport schemes hire out minibuses for voluntary organisations and can often give advice on local transport services. Include their address. Give eligibility criteria for services. For those that are available to individuals, give prices. Contact public transport co-ordinator, CVS or community transport.
- Volunteer car schemes (also known as community car schemes or social car schemes or hospital car service or emergency transport service). Transport is the main function of schemes with one of these names. Volunteer drives give lifts in their own cars. Some schemes operate adapted wheelchair accessible vehicles. Contact public transport

coordinator, CVS, community transport, or volunteer bureau. (Many organisations arrange their own voluntary driver schemes. These are unlikely to be shared or available for other purposes, and may better be mentioned with the respite services with which they are associated.)

- Dial-a-ride (or Ring and Ride) Door to door transport for individuals in adapted vehicles. Give details of areas, hours, fares, assistance, and booking rules.
- Taxis In London subsidised fares are available through the Taxicard scheme. Otherwise you can list companies which operate wheelchair accessible taxis (called FX4W or Metrocab).
- Statutory organisations Give details of any special services offered by social services or education departments (or other local authority departments) or local hospitals.
- British Rail Intercity services are now accessible to wheelchair users and all mainline stations are equipped with accessible toilet facilities, adjacent parking and ramped access. Provision on provincial services is improving and it is worth getting in touch with British Rail to check out any particular route or jounrey that is not Intercity.

Contact Sheridan Hughes, British Railways Board, Room 16, King's House, 240 Pentonville Road, London N1 9JZ Tel: 01-928 5151 ext 40436

It would also be desirable to include in your guide any general contacts for carers, such as the public transport co-ordinator, disablement association, and community transport. For further information on transport for people with disabilities you could contact:

Disability Unit
Department of Transport
2 Marsham Street
London SE1P 3EB
tel 212 4431

CAMPAIGNING & PLANNING

Taking a Break gives information on who to contact for campaigning, planning or pursuing complaints. How much you include in the way of local details is up to you. But these are some suggestions:-

Joint Planning (See Taking a Break p32-33)

- how to find out about election of voluntary sector members and the names and addresses of current members.
- the name of the joint planning officer (contact CVS or CHC)

Health Services Planning

Health authorities produce strategic and operational plans on a regular basis. You could refer to these (contact reference library, CHC or health authority direct) and give:—

- details of sections on carers (if any)
- name of community unit manager
- CHC address

Social Services

Some departments have liaison committees or joint committees which act as a contact point or forum for discussion of policy issues, eg. on elderly people or disabled people. You could list these and give the name of the officer responsible.

Voluntary Sector

- contacts for carer support groups and branches of national voluntary organisations
- details of local community care or health forum
- regional workers of carer organisations and disability organisations
 (only include these if they are in a position to offer help and advice on carer issues).

NHS & Community Care Act 1990

As a result of this legislation, both health authorities and social services authorities will have to draw up and publish community care plans. The arrangements for joint planning may change.

TYPES OF BREAK — MAKING THE MOST OF YOUR INFORMATION side 17

EXPLORING ALL THE ANGLES

Have you asked all Departments?

Since structures of authorities vary so much, think if there are any gaps in the information you've received. For example, ask yourself which department is responsible for grant aid for voluntary organisations. Sometimes this is handled centrally, eg by the chief executive's department, rather than by social services.

Have you been given the information carers need?

Caring is a very personal task and carers want to be sure that a service will suit the person they look after. Naturally, people with disabilities themselves are equally concerned, and need the same information. But just to be told a service exists isn't enough. Both users and carers need to have some details about it, and then need details of how to get in touch and how to use it. Remember, carers may be exhausted by long hours and feel worn down by previous bad experiences. They probably won't have a professional worker's understanding of the different responsibilities of different agencies. Your information should tell them immediately what kind of service is offered, by whom, at what cost and whether transport help can be provided. Then they need to know whether there is a waiting list and whether criteria exist which may rule out the person they care for. So the policy of each service should be clearly and simply stated.

Sometimes the people giving information will not realise how a particular service can help carers. They may only give the standard information they keep for disabled or elderly people. In particular, guides for services for people with disabilities (which authorities have a duty to produce under section of the Chronically Sick and Disabled Persons Act 1970 as

amended by the Disabled Persons Act 1986) may not give you the information that is relevant to carers. Finally, there may not be enough information — the name, address and brief description don't really explain enough for carers.

The personal touch

Do try and find out about the people who work in a particular respite centre, the people who use it, the style of operation or the buildings it uses. You can do this through telephone conversations, or through talking to carers who have used the service. This will help you pick out those aspects which are worth a special mention — an open day, a forward looking policy, a way of welcoming visitors, or some other special feature. Mention these positive aspects if you can.

Checking

If you need more information about a particular service, or if you are not clear, or even if you think there seems to be an omission, ring up and put your query to the officer or manager concerned.

Trawling

You may have to wait for information to be sent to you. Whilst you are waiting, there is no harm in doing some 'trawling' — going out and looking for information. Consult annual reports and newsletters of local voluntary organisations, publications and policy statements of health and local authorities, asking your contacts in the various services. Another way is to visit one centre and ask about others.

Another useful way is to contact officers who have a special responsibility for a particular client group, and check whether they feel your information is relevant to the people they work with. Good examples are ethnic minority advisers, disability or equal opportunity officers, workers on HIV/AIDS issues, etc.

DESIGN CONSIDERATIONS

The main purpose of a local information pack or directory of respite care is to help carers find the services they want. We suggest you keep the order of arranging the information that is used in *Taking a Break*.

Next consider how your information pack or directory works as a reference tool. Carers need to find their way around it. This means a manageable overall size and a way to distinguish sections from each other. On each page, make sure the main information stands out and can easily be used. This is likely to be the name and address and telephone number of each service. Stereotypes of disability, age, race or gender should be avoided.

Consider the following:

- clear page headings and 'running heads'
- different colour paper for different sections
- use of symbols to indicate main types of provision
- illustration to break up the text and give a lighter feel
- printing in two colours
- · an attractive cover

These are the stock in trade of professional designers. If there are adequate funds, or if a local or health

authority in house designer can be involved, do get the advice and services of a professional.

A good publication for people who want to make the most of limited resources or who are beginners is:

Graphics Handbook, by Richard McCann

An introduction to design and printing for the non-specialist published by the Health Education Authority available from National Extension College 18 Brooklands Avenue Cambridge CB2 2HN tel 0223 316644 (enquire for price)

Quotations or extracts from the text of *Taking a Break* may be used by non-profit organisations. The Carers Unit of the King's Fund Centre can supply technical details for design, illustration, typeface and printing of *Taking a Break* for any organisation who wishes to use the same design style.

CHECKLIST

side 1

These checklists contain the respite services operated by statutory agencies. They can be listed when writing to the appropriate agency. It is worth asking them to include voluntary sector provisions supported by them.

Title used in TAKING A BREAK	SERVICE PROVIDING AG	ENCY	
CARE AT HOME	SOCIAL SERVICES	HEALTH	EDUCATION
Sitting Service	Sitting Services		
	Neighbourhood Care Schemes		
Care Attendant Schemes	Home Care Service	Care Attendant Services	
	Extended Home Care Service		
		Hospice-at-home	
	Crossroads-type schemes		
	Family Support Services		
Night Services/ Living-in Help	Peripatetic Services	Night Nursing Services	

Taking A Break - Information sheet

Title Used in TAKING A BREAK	SERVICE PROVIDED BY:		
CARE AWAY FROM HOME	SOCIAL SERVICES	HEALTH	EDUCATION
Day Care — Children	Day nurseries Playgroups—which take children with special needs Playschemes—which take children with special needs Childrens & Family Centres	Playschemes for children with special needs	Nursery Schools & Classes Special schools Youth clubs Further/Higher Education Playschemes
Day Care — Adults	Day Centres Work/Training Centres Lunch/Social Clubs Residential Care Homes with day places	Day Hospitals Hospitals with day places Stroke Clubs Work Centres	Adult education training centres
Residential Breaks — Children	Homes/Hostels for short-term stay (including thosenot directly provided but with which the authority has contract or regular arrangements)	Hospital wards with holiday beds Hospices	Hostels attached to special educational provisions
Residential Breaks — Adults	Residential care homes with holiday beds Short-term respite homes Hostels for short-term stay (including those with contract arrangements)	Hospital wards or units with holiday beds Special short stay units or wards Back to back or shared care Hospices	
Short stay with another family (for children or adults)	Family placement, schemes Family Link schemes		

PLEASE INCLUDE THOSE VOLUNTARY ORGANISATIONS WHICH THE AUTHORITY GRANT-AIDS TO PROVIDE A RESPITE CARE SERVICE

SAMPLE FORMAT FOR LOCAL INFORMATION

What kind of respite is offered? short	description
What kind of respite is offered? Short	description.
Who is it intended for? short descript	ion:
Who is it managed by? short descript	tion:
NAME OF SERVICE:	
ADDRESS:	
Telephone number:	If switchboard, give extension:
Times of day telephone is answered:	
Does telephone answerphone operate at oth	er times?
NAME OF MANAGER / SENIOR OF	FICER:
0	
Services available:	
Eligibility criteria:	
Transport arrangements:	
Charges:	
Details of any financial help available	•
Details of any infancial fielp available	•
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Access:	
Ninhan and annuality of the little	
Notes on multi-cultural care:	
How to apply:	

TRANSPORT AND HOLIDAY INFORMATION

Advice

Taking a Break points carers to two principal sources of advice:

HOLIDAY CARE SERVICE, 2 Old Bank Chambers, Station Road, Horley, Surrey RH6 9HW (free) and

RADAR, 25 Mortimer Street, London W1N 8AB (Fact Sheets cost 45 pence including postage)

For information and advice on camping and campsites, contact

Camping for the Disabled 20 Burton Close Dawley Telford SHROPSHIRE Tel. 074 377—489

Helpers

Holiday Care Service, 2 Old Bank Chambers, Station Road, Horley, Surrey RH6 9HW runs a Holiday Helpers Scheme for people of all ages with disabilities who need assistance whilst on holiday. This puts people in touch with volunteers who can meet their needs.

Publications - holidays

Holidays for Disabled People — RADAR Royal Association for Disability and Rehabilitation, 25 Mortimer Street, London W1N 8AB (£3.00 + £1.00 p&p)

Lists holiday establishments in the UK with a short description and an easy to use system of symbols to show the facilities available, plus other useful information.

Travellers Guide for the Disabled — AA Automobile Association, Fanum House, Basingstoke, Hampshire RG21 2EA (£2.95, free to members)

Gives lists and charts of accommodation, places to eat and visit, and toilets, including some foreign information.

Holidays and Travel Abroad — RADAR Royal Association for Disability and Rehabilitation, 25 Mortimer Street, London W1N 8AB (£2.00 + .75 p&p)

Travel advice and details on 38 countries (all of these include lists of useful publications).

Holiday and Accommodation Guide MENCAP Royal Society for Mentally Handicapped Children and Adults, 123 Golden Lane, London EC1Y ORT (£1.00 + .40 p&p)

Access in London Published by Nicholson (£2.50 incl.p&p)

Contains information on Accommodation (pp38-57) and London Tourist Information.

Several guides include information on accommodation or activities for people with disabilities. These are not listed comprehensively — all guides and holiday companies should do it — but include;

- Where to Stay English Tourist Board (uses wheelchair symbol)
- Handbook and Hotel Guide RAC (shows which have facilities on ground floor and no more than one step)
- Activity and Hobby Holidays in England English Tourist Board.

A good summary of information on holidays is contained in the Spring 1987 Newsletter of GLAD, Greater London Association for Disabled People, pages 10 & 11. (Address: 336 Brixton Road, London SW9 7AA).

Transport publications

Care in the Air — Air Transport Users Committee 129 Kingsway, London WC2B 6NN (Tel 01-242-3882) (Free)

Access at Channel Ports — RADAR Royal Association for Disability and Rehabilitation, 25 Mortimer Street, London WN 8AB (£2.50 incl.p&p)

Door to Door (2nd Edition) published by Department of Transport available from: Door to Door Guide, Freepost, Victoria Road, South Ruislip, Middlesex HA4 0NZ

Travelling with British Rail — RADAR Royal Association for Disability and Rehabilitation, 25 Mortimer Street, London W1N 8AB (£2.70 incl.p&p)

Access to the Underground — London Regional Transport Public Relations Office, 55 Broadway, London SW1. Tel 01-222 5600 (£0.80)

Motoring & Mobility for Disabled People by Ann Darnborough and Derek Kinrade. Royal Association for Disability and Rehabilitation, 25 Mortimer Street, London W1N 8AB (£4.00 incl.p&p)

Other sources of transport information

National Advisory Unit for Community Transport Head Office Keymer Street Manchester M11 3FY 061 273 6038

A-Ca

LOC Services	AL Meetings		Police	NATIONAL Relief Holidays Advice F		
COLVIDOS	Wildings	AFASIC Association for All Speech Impaired Children 347 Central Markets Smithfield London EC1A 9NH Tel: 071-236 3632	ranai	Tolluays	Advice	Funds
		Age Concern England Astral House 1268 London Road London SW16 4EJ Tel: 081-679 8000				
		Alzheimer's Disease Society 158-160 Balham High Street London SW12 9BN Tel: 081-675 6557				
		Arthritis Care 5 Grosvenor Crescent London SW1X 7ER Tel: 071-235 0902				
		ASBAH Association for Spina Bifida and Hydrocephalus 42 Park Road Peterborough Cambridge PE1 2UQ Tel: 0733-555988				
		Dr Barnardo's Tanners Lane Barkingside Ilford Essex 1G6 1QG Tel: 081-550 8822				
		BLESMA British Limbless Ex-Service Men's Association Frankland moore House 185/187 High Road Chadwell Heath Essex RM6 6NA Tel: 081-590 1124	•			
		British Polio Fellowship Bell Close West End Road Ruislip Middlesex HA4 6LP Tel: 0895-675515	•			
		British Red Cross 9 Grosvenor Crescent London SW1X 7EJ Tel: 071-235 5454				
		Cancer Relief Macmillan Fund Anchor House 15/19 Britten Street London SW3 3TY Tel: 071-351 7811				

Ca-F

LOCAL Services Meetings	Information about CANCERLINK can be found on sheet V-W	Relief	NATIONAL Holidays Advid	æ Funds
	Carematch 286 Camden Road London N7 OBJ Tel: 071-609 9966			
	Carers National Association 29 Chilworth Mews London W2 3RG Tel: 071-724 7776			
	Leonard Cheshire Foundation 26/29 Maunsel Street London SW1P 2QN Tel: 071-828 1822			
	Chest Heart and Stroke Assoc. CHSA House 123/127 Whitecross Street London EC1Y 8JJ Tel: 071-490 7999			
	COMBAT Association to Combat Huntingdon's Chorea 34a Station Road Hinckley Leicestershire LE10 1AP Tel: 0455-615558			
	Contact a Family 16 Strutton Ground London SW1P 2HP Tel: 071-222 2695			
	Counsel and Care for the Elderly (CCE) Twyman House 16 Bonny Street London NW1 9LR Tel: 071-485 1550			
	Association for Crossroads Care Attendant Schemes Ltd 10 Regent Place Rugby Warwickshire CV21 2PN Tel: 0788-73653			
	Down's Syndrome Association 12/13 Clapham Common Southside London SW4 7AA Tel: 071-720 0008			
	Disability Alliance 25 Denmark Street London WC2H 8NJ Tel: 071-240 0806			
	Family Welfare Association 501/505 Kingsland Road Dalston London E8 4AU Tel: 071-254 6251		0	

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LOCAL Services Meetings		Relief	NATION Holidays	IAL Adviœ	Funds
	GRACE (Advice on Nursing Homes) 35 Walnut Tree Close Guildford Surrey GU1 4UL Tel: 0483-304354				
	John Groom's Association for the Disabled 10 Gloucester Drive London N4 2LP Tel: 081-802 7272	O. C.			
•	Headway 200 Mansfield Road Nottingham NG1 3HX Tel: 0602-622382				
	Help the Aged St James's Walk London EC1R OBE Tel: 071-253 0253				
	Holiday Care Service 2 Old Bank Chambers Station Road Horley Surrey RH6 9HW Tel: 0293-774535				
	Hospice Information Service St Christopher's Hospice 51-59 Lawrie Park Road Sydenham London SE26 6DZ Tel: 081-778 9252				
	Invalid Childrens Aid Nationwide (ICAN) 198 City Road London EC1V 2PH Tel: 071-608 2462				
•	Invalids-at-Home 17 Lapstone Gardens Kenton Harrow HA3 OEB Tel: 081-907 1706				
	Jewish Care 221 Golders Green Road London NW11 9DW Tel: 071-458 3282				
	Marie Curie Memorial Foundation (Cancer Care) 28 Belgrave Square London SW1X 8QG Tel: 071-235 3325				
	MENCAP Royal Society for Mentally Handicapped Children & Adults 123 Golden Lane London EC1Y ORT Tel: 071-454 0454				

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		NATI(DNAL	•
	Relief	Holidays	Advice	Funds
MIND (National Association for Mental Health) 22 Harley Street London WIN 2ED Tel: 071-637 0741				
Motor Neurone Disease Assoc. PO Box 246 Northampton NN1 2PR Tel: 0604-22269/250505				
Multiple Sclerosis Society 25 Effie Road Fulham London SW6 1EE Tel: 071-736 6267	•			1
Muscular Dystrophy Group of Great Britain and Northern Ireland Nattrass House 35 Macaulay Road London SW4 OQP Tel: 071-720 8055				
National Association of Disablement Information and Advice Lines (DIAL UK) Park Lodge, St Catherine's Hospital Tickhill Road Belby, Doncaster S Yorkshire DN4 8QN Tel: 0302-310123				
National Council for Carers and their Elderly Dependants see Carers National Association				
National Federation of Gateway Clubs Mencap National Centre 123 Golden Lane London EC1Y ORT Tel: 071-454 0454				
National Schizophrenia Fellowship 28 Castle Street Kingston upon Thames Surrey KT1 1SS Tel: 081-547 3937				
Parkinson's Disease Society 36 Portland Place London W1N 3DG Tel: 071-323 1174				
PHAB Physically Handicapped and Able Bodied 12/14 London Road Croydon Surrey CRO 2TA Tel: 081-667 9443				
	(National Association for Mental Health) 22 Harley Street London WIN 2ED Tel: 071-637 0741 Motor Neurone Disease Assoc. PO Box 246 Northampton NN1 2PR Tel: 0604-22269/250505 Multiple Sclerosis Society 25 Effic Road Fulham London SW6 1EE Tel: 071-736 6267 Muscular Dystrophy Group of Great Britain and Northern Ireland Nattrass House 35 Macaulay Road London SW4 COP Tel: 071-720 8055 National Association of Disablement Information and Advice Lines (DIAL UK) Park Lodge, St Catherine's Hospital Tickhill Road Belby, Doncaster S Yorkshire DN4 8QN Tel: 0302-310123 National Council for Carers and their Elderly Dependants see Carers National Association National Federation of Gateway Clubs Mencap National Centre 123 Golden Lane London EC1Y ORT Tel: 071-454 0454 National Schizophrenia Fellowship 28 Castle Street Kingston upon Thames Surrey KT1 1SS Tel: 081-547 3937 Parkinson's Disease Society 36 Portland Place London W1N 3DG Tel: 071-323 1174 PHAB Physically Handicapped and Able Bodied 12/14 London Road Croydon Surrey CRO 2TA	MIND (National Association for Mental Health) 22 Harley Street London WIN ZED Tel: 071-637 0741 Motor Neurone Disease Assoc. PO Box 246 Northampton NN1 2PR Tel: 0604-22269/250505 Multiple Sclerosis Society 25 Effic Road Fulham London SW6 1EE Tel: 071-736 6267 Muscular Dystrophy Group of Great Britain and Northern Ireland Natrass House 35 Macaulay Road London SW4 OOP Tel: 071-720 8055 National Association of Disablement Information and Advice Lines (DIAL UK) Park Lodge, St Catherine's Hospital Tickhill Road Belby, Doncaster S Yorkshire DN4 8CN Tel: 0302-310123 National Council for Carers and their Elderly Dependants see Carers National Association National Federation of Gateway Clubs Mencap National Centre 123 Golden Lane London ECIY ORT Tel: 071-454 0454 National Schizophrenia Fellowship 28 Castle Street Kingston upon Thames Surrey KT1 1SS Tel: 081-547 3937 Parkinson's Disease Society 36 Portland Place London WIN 3DG Tel: 071-323 1174 PHAB Physically Handicapped and Able Bodied 12/14 London Road Croydon Surrey CRO 2TA	MIND (National Association for Mental Health) 22 Harley Street London WIN 2ED Tel: 071-637 0741 Motor Neurone Disease Assoc. PO Box 246 Northampton NN1 2PR Tel: 0604-22269/250505 Multiple Sclerosis Society 25 Effic Road Fulham London SW6 IEE Tel: 071-736 6267 Muscular Dystrophy Group of Great Britain and Northern Ireland Natrass House 35 Macaulay Road London SW4 OOP Tel: 071-720 8055 National Association of Disablement Information and Advice Lines (DIAL UK) Park Lodge, St Catherine's Hospital Tickhill Road Belby, Doncaster S Yorkshire DN4 BON Tel: 0302-310123 National Council for Carers and their Elderly Dependants see Carers National Association National Federation of Gateway Clubs Mencap National Centre 123 Golden Lane London EC1Y ORT Tel: 071-454 0454 National Schizophrenia Fellowship 28 Castle Street Kingston upon Thames Surrey KT1 15S Tel: 081-547 3937 Parkinson's Disease Society 36 Portland Place London W1N 3DG Tel: 071-323 1174 PHAB Physically Handicapped and Able Bodied 12/14 London Road Croydon Surrey CRO 2TA	MIND (National Association for Mental Health) 22 Harley Street London Will XED Tel: 071-637 0741 Motor Neurone Disease Assoc. PO Box 246 Northampton NN1 2PR Tel: 0604-22269/250505 Multiple Sclerosis Society 25 Effic Road Fulham London SW6 1EE Tel: 071-736 6267 Muscular Dystrophy Group of Great Britain and Northern Ireland Natrass House 35 Macaulay Road London SW4 COP Tel: 071-720 8055 National Association of Disablement Information and Advice Lines (DIAL UK) Park Lodge, St Catherine's Hospital Tickhill Road Belby, Doncaster S Yorkshire DN4 8QN Tel: 0302-310123 National Council for Carers and their Elderly Dependants see Carers National Association National Federation of Gateway Club. Mencap National Centre 123 Golden Lane London ECITY ORT Tel: 071-454 0454 National Schizophrenia Fellowship 28 Castle Street Kingston upon Thames Surrey KT1 1SS Tel: 081-547 3937 Parkinson's Disease Society 36 Portland Place London Win 3DG Tel: 071-323 1174 PHAB Physically Handicapped and Able Bodied 12/14 London Road Croydon Surrey CRO 2TA

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LOCAL Services Meetings	Meetings		NATIONAL Holidays Advice Funds		
	Pre-school Playgroup Association 61-63 Kings Cross Road, London WCIX 9LL Tel: 071-833 0991				
	The Richmond Fellowship 8 Addison Road, London WI4 8DL Tel: 071-603 6373				
	RADAR Royal Association for Disability and Rehabilitation 25 Mortimer Street London W1N 8AB Tel: 071-637 5400			•	
	RNIB Royal National Institute for the Blind 224 Great Portland Street London W1N 6AA Tel: 071-388 1266		•		
	Royal British Legion 48 Pall Mall London SW1Y 5JY Tel: 071-930 8131				
	Sue Ryder Foundation Cavendish Sudbury Suffolk CO10 8AY Tel: 0787-280252				
	Sense The National Deaf-Blind and Rubella Association 311 Gray's Inn Road London WC1X 8PT Tel: 071-278 1005/1000				
	Shaftesbury Society 2a Amity Grove Raynes Park London SW20 OLH Tel: 081-946 6635				
	The Spastics Society 12 Park Crescent London W1N 4EQ Tel: 071-636 5020	•			
	Spinal Injuries Association 76 St James's Lane London N10 3DF Tel: 081-444 2121	0			
	Terrence Higgins Trust 52-54 Grays Inn Road London WC1X 8JU Tel: 071-831 0330				
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LOC	AL		NATIONAL			
Services	Meetings		Relief	Holidays	Adviœ	Funds
		Voluntary Council for Handicapped Children 8 Wakley Street London EC1V 7QE Tel: 071-278 9441				
		WRVS Women's Royal Voluntary Service 234-244 Stockwell Road London SW9 9SP Tel: 071 733 3388				
		Cancerlink 17 Britannia Street London WC1X 7JN Tel: 071-833 2451				

KEY TO CHART OF SERVICES PROVIDED BY NATIONAL ORGANISATIONS

Note: This sheet is not intended to be a comprehensive description of all the services provided by voluntary organisations. It is intended to indicate the main ways in which they can help with respite.

LOCAL BRANCHES

Relief Services: respite services such as day centres, holiday schemes, sitting or care attendant services run by local branches, mainly for carers in that area. This column indicates either that the main purpose of local branches is to provide respite or that a local branch runs such a service as well as its group, club or other meeting. Note that this column does not mean that every branch runs respite; but that some do.

Meetings, Groups or Clubs: The local organisation runs meetings or activities which carers or people with disabilities can attend for support or social reasons. The national office can put enquirers in touch with the local representative.

NATIONAL ORGANISATION

Relief services: The National office can give enquirers details of respite services which it provides and administers nationally or regionally. This will usually be some kind of residential care.

Holldays: holiday activities or accommodation are run by the national organisation.

Advice: carers can telephone and ask for a wide range of information and advice on respite services or on arranging breaks.

Funds: the organisation can sometimes make small grants to individuals to cover holidays or relief care (whether at national or local level) provided its criteria are met. Source — annual reports and "A Guide to Grants for Individuals in Need 1987"

TAKING A BREAK

Guidelines for Compiling Local Information

Summary

This sheet summarises the advice given in the Kings Fund Informal Caring Support Unit's 'Guidelines for Compiling Local Information' which gives full details, including working sheets, and costs £1.50 (from Informal Caring Support Unit, Kings Fund Centre, 126 Albert Street, London NW1 7NF)

Local Information on Respite Care

There are many ways local information can be used: as fact sheets, as part of packs or directories, in reports. But the common purpose is to provide an effective way to help carers find out what is available in their own area, and choose the most appropriate break.

Existing information is likely to be patchy and probably does not give everything carers need to know. Always aim to give the name and address of the service itself - not a contact who will pass carers on. Remember that carers don't just need names and addresses, but details on transport, charges, access, aims, policies and suitability for different cultural or religious backgrounds.

So the tasks of anyone providing information - whether from a statutory or voluntary agency - are to undertake thorough research and to understand the carers point of view. And when you have the information, your skill in presenting, organising, designing and distributing it will be crucial.

Always start by checking whether any carers information is already available or in preparation in your area. If you go ahead yourself, consult widely - including carers - and explain what you are doing to those whom you are asking for information.

Asking for Information

Use the telephone to find out how local services are organised, to make contact with helpful individuals, and to check points you are unsure of.

Write for information, listing the specific information you want and the ages and categories of people you are concerned with. Use a check list. Give details of your own organisation and your aims in asking for information.

Use directories - use standard directories to check your information is comprehensive.

Follow up your enquiries with telephone calls, look up reports or reference sources, and check out any provision that strikes you as unusual, especially relevant - or missing!

What to include

Statutory Services

Social Services: here you need to enquire about provision for all client groups, all ages and different types of care (in the home, residential or placements). Find out the structure by phone and write to the assistant directors who may be able to help. Contact specialist officers (eg ethnic minorities, HIV/AIDS, holidays).

Health service: Again, all client groups, ages, and types of care must be covered. Find out the structure by telephone (the Community Health Council are worth approaching for help, too). Write to all the unit general managers.

Education: You will be asking about day and residential provision in special and mainstream education. There is usually an education officer with special responsibility who can be contacted.

Voluntary sector

There will be local voluntary organisations which provide respite services - they may be quite independent of any national structure or local network. You will have to start with local 'umbrella' organisations (Councils for Voluntary Ser vice, disablement associations, community relations councils, etc) and check any directories. Word of mouth may be an important way to find out more. Other voluntary sector respite care services will be part of national organisations, so it is worth contacting head offices to find out if they have branches in your area.

You should also ask about religious and neighbourhood groups. Include carer organisations in your directory as part of your standard information.

Private Sector

For care attendants, nurses, sitters, etc - contact local employment agencies and nursing agencies to see what respite care they provide.

For pre-school provision, contact the social services department - nurseries and playgroups will be registered. Each may have to be contacted individually about their provision for children with special needs.

For short stay residential care, contact the registration officers in the social services or health authority.

Again, homes will probably have to be contacted individually to get the required information.

Holidays

Statutory and voluntary services in your area should be asked for details on holidays they provide. However, a lot of provision is organised on national basis. There are two courses open to you: either research the national information you judge likely to be most relevant to carers in your area, or give an account of the books and guides that are available. Individuals will be concerned about appropriate advice on holiday provision, so you should state where they can get it.

Other information to help carers use respite care

The names and addresses of respite care providers will tell carers who to contact. But they may still need additional help and information on how to make arrangements. There are four main areas:

counselling

finance

transport

planning and campaigning

Here you should provide information about what practical help exists locally, and supplement it with nationally relevant information and advice. The local details will have to be researched from several sources. The amount of national information you include will depend on your judgement and your resources.