CARERS Scotland the voice of carers **FACTSHEET**



How do I get help?

Why this factsheet may help you

Carers look after family, partners and friends in need of help because they are ill, frail or have a disability. The help they provide is unpaid.

It doesn't matter if the person you care for is a child or elderly, or they live with your or not, you are still a carer.

If you are providing most of the care your friend or relative needs, you should be properly supported so that you don't have to cope on your own.

This factsheet concentrates on accessing support through your local social work department to help you in your caring role.

SECTION 1

What is community care?

Social work departments of local authorities are responsible for arranging support to help people who are elderly or have a disability and live in the community.

If the person you look after needs care, you can ask the social work department to carry out a "community care assessment" of what services they need. The assessment is based on a discussion with the person needing care, their relatives and carers, and if necessary on information from other relevant bodies such as health or housing.

Sometimes the social work department will provide services such as home care or may "buy in" services from voluntary organisations such as Crossroads or a privately

What about carers?

If you provide or intend to provide a substantial and regular amount of care for a friend, relative or disabled child, you have a legal right to ask the social work department to carry out a "carer's assessment". The carer's assessment should look at your ability and willingness to continue looking after the person and the impact that caring has on you.

The social worker or person carrying out the assessment should not assume you want to continue providing the same amount of care (See **"What will happen at these assessments"** on page 5).

Young carers

If you are under 16 years old and look after somebody, you also have a legal right to ask the social work department to carry out a carer's assessment.

What information is available?

The social work department is required to give people information about their rights. This should include how to apply for an assessment; what happens to your application; services available (not just those provided by the social work department); and how to complain.

Community Care & Health (Scotland) Act 2002

A new piece of legislation called the Community Care & Health (Scotland) Act 2002 was introduced in 2002. The new law means that carers of any age in Scotland now have the right to an assessment of their needs whether or not the person they are caring for has been assessed.

Local authorities have a duty to inform eligible carers of their right to this assessment. The new law also requires that local authorities must take account of the care provided by the carer and the views of the person being cared for and their carer before deciding what services to provide.

The new law also recognises carers as "key partners in the provision of care" rather than as service users. This principle recognises the unique role that carers play in providing care in the community. Carers are usually the main care providers for the person they look after and have extensive knowledge and expertise about the needs of the person they care for. Local authorities should recognise and draw on your knowledge and expertise to ensure that the person you care for receives services that are right for their needs.

How to get an assessment

You can request a carer's assessment from your local social work department. You can also ask for a community care assessment of the person you are looking after, or a reassessment or review if their needs have changed and they need more help.

The telephone number and address of the social work department will be listed in the phone book under the name of the local authority. You can also ask your GP or district nurse to contact the social work department on your behalf.

Try to talk to the person you are looking after before you call the social work department, and agree that you will ask for assessments for both of you and what points you want to raise. S/he will be involved in the assessment itself.

The local authority cannot refuse to carry out an assessment. A social worker or person carrying out the assessment will come round and discuss with you what support the person you are caring for needs.

Sample letter requesting a carer's assessment

Opposite is a sample letter asking the social work department for an assessment. We have used brackets [] where you should write details about yourself and the person you care for. Try to make a copy of your letter so that you can refer to it in the future. Someone will contact you, probably a social worker.

Contact the social work department if you do not hear from them within 2 weeks. If you need help urgently, add an extra sentence explaining the urgency, or call the social work department asking for their immediate help. In emergencies, the social work department can provide services before carrying out a full assessment.

> Your address Your telephone number Date Social work department address

Dear Sir/Madam

I am writing to request a Carer's Assessment under the Community Care & Health (Scotland) Act 2002. I have been caring for [name and address of the person you care for] since [date]. S/he is my [mother, father, friend, etc).**

[Name of person] needs help because s/he is [list the disabilities the person has e.g. she is 90 years old, has arthritis and is frail]. The main things [name of person] needs help with are [having a bath, cleaning, dressing, etc.]

The main difficulties I am having are [list some things you think you need e.g. a break from caring]. Could you please write to me at the above address or telephone me on [put your number here] to let me know when you will be able to carry out an assessment.

Yours faithfully [your name]

** Remember you can also ask for a community care assessment (also called single shared assessment) for the person you are caring for by adding the sentence "I would also like to request an assessment for community care services for [name of person you are caring for].

SECTION 2

Getting ready for an assessment

It can be hard preparing for an assessment and thinking about the kind of help to make it easier to look after the person you care for.

Before the assessment make a full list of everything you do to help look after the person you are caring for. Try to do this with the person you look after. The list will form a starting point for further discussion. Have the list ready to discuss with the social worker when they come to visit, or you might just give them the list.

For example:

- Cooking for the person you care for.
- Bathing the person you care for.
- Helping them to get dressed
- Shopping.
- Collecting their pension for them
- Going to the shops with them
- Helping them up and down the stairs.
- Picking up medicine/prescriptions

Practice carer's assessment form

Here are some topics that are likely to be covered in the assessment and some questions to think about. If you take some time to work through these, you will be better prepared for "the real thing" and you will get more out of it.

Housing

Do you and the person you care for live together or apart? If this arrangement satisfactory? If not, say why.

Does the person you care for have any difficulty moving about the home? Special equipment (aids or adaptations) could make life easier for the person you look after and caring easier for you.

Health

Does the person you care for have any health problems you find hard to deal with? Describe as fully as possible. Do you have any health problems? Describe as fully as possible (e.g. if you have a bad back, you might be able to get lifting equipment) □ Laundry?

Do you have to help at night, during the day or both?

Are you getting enough sleep?

- Yes
- 🛛 No

Do you feel you are suffering from stress or depression?

- Yes
- No

Time

How many hours a week do you care? (include all the time you spend with the person you care for, the things you do and how long they take you –the answer might surprise you!) Does anyone else help with this? If so, who and for how long?

Would you like some help (or some extra help) with these jobs?

Do you have to help with:

- □ Housework?
- □ Shopping?
- Bathing?
- Toiletting?
- □ Cooking?
- Other personal care e.g. dressing?
- □ Keeping an eye on them?
- Dealing with money (cashing pensions etc)?

List the tasks you would most like some help with, putting the most important first.

Are there things that you find enjoyable and relaxing which you can't do any more because of your caring responsibilities?

Feelings

Do you feel you don't have a choice about providing care? (You may feel that you cannot carry on at all or only if you reduce the amount you do. It is not unusual to feel this way, tell the social worker about these feelings)

What would you most like to change about your situation?

When was the last time you had a <u>whole</u> day to Yourself?

By now you should have a clearer idea of what your needs and priorities are. Now look at what services you might want to discuss with the social worker.

Things to discuss with the social worker

Think about the range of services listed below. Would any of these help you?

- □ Changes to home or equipment?
- Someone to help with personal care (like bathing)?
- □ A meal delivered to the person you care for?
- □ A few hours break for yourself regularly?

- □ A few weeks break occasionally?
- A discussion about permanent residential care?
- □ Counselling/talking to someone?
- □ To be put in touch with other carers?
- □ Information about what is available and their costs?
- Information about benefits?

Put down anything else you need which is not on the list, including whether you wish to continue working, if you are in work, or want to return to work.

The services should be arranged at times to suit you and the person you care for. You don't have to accept all the services offered to you. You may decide to accept some and not others. Remember, if your situation changes and you need more help you can ask for a reassessment.

What will happen at these assessments?

Assessments should be as simple, speedy and informal as possible. They are aimed at making caring easier for you and providing help and support for the person you are looking after. Assessments should be carried out in a convenient place such as your home or the home of the person you are caring for.

Normally one person – a social worker or someone else – will carry out the assessment. But a meeting may be needed with your GP or district nurse as well if a lot of care is needed. You can ask for a time to talk confidentially to the person carrying out the assessment without the person you are caring for being present.

The assessment will look at things like:

- What kind of help and support the person you are caring for needs.
- What kinds of things you do in caring for them.
- How much time you spend caring and who else cares for the person as well.
- Whether you live with the person you care for or not.
- Your age, views, preferences and the amount of support you already have.

• Your health and wellbeing.

The purpose of the assessment is to make sure that the social work department listens to you and offers the help you need to make caring easier for you or so that you can go on caring.

To help you in your caring, the social work department will provide help or support directly to the person you are looking after. They cannot provide services to carers but can also help you by, for example, providing information and advice and details of your local carers centre.

Remember to tell the person carrying out the assessment if you are in full-time work or want to return to work and whether you have children.

If either you or the person you care for has difficulty in communicating you should let the social work department know – they will provide help for communication.

SECTION 3

After the assessment

It is important that you are able to make an informed choice about how much you do as a carer. When the social work department decide what to provide they have to take into account both your carer's assessment (you should receive a written copy of your carer's assessment) and the community care assessment of the person you care for.

Then they will draw up a care plan for the person you care for and a copy should be given to both of you.

The care plan should include a range of services to make it easier for you to continue caring.

The care plan offered to the person you care for could include:

- A home help to do shopping or help with personal care
- A place at a day centre and transport to get there

- A meal at home or at a day centre
- Special equipment and changes to the home (called aids and adaptations) to make caring safer and easier.

The social work department is also responsible for arranging permanent residential care and nursing home care when necessary, or when the cost of providing services is too great. They can also arrange respite care for the person you are caring for – such as days away at a residential care home every few weeks – to give you a complete break.

Independent Living Fund

If your needs have not been fully met after the assessment, the social worker may be able to refer your case to the Independent Living Fund. The fund pays for extra care for people with very severe disabilities. It can give regular payments to buy in extra services. The fund can only do this if:

- The person you care for is between 16 and 65.
- The person you care for is on income support or has an income not much higher than income support after they have paid for their care needs.
- The person you care for gets disability living allowance care component at the higher rate.
- The person you care for is living alone or their, or their carers cannot meet all their needs.
- The social worker has arranged care package which is worth at least £200 per week.
- The total cost of their care will not exceed £665 per week.
- The person you care for is expected to live for a further 6 months or more.

If you think the person you care for meets these conditions, it is worth asking your social worker about the Independent Living Fund.

Direct Payments and Self Directed Support

In some circumstances social work departments can give a cash payment instead of services to people that have been assessed as needing community care services. This is called a direct payment or self directed support. This allows people to make their own arrangements for getting the services they need, although they cannot normally pay a close relative to care for them under this scheme.

Decisions on services to be provided

Both you and the person you care for should be fully involved in discussions with the social worker on the results of the assessments and the proposed care plan. However, following the assessment you may be told that a particular service cannot be provided because the social work department cannot afford it. If you have been told this, you should bear in mind the following:

- Once the social work department has decided that a service should be provided, then it must be - whether or not the local authority has the money.
- Services cannot be withdrawn simply because the social work department has less money – they must carry out a reassessment of the person you are caring for.
- The availability of resources is only one of the factors to be taken into account when deciding whether a service can be provided.
- In some cases, services must be provided, regardless of resources – for instance when the person cared for would be at severe physical risk if the services were not provided.

If you are unhappy about the level of services offered by the social work department to the person you care for, you can make a complaint. (See **"How do I complain**" in Section 4).

Will I have to pay for services?

Community care assessments and carer's assessment are free. However, the social work department can charge for some community care services and, they have to charge for long term residential care. As a result of this, the person you care for is likely to be asked questions about their money e.g. wages, pensions, savings or benefits. They do not have to give this information but the social work department will assume they can pay the full cost if they do not.

In general, for home care services, only the person for whom the service is to be provided should be asked to pay. You, as a carer, should not be asked about your finances.

However, the Convention of Scottish Local Authorities (CoSLA) has produced guidance for local authority social work departments on charging older people for non personal care services. This indicates that the social work department may take the income of any partner into account when deciding whether or not to charge for services. The Scottish Executive has powers to regulate charging but is, at present, holding off using these powers pending an assessment of the CoSLA guidance. This assessment is unlikely to be completed before October 2003.

Therefore, at present, it is likely that if you are caring for your partner, your finances may be taken into account by the social work department when deciding whether or not s/he will be asked to pay for services.

If the person you care for is asked to pay for services, you should ask the social work department for details of their charging policy and an explanation of how they calculated the charges. There are no national guidelines on charging and rates will vary from area to area. However, all social work departments must follow these points:

- The charges must be "reasonable":
- The social work department should only charge what people can afford.
- No-one should be caused hardship, or denied a service they need because they cannot pay.
- The social work department should consider the person's everyday needs, including any extra costs as a result of disability or ill health.
- If you can show that a charge would cause hardship, the social work department must consider reducing or dropping them.
- Benefit income may be taken into account except for the Disability Living Allowance mobility component.

If you or the person you are caring for is unhappy with the amount being charged for the services you should consider making a complaint on their behalf. (See **"How do I** complain" in Section 4).

For information on residential services, see our booklet *"When caring comes to an end"* which explains how charges are made.

Free personal care

The Community Care & Health (Scotland) Act 2002 introduced free personal care for older people aged 65 or over who live in Scotland. This personal care is free to both older people living in the community and for those living in residential care. Free nursing care was also introduced for care home residents of any age, providing they have been assessed as requiring it.

If the person you care for is aged 65 or over and lives in the community, they will not have to pay for the personal care element of any services they are assessed as needing and/or currently receive.

Free personal care includes:

- Personal hygiene (help with bathing, showering, hair washing, shaving, oral hygiene, nail care)
- Personal assistance (help with dressing, surgical appliances and prostheses, help to get up and go to bed, use of a hoist)
- **Continence management** (toileting, catheter/stoma care, skin care, incontinence laundry, bed changing)
- Food and diet (help with eating, and the preparation of meals)
- Problems of immobility (dealing with the consequences of being immobile and help with moving about indoors)
- Counselling and support (behaviour management, psychological support, reminding and safety devices)
- Simple treatments (help with medication, application of creams and drops, simple dressings, oxygen therapy).

However, they may still need to make a contribution towards non-personal care such as day care, home helps, lunch clubs, meals on wheels, community alarms and help with shopping and housework For information on free personal and nursing care, see our factsheet *"Free Personal Care"* which gives more details.

Services to children

The social work department can make a "reasonable charge" for services to disabled children and their families. However, the following must be provided free:

- Advice, guidance and counselling services
- Services to families on Income Support, income based Jobseekers Allowance or who are receiving any element of the Child Tax Credit other than the Family Element.

Social work departments can provide services free of charge if they choose. Any charge will be made direct to:

- The parents or adults with parental responsibility for the child, or
- To the child if s/he is over 16, or
- To the member of the child's family receiving the service.

The person being charged should be means tested to ensure only a reasonable charge is made.

SECTION 4

How do I complain?

There may be reasons why you are unhappy. The following are examples of the problems people might face:

- A request for an assessment has been refused with no explanation;
- A long delay between requesting an assessment and getting one;
- A long delay between getting an assessment and receiving a service;
- The social work department has decided not to provide a service although you have been assessed as needing it.

If you are not satisfied with anything about a community care assessment, your carer's assessment, the care provided, or the amount charged for the services, there are various ways in which you (and the person you care for) can complain. If the person you care for is unable to make a complaint or asks you to make a complaint, you can do this on his or her behalf.

Preparing for the complaint

Write down all the things that you wish to complain about and, if possible, discuss them with the person for whom you care. You should also consider what outcome you want.

Consider asking the social work department for a copy of your file and, if the person you care for gives permission, for a copy of his/her file. Ask in advance if there will be a fee. When writing to the social work department, you should state that you are asking for copies of these documents under the Access to Personal Files (Social Work) (Scotland) Regulations 1989, and that under these regulations you should receive this information within 40 days.

Local authority services

If you are not satisfied with anything about a community care assessment, your carer's assessment, the care provided, or the amount charged for the services, there are various ways in which you (and the person you care for) can complain. This includes not only services the local authority provides but also services provided by another organisation or agency that are funded by the social work department.

Using the local authority complaint procedure

Every local authority is required to have a procedure for dealing with complaints about social work services. If the person you care for is unable to make a complaint or asks you to make a complaint, you can do this on his or her behalf. You can also make a complaint on your own behalf, for instance, if you are unhappy about the way in which the social work department carried out your carer's assessment. Most local authorities will have a dedicated officer who The complaints procedure has three stages:

Stage 1 - the informal stage

This stage enables you to raise your concerns, on an informal basis, and gives the social work department the opportunity to try to resolve the problem. Although you can complain in person, or on the phone, it is better to write and keep a copy of the complaint. You do not have to use Stage 1, so you may prefer to ask that your complaint is dealt with on a formal basis which is Stage 2 of the complaints procedure (see below).

There is no set time limit for dealing with complaints at this informal stage. However, your local authority will have a published Complaint Procedure which should provide information on timescales. It is worth clarifying how long you will have to wait for a reply when you make your complaint.

If you are not satisfied with the way in which the complaint is resolved, the local authority should give you an explanation of the complaints procedure and ask you to put your complaint in writing if you wish to proceed to the next stage.

Stage 2 - the formal stage

If your complaint cannot be resolved informally, or if you choose not to use the informal stage, it will be deal with formally. Your complaint must be put in writing. Social work departments have 28 days in which to investigate your complaint and send you a written reply. If the department wants to extend the time limit of 28 days, it can only do so if you agree.

The social work department should be able to provide help to people making a complaint. It is therefore worth asking what help is available, in particular whether there are any advocacy services which can assist you.

The local authority has to tell you, in writing, the outcome of the "formal stage". If you are making a complaint on behalf of the person you care for, he or she should be informed of the outcome of the investigation, unless the social work department consider that he or she is not able to understand the complaint or it would cause him or her distress.

The local authority's reply should advise you of your right to ask for the complaint to be referred to for review if you feel that the problem is not resolved.

Stage 3 – the review stage

If you are not satisfied with the response to your complaint, you can request to have your complaint referred for review. You must put

your request in writing, within 28 days of receiving the Stage 2 decision.

The panel will consist of three people, at least one of whom must be independent and who should chair it. It is the panel's job to reexamine the previous decision. It is in your interest to attend if you can. The panel will find it easier to understand your situation if they can ask you questions. You are entitled to be accompanied by another person, for instance an advice worker, who could speak on your behalf if you wish.

The panel must make recommendations in writing to the local authority within 56 days of receiving notice of the complaint. The social work department then has 28 days to respond to the recommendations. Their response should be sent in writing to you. The letter should explain the social work department's decision and the reason for it.

Complaint to the Scottish public service ombudsman

If you are unhappy with the outcome of your complaint to your local authority or it has not been resolved to your satisfaction, you can ask the Scottish Public Services Ombudsman to investigate further.

The Scottish Public Service Ombudsman can investigate complaints again local authorities, the NHS or any private or voluntary sector services paid for by the local authority or the NHS. You will need to go through their complaints procedures before you can make a complaint to the Scottish Public Service Ombudsman. You should put your complaint in writing and provide proof that you have already used the appropriate local complaints procedure, for example, letters to and from the authority involved. The Ombudsman does not have to investigate your complaint if they do not think it is justified. You can contact the Ombudsman at: The Scottish Public Service Ombudsman, Freepost EH641, Edinburgh EH3 OBR Tel: 0800 377 7330, email: ask@spso.org.uk or complain online at www.spso.org.uk.

Judicial review

Where social work departments appear to have acted unlawfully in reaching a decision, an application can be made to the Court of Session

in Edinburgh asking the judge to review the decision. You must get expert legal advice before taking this course of action. People on low incomes can get legal aid but otherwise this is a very costly process. Judicial review might be appropriate in cases where the social work department has refused to carry out an assessment or reach a decision, particularly if services are required urgently.

Where to get help in making a complaint

You can get help with your complaint from an advice centre like the Citizens Advice Bureau, local law centre or from a disability organisation. These organisations may be able to give your details of lawyers who are able to advise on community care law.

For more information on making complaints, see our factsheet *"Making a Complaint"* which gives more details.

Useful Contacts

Carers Scotland

The Cottage 21 Pearce Street Glasgow G51 3UT Tel: 0141 445 3070 Email: <u>info@carerscotland.org</u>

CarersLine

Freephone: 0808 808 7777 (Wed & Thurs, 10am – 12 noon & 2pm – 4pm) Minicom No. 020 7521 8969

About Carers in Scotland

1 in 8 of the Scottish population are carers – 660,000 people

 Every day almost 500 people take on a caring responsibility – that equals over 178,000 people per year. By 2037 it is anticipated that the number of carers will increase to 1 million.

- 110,000 people care for 50 hours or more each week.
- There are 16,000 young carers in Scotland. However, research estimates that there may be as many more hidden young carers, perhaps as many as 100,000 in total.

Carers are a third more likely to be permanently sick or disabled

- Three quarters of carers say their health is worse because of their caring responsibilities and a staggering 95% regularly cover up or disguise the fact that their health is suffering in order to continue with their caring responsibilities.
- Almost three quarters of carers have not been able to take at least one week of "holiday" or "free time" when they were not having to care for someone

Carers save the economy £7.6 billion per year, an average of £15,000 each

- The main carers benefit Carers Allowance

 is just £53.10 for a minimum of 35 hours
 equivalent to £1.51 per hours far short of the national minimum wage of £5.52 per hour.
- 79% of carers are struggling to pay utility bills like gas, electricity, water or telephone bills. More than half are cutting back on food and heating to make ends meet
- Over half of carers are in debt with a third owing more than £10,000 and over a third are struggling to pay their rent or mortgage
- Over 250,000 juggle work care with work, however because of the demands of caring 1 in 5 carers are forced to give up work altogether

About Carers Scotland

Carers Scotland is the voice of carers.

Carers provide unpaid care by looking after an ill, frail or disabled family member, friend or partner.

Carers give so much to society yet as a consequence of caring; they experience ill health, poverty and discrimination. Carers Scotland is an organisation of carers fighting to end this injustice.

Carers Scotland is here to improve carer's lives

- We fight for equality for carers. We want carers to have the same rights as everyone else to an ordinary life – a fair level of income, access to support to protect their health and wellbeing and access to the world of work, leisure and education.
- We seek to empower carers. We want carers to be actively involved in the design, development and delivery of services. We want carers to be recognised and involved as key partners in the provision of care.

Carers Scotland achieves this by

- campaigning for the changes that make a real difference to carers' lives.
- providing information and advice to carers about their rights and how to get support
- mobilising carers and supporters to influence decision-makers at local and national levels
- gathering hard evidence about what needs to change and disseminating this to policymakers and services providers
- transforming the understanding of caring so that carers are valued and not discriminated against
- providing carer awareness training for staff in health, social care and the voluntary sector
- promoting training for carers to maximise their skills and experience

Join Us, Make Your Voice Heard!

Carers Scotland is part of Carers UK. Carers Scotland and Carers UK want carers to be recognised for the contribution they make to society. We need you to add your voice by joining Carers UK to help us win better support for carers.

We welcome any individual who supports our aims. You will benefit by receiving the latest information written by our team of experts.

We're offering <u>free</u> membership to carers and former carers because we know that carers have many calls on their finances.

Join today and you'll receive:

• Our members' magazine, "Caring" and Scottish magazine "Carers", with the latest

information on caring, carers' stories and how Carers UK is making a difference.

- Helpful free telephone advice on all aspects of caring from our CarersLine experts.
- Free information booklets written by experts covering a wide range of topics from carer benefits to practical help.
- Invitations to our Members' Conference and Annual General Meeting and a ay in how Carers UK is run with a vote on electing our Trustees, the majority of whom are carers themselves and who ensure Carers UK is carer- led.

How to Join

Telephone our membership hotline on 020 7566 7602, email: <u>membership@carersuk.org</u> or join online at <u>www.carerscotland.org</u>

Affiliate Membership

We also offer membership for professionals groups and organisations. For further information contact our membership hotline or visit <u>www.carerscotland.org</u>.

Other Publications

Carers Scotland produces a range of publications for carers including factsheets and leaflets. We also publish research and good practice on, for example, carers and employment, carers and health and carers and poverty.

For more information, call Carers Scotland on 0141 445 3070. Many of our leaflets, reports and factsheets are also available online at www.carerscotland.org

Carers Scotland The Cottage 21 Pearce Street Glasgow G51 3UT Tel: 0141 445 3070 Fax: 0141 445 3096 E: info@carerscotland.org W: www.carerscotland.org

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