



Community care and assessments

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Much of the care given in the community is provided by family members, partners and friends. This information sheet aims to show people with dementia and their carers how they can have their needs for community care assessed and have services put in place to help them. It replaces the May 1998 information sheet entitled "Community care - a guide for carers of people with dementia".

What is Community Care?

Community care is about providing suitable services that help people to be as independent as possible, and to have as good a quality of life as possible, for as long as possible. In the past, many people with dementia were cared for in hospital or in care homes but community care services have developed over the last 20 years and more people with very high levels of need are now being supported at home. The government's ongoing community care policy means that more people should have the choice of receiving services so that they can live as independently as possible in their own house or in a care home if they can no longer cope or no longer wish to stay at home.

Community care is a major priority of the Scottish Parliament. It aims to provide support and services for people with physical and/or mental health problems who are living

at home or in a care home. These services can include:

- personal care - (now provided free of charge for those over 65 years who are assessed as needing it, for instance help with washing and dressing)
- help at home with housework, shopping
- short breaks/respite care
- home adaptations; including disabled aids and equipment
- meals
- alarm systems to get help
- information about local services
- day care
- transport to and from day care
- advocacy services
- befriending services
- holidays.

Some of these services may have to be paid for. The section, **How do you pay for services?** explains how the financial assessment works and how much the person with dementia may have to pay towards the services.

Local authorities or councils have traditionally held the lead responsibility for assessing local need and for providing and co-ordinating services, through their social work departments. However, services can be provided by, and commissioned from, different organisations such as: housing associations, health authorities, voluntary sector agencies (for example Alzheimer Scotland) and private service providers.

The Community Care and Health (Scotland) Act 2002 introduced a number of important reforms. The Act extended the range of duties placed on local authorities and assigned new powers to local authorities and NHS Scotland. Reforms included:

- free nursing and personal care for those over the age of 65
- expanded local joint working between local authorities and NHS Scotland
- widening access to direct payments for home care services

- extending the right to assessment for informal carers, including young carers, and ensuring that they are made aware of that right
- enabling the contribution and views of carers, as well as the person they care for, to be taken into account by local authorities before deciding which services to provide.

See later section on **Free personal care** for a full list of what this covers. A Direct Payment is money given to an individual, by the local authority, to pay for community care services that they have been assessed as needing. For more information, see the Alzheimer Scotland information sheet **Direct Payments**.

Dementia is different

Over 36,000 of Scotland's 61,000 people with a diagnosis of dementia live at home; possibly two-thirds of whom have moderate to severe dementia. About 29,000 unpaid carers, usually family and friends, provide substantial care to someone with dementia at home. People with dementia and those who care for them will need a range of support, information and services throughout the illness. Dementia has a profound effect on the psychological, physical, social and financial well-being of a person.

Although there are common symptoms, the impact of dementia is different, depending on the course of the illness and the ability of each individual to cope. Supporting and caring for someone with dementia involves understanding and meeting their complicated and changing needs. This includes:

- emotional support
- help with decision-making
- help with day-to-day activities
- coping with risks
- behaviour and personality changes
- intimate personal care.

People with dementia often have additional health care needs, especially those who are very elderly. Health and community care

services are a source of help and support for people with dementia and their carers.

How to get community care services

Assessments for people with dementia

To access services, including free personal care, it is necessary to have an assessment of need. To arrange an assessment, contact the local authority Social Work Department or ask the family doctor or GP to make a referral for you. An assessment can be requested by the person with dementia, a carer or family member. The **Further Information** section at the end of this sheet details how to contact the local Social Work Department. If you are looking after someone with dementia, you also have a right to an assessment of your own needs in relation to your caring role. For further details, see the section **Carers' assessments**.

What is an assessment and why have one?

The aim of an assessment is first of all to identify what your needs are and then to look at what support and services will meet these needs. The assessment should be 'person centred' and should focus on what is important to you and how your quality of life can be improved. Your carer should also be consulted, so that his or her needs are taken into account. See the section on **Carers' Assessments**.

Single shared assessment

Single shared assessment means that a person who needs community care services no longer has to have several assessments from different agencies such as social work and the NHS. This assessment process:

- seeks information once
- has a lead professional who co-ordinates documents and shares appropriate information
- co-ordinates all contributions
- produces a single summary assessment of need.

There are different types of assessments. They include simple assessment, comprehensive assessment, specialist assessment, and self-assessment. A full description of these different types is beyond the scope of this information sheet but the type of assessment should be appropriate to the perceived needs of the individual. Usually, the assessment is carried out by a social worker, health or housing professional. Once the assessment is completed, the assessor, often the social worker, will discuss what services are needed and draw up a **care plan**. The care plan is the package of care put together from the information gathered during the assessment. It sets out decisions about the individual's agreed care needs, the desired outcome and what is going to be done, by whom and when. With your permission, or your representative's permission, the assessor will share information with other appropriate agencies to co-ordinate the provision of support and services.

Informed consent

Informed consent must be given before the information is shared and you should have access to a copy of the assessment and care plan. Agencies should always obtain the informed consent of the person who needs the assessment. The Adults with Incapacity (Scotland) Act 2000 states that, where an individual is apparently unable to give proper consent, for whatever reason, every attempt should be made to establish the person's views on their past and present circumstances and on any proposed action arising from the assessment. The person's interests should always be safeguarded through the involvement of a legal representative, specialist worker, a carer or advocate.

If services are needed urgently

Once a community care assessment has been requested, the appropriate professional will make an appointment to visit and discuss what services and support are needed. There is usually a waiting list for assessments in most areas, so it could take a few weeks before you are assessed. If help is needed

immediately, services can be organised before a full assessment is carried out. Contact the local authority Social Work Department office or community care team to organise this. It is also a good idea to put this request in writing to follow up your telephone request.

Before the assessment

Before meeting the assessor to discuss care needs, think about what support you would like and what you would like to do. It often helps to write everything down. Talk to family and friends who help out or visit regularly and discuss with them what services and support would help. Some people find it useful to keep a diary for a week before the assessment, noting what they do each day, how long it takes, and what help they already get. Remember to include things that happen on a monthly as well as on a daily/weekly basis. Also think about what you would like to be able to do if you had extra help and support. The Social Work Department may not be able to offer assistance with all the tasks and areas of help identified, but the assessment will help to ensure nothing is overlooked. The assessment should not just look at practical help that may be needed but should also take into account any cultural, dietary or religious needs and help with maintaining a social life.

During the assessment for the person with dementia

When the assessor carries out the assessment, it is a good idea to have a family member or friend with you to provide support and help. If you have a carer, they should also be involved in the assessment, as their views and needs in relation to their caring role should be taken into account. During the assessment, the social worker, or relevant specialist, will ask questions about: how you are coping with the day-to-day routines, what tasks you find difficult and what help you would like to enable you to do the things you would like to do.

Explain what your needs are and what services you think would help. If you need more information on services or advice on what services to ask for, discuss this at the assessment. The more information you can give to the assessor, the more likely you are to receive the services and support which suit your needs and your carer's needs properly.

Financial assessment

Some services identified through the assessment may be available free but there will be a charge for other services. The care plan should set out which services are free and which are charged for. The amount to be paid will depend on an assessment of your finances. See the section **How do you pay for services?** for more information on financial assessment.

After the assessment

Once the assessment is completed, the social worker will decide which services would help and are available and should be put in place to help you. The information about what services are needed should be set out in a care plan. The care plan should include:

- the decisions made about your care needs
- what services will be needed
- how these services are to be organised
- by whom
- and when.

The care plan should accurately reflect your needs. Check it carefully and perhaps ask someone who knows your needs to look at it too. You can ask for a review of the care plan and meet with the social worker to discuss it again. Do not feel you have to accept the services offered if you do not think they are appropriate or you do not want them.

Even though you have been assessed as having particular needs and services, the relevant agency, for example the Social Work Department, does not have to provide all of these services unless they have a duty to do so. The Chronically Sick and Disabled Persons Act 1970 requires local authorities to make

arrangements for the provision of certain services to individual chronically sick and disabled people resident in their area. These services are:

- provision of practical assistance within the home
- provision of disability aids and equipment
- assistance with adaptations to the home
- provision of meals at home or elsewhere
- provision of, or assistance in, getting a telephone or any special equipment needed to use a telephone
- provision of holidays
- provision of, or assistance with, taking advantage of education or recreational facilities both inside and outside the home. This includes provision of, or assistance with, transport to and from such facilities.

You have a right to certain services and if you are not happy with the services being offered, request another meeting. You can ask your carer or someone who knows your situation to go to the meeting with you to discuss the services you feel you need.

Reviews

Regular reviews to discuss ongoing and changing care needs are essential, as dementia is a progressive illness and, over time, different support and services will be needed. The social worker should set a date for a review within the care plan. You and your carer should be given a copy of the care plan with the date of the next review and who will do it.

What if I'm not happy with the assessment or the care plan?

If you do not agree with the assessment or are not happy with any of the services being offered, you should discuss the problems with the person who has been co-ordinating the assessment and negotiate any changes you may need. If you feel that you are still not getting a satisfactory explanation or the changes you need, you can make a formal complaint. Telephone the local authority Social Work Department and ask for information on

how to make a complaint. Every Social Work Department will have a leaflet and information on how to make a complaint. This can include complaining where the local authority has not assessed you as needing a service that you believe you need, as well as complaining about the service it offers.

If you are still not satisfied after making a formal complaint, you can approach the Scottish Public Services Ombudsman and/or the Mental Welfare Commission or ultimately appeal through the courts. Contact the **Dementia Helpline (0808 808 3000)** or see www.alzscot.org for a free information sheet on **Complaints**.

Who can make decisions for me when I no longer can?

The best way of making sure that you can choose who will take decisions about your future care and make decisions on your behalf is to appoint someone you trust as your **welfare power of attorney**. This can only be done while you have the capacity to make these appointments. The person who is appointed the **welfare attorney** can be given powers to:

- decide on care arrangements
- make decisions about clothes, personal appearance, diet, leisure activities or holidays
- decide where you should live
- have access to confidential or personal information such as health records
- consent to medical treatment
- bring or defend legal actions to do with your welfare
- organise direct payments.

You can also make an **advance statement** (sometimes called an advance directive or living will), which will detail what medical treatments you would prefer or want to refuse in the future. Contact the **Dementia Helpline (0808 808 3000)** or see www.alzscot.org for a free copy of **Dementia - Money and Legal Matters, A Guide**, which describes how to create a power of attorney,

make a living will or advance directive and organise arrangements for the future.

Carers' assessments

Under the terms of the Community Care and Health (Scotland) Act 2002, every carer has a right to an **independent** carer's assessment. Previously, carers only had the right to be assessed at the same time as the person they care for but the Act gave carers the right to be assessed independently, even if the person they care for refuses an assessment. The Act states that carers must be seen as 'partners' in the provision of care, rather than as 'clients' in need of services. This means that the Social Work Department or other relevant agencies **must** take into account what help carers need, so that carers can continue caring for the person with dementia without harming their own physical or emotional health. Usually carers will be assessed when the person they care for is assessed. The social worker or appointed care manager will carry out a single shared assessment looking at both the needs of the person with dementia and the carer. This will mean that the carer's needs are taken into account when the social worker looks at what support the person with dementia needs.

You are entitled to an assessment if you are a carer, or expect to be in the near future, providing substantial and regular care (which is more than likely if you are caring for someone with dementia), either living with or apart from the person. There is no legal definition of what is 'substantial' or 'regular' care and it is up to each local authority to interpret these terms in relation to individual cases.

Early access to advice, support and services allows carers to plan for the future and cope with their caring role without damaging their own health. As the carer of a person with dementia, you may need help, whether it is for information, services or emotional support. If you are unwell, tired, need a rest, or if you need someone to listen to you and advise on

how to cope, or you just need some time to yourself, contact your Social Work Department or GP and ask for an assessment.

Alzheimer Scotland has produced a booklet to help carers cope with their caring role. Contact the **Dementia Helpline (0800 808 3000)** for a free copy of *Looking after yourself*.

What is the assessment for?

As a carer, you will, along with the person you care for, have varied and changing needs. The Social Work Department will need to look at all the different aspects of your caring role to understand what your needs are and, from this, provide relevant services to help you cope with your caring role. The assessment should allow the assessor to:

- identify what care you already provide and ask what you think about your caring role, so that your views can be taken into account before the Social Work Department and its partner agencies decide what package of care to provide to the person with dementia.
- find out what level of care you are willing and able to provide, and discuss whether you think you will be able to continue caring
- look at what services you need to support you in your caring role, and decide how these services can best be provided
- look at what help you need to maintain your own health and well-being, and decide how to provide this support.

Once you have been assessed, the type of services that might be offered are:

- short breaks/respite care for the person you care for
- information and educational courses on aspects of your caring role you find difficult
- information on local carers' support groups
- day care for the person you care for
- companion service in your own home so you can go out
- home support to help with work in the house

- equipment and adaptations.

Unfortunately, a carer's assessment does not guarantee services but local authorities must take the results of the assessment into account when deciding what services could support you and the person you care for.

If you are assessed as needing services to help you continue caring for the person with dementia, you should not be charged for them. The guidance notes from the Scottish Executive say that local authorities should not charge carers for support or resources which are provided to help carers sustain their caring role (Scottish Executive 2003). The guidance notes also say that local authorities must consider how the carer will be affected if the person with dementia is charged for the services. See the section called **How do you pay for services?** for more information on charges and financial assessment. Once the financial assessment has been carried out, check it carefully and, if you feel it will have a negative effect on how you can manage your income, speak to the local authority Social Work Department and ask for a review.

There may be other benefits you and the person you care for are entitled to. You can also contact the **Dementia Helpline** for advice or contact the Alzheimer Scotland Welfare Benefits Office on **0141 204 5908** for more information on benefits or your local Citizens Advice Bureau (number and address in the phone book).

What you need to think about before the carer's assessment

The carer's assessment should include looking at your other commitments such as your job, family commitments, if you have young children, your physical, emotional and mental health. Being prepared before the assessment will help you remember all the aspects of your caring role you need to discuss. Write down what you do each day, and which things you find difficult - such as bathing the person you care for or getting them up in the morning.

Think about what services and support would make your life easier and discuss this in the assessment.

Once you have requested an assessment, it should be carried out within a reasonable time. If there is an urgent need for services, contact the Social Work Department immediately and they should provide the necessary services as soon as possible. A full assessment can be done later.

Record of the carer assessment

The Social Work Department should inform you of the outcome of your assessment. They should also give you a written record of the final assessment. If you need to discuss the results, contact the person who carried out the assessment.

The information from the assessment should cover:

- all the needs identified during the assessment, which can either be on the care plan of the person you care for, if you and the person you care for agree to this, or separately on the carer's assessment form
- the level and type of care provided by you - this will enable the social worker to review your role regularly and identify new needs
- any decisions about giving consent or refusing consent and sharing information
- the resources or other services provided, including care provided by you and any needs that are not met by these services.

What if the person you care for refuses an assessment?

As the carer, you do not need to have an assessment at the same time as the person you care for. You are entitled to an assessment even if the person you care for refuses an assessment or refuses to accept services. The social worker will be able to look at what care you are providing and decide if you are eligible for an assessment. They will also look at whether the person you care for is

eligible for community care, and should approach them to see if they would agree to an assessment.

If the person you care for refuses services, they cannot be forced to take them. If necessary, counselling, advocacy and mediation services can be provided to try to help you and the person you care for come to an understanding about what services are needed. Discuss the problems you and the person with dementia are having and see if there is a way to work out how to provide services which may enable the person with dementia to accept the services more readily; for example, using a more gradual approach, such as introducing new services by having short trial periods. The carer could go with the person with dementia to the day care centre until he or she becomes used to the staff and the surroundings. If the person you care for is experiencing difficulty and seems to be unhappy at the centre, try to work out with him/her what the problem might be and ask staff to help suggest a solution.

If the person with dementia is assessed as lacking the capacity to give informed consent and refuses services, it will be necessary to apply for an intervention order or a guardianship order so that essential services are provided for the benefit of the person. You can ask to be seen separately to discuss your needs and views without the person you care for being present.

How do you pay for services?

Each of the 32 local authorities in Scotland has a different charging policy for services, so charges can vary depending on where you live. You, the person with dementia, may need to pay towards some of the services. Your carer should not have to pay for services he or she is assessed as needing, as these services are to help care for you. The amount you will be asked to contribute should depend on what you can afford, taking into account your income and what you need to meet everyday costs and any extra costs because of

disability. The Social Work Department will make a contribution for people on lower incomes.

The care plan should include information about which services you will be asked to pay for. The Social Work Department will work out the level of payments you will have to make for services, such as day care or lunch clubs. If you are over 65 years, you will not have to contribute towards personal care services, (see next section for more information on personal care services).

Financial assessment

The financial assessment should only be carried out after the assessment of your needs and should not influence the package of care that is offered. In most cases, your contribution will be assessed based on your income and capital in the form of savings, shares and investments. The value of your house is not included in the calculations if you live at home. The income threshold beyond which you will be asked to make a financial contribution can be different in each local authority area, so ask for these details when the financial assessment is being carried out. Also ask for a review of the financial assessment should your income levels change or when you turn 65, as you will then be entitled to free personal care.

The Social Work Department will be able to tell you exactly how the financial assessment has been worked out and you will be able to appeal if you think the assessment is unfair or inaccurate.

If you refuse to pay

If the Social Work Department has agreed to provide a service, they cannot withdraw it just because you refuse to pay. But, if you do not pay, you will run up a debt and the Social Work Department may go to court to try to recover the money. Seek advice if this happens.

Contributions from spouses

Some local authorities may ask your husband or wife to contribute towards the cost of respite care or short breaks, especially when regular breaks are planned. This is because married couples are legally obliged to maintain one another. But local authorities do not have the power to ask a carer about his or her financial circumstances. If a carer is asked to contribute, he or she can agree to pay if the amount is thought to be reasonable. If the carer refuses to pay, the local authority would have to consider whether it was worth going to court to set an amount of maintenance. They cannot refuse or withdraw a service because the carer won't pay.

The authority to treat a married person as liable to maintain their spouse comes from Section 42 of the National Assistance Act 1948. The new Pension Credit ended this rule for people over 60 but only for Social Security. It still remains for care charges. However, the Department of Health has announced that it intends to remove this rule from English care charging at the earliest legislative opportunity. Following consultation, the Scottish Executive has announced that it plans also to repeal Section 42 at the earliest legislative opportunity. In the meantime, the Executive is encouraging Local Authorities to use their discretion not to apply the rule. Seek advice if your Local Authority applies this rule.

Free personal care

The new free personal and nursing care arrangements in Scotland came into effect on 1 July 2002 under the Community Care and Health (Scotland) Act 2002. **Personal care** is provided free for people **over 65**, provided they are assessed as needing it. Personal care is free both for older people living in their own home and for those living in care homes.

What counts as personal care?

Personal care includes help with:

- personal assistance - help with dressing, surgical appliances, getting up and going to bed, using a hoist

- personal hygiene - bathing, washing hair, shaving, oral hygiene, nail care
- continence management - toileting, catheter/stoma care, skin care, extra laundry, bed changing
- food and diet - help with eating, special diets, meal services, preparing specialist meals such as pureed food
- problems of immobility as they affect personal care, and help with moving about indoors
- behaviour management and psychological support, including reminding and safety devices
- simple treatments - help with eye drops, creams and lotions, simple dressings, oxygen therapy.

People **over 65** who need personal care services will be assessed by the Social Work Department, and any personal care services provided will be free of charge. People whose situation changes can be reassessed to see if they need a different package of care. As in the past, local authorities will prioritise providing any services people are assessed as needing, on the basis of their care needs. People over 65 leaving hospital are entitled to up to 4 weeks of free home care which includes both personal and non-personal care.

Other services

Social work departments still charge for other, non-personal, care services, such as day care, lunch clubs, meals on wheels and community alarms. Eligibility for and payment of Attendance Allowance and Disability Living Allowance **for people living at home** is not affected by the introduction of free personal care.

Respite and other short-term arrangements

For people over 65, the Social Work Department will pay towards the personal and nursing care element of a respite break in a care home, or other short-term arrangements such as emergency help if a carer is ill, or a trial stay in a home. For those under 65, the

Social Work Department will pay towards the nursing cost of a stay in a care home. The Social Work Department will decide how much they will pay based on their records or the home's records about the individual. They may still charge for the 'board and lodgings' element.

Direct payments

What is a direct payment?

A direct payment is money paid by the Social Work Department directly to a person assessed as needing community care services, so that they can buy in services. For a person with dementia it will be necessary, especially in the middle to later stages of the illness, to have someone who has power of attorney, or a guardian, with the relevant powers to make arrangements on his or her behalf. Full details on how direct payments work can be seen in the Alzheimer Scotland information sheet – **Direct Payments** – call the **Dementia Helpline (0808 808 3000)** for a free copy or see www.alzscot.org

Further information

How to contact your local Social Work Department

Details of your local Social Work Department will be in the phone book; or ask at your doctor's surgery, Citizen's Advice Bureau or local library for contact numbers.

Website with all local authorities and Social Work Department contact details:
www.ukonline.gov.uk

Local service guides detailing all relevant contact numbers are available for some areas in Scotland – freephone **Dementia Helpline (0808 808 3000)** for a free copy or look at the website: www.alzscot.org

Publications

Carers, Community Care and Health (Scotland) Act 2002. Guidance on sections 8 – 12. Scottish Executive Circular CCD 2/2003.

This publication will help carers understand the new legislative rights for carers, and how the Scottish Executive has advised statutory agencies to implement them. Available from: Community Care Division 1, St Andrews House, Regent Road, Edinburgh, EH1 3DG. Tel: 0131 244 5455

The full guidance from the Scottish Executive Health Department (Circular no. CCD 4/2002) *Free personal and nursing care in Scotland* is available at www.scotland.gov.uk/about/HD/CCD1/00017655/guidance.pdf or from: Community Care Division 1, St Andrews House, Regent Road, Edinburgh, EH1 3DG. Tel: 0131 244 2456

Helplines

Direct Payments Scotland helpline for information on direct payments or support organisations in your area. **Helpline: 0131 558 3450** (open Tuesday and Wednesday 10am – 12pm, and Thursday 2-4pm). Address: Direct Payments Scotland, 27 Beaverhall Road, Edinburgh, EH7 4JE. email: info@dpscotland.org.uk; website: www.dpscotland.org.uk/

Alzheimer Scotland - call the freephone **Dementia Helpline (0808 808 3000)** for support and information on any aspect of dementia day or night, or see information on website: www.alzscot.org or contact your local Alzheimer Scotland service.

NHS Helpline - freephone: **0800 22 44 88** (The line is open from 8am to 10pm, seven days a week). The NHS Helpline provides information on: Scottish health services, health matters and social care services in your area.

Other support for carers

Carers Scotland, 91 Mitchell Street, Glasgow, G1 3LN. Tel: 0141 221 9141
www.carersonline.org.uk/

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Reference

Scottish Executive Circular No. CCD 2/2003. Community Care and Health (Scotland) Act 2002. New Statutory Rights for Carers: Guidance. www.show.scot.nhs.uk/sehd/publications/CC2003_02full.pdf

Available from: Community Care Division 1, St Andrews House, Regent Road, Edinburgh, EH1 3DG. Tel: 0131 244 5455



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