Many people diagnosed with dementia will reach a stage where they need professional care and support at home to help them live well with the condition. Friends and family who care for a person with dementia who is living at home may also need support to carry out this role.

Social care can take a number of different forms, depending on the needs of the person in question. Examples include day care centres, replacement care (sometimes called respite care or short breaks) and personal care (such as help with bathing or going to the toilet) at home. This factsheet outlines how people with dementia and their carers can access care and support at home, including day centres or short breaks.

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Assessment for care and support in England

Some people with dementia and their carers will be entitled (often called ‘eligible’) to have their needs for care and support met by the local authority, free of charge or at a reduced cost. They must meet certain criteria to be eligible. Anyone wishing to get care and support paid for by the local authority must have a care needs assessment (for a person with dementia), or a carer’s assessment (for a carer).

This factsheet is for people living in England and is not intended for Wales and Northern Ireland, where the laws are different. For information about the laws in Wales see factsheet W418, Assessment for care and support in Wales; and for Northern Ireland see factsheet NI418, Community care assessment.

Support for people with dementia: the care needs assessment

A local authority (also known as local council) has a duty to assess the care needs of a person with dementia. The assessment will determine what care needs they have, and whether the local authority will contribute towards meeting them. Any person has a right to this assessment, even if they will end up paying for their own care.

The process is called a ‘care needs assessment’. The aim is to work out exactly what the person’s needs are, and the level and type of care and support required to meet these needs. It will also help the local authority to decide whether or not someone is eligible for care and support funded by the council. Even if the person is not eligible, the care needs assessment may still be useful, as it might provide valuable information on the kind of care and support that is required, and which can be accessed through other options. A local authority cannot refuse to carry out an assessment because they think the person will not be eligible for funded care and support.
For more information about paying for care see ‘Financial assessments’ below, or factsheet 532, Paying for care and support in England.

Getting a care needs assessment
There are a number of ways someone can get an assessment. The person needing the assessment can request it themselves via their local authority’s social services department (this may be called different things in different areas, such as Adult services). To find out how to contact your local authority, see ‘Other useful organisations’. Alternatively, contact details should be on a Council tax bill or available at the GP surgery or local library. There are other people who can arrange the assessment on behalf of the person:

- The person’s GP, consultant or another health or social care professional can make a referral to the local authority.
- A carer or relative can contact the local authority asking for an assessment.
- If the person is in hospital, a hospital social worker can make the referral.

If the assessment is requested on behalf of someone, the person making the referral must get the individual’s consent before contacting the local authority. Some people with dementia may lack the ability (mental capacity) to give this consent. For more information on this see factsheet 460, Mental Capacity Act 2005.
What to expect
A care needs assessment will usually involve a series of questions, often in the form of a discussion, which the person should be given in advance. They are designed to find out:

- the person’s present arrangements for living and care
- the person’s health and disabilities, and what they can and cannot do
- the person’s concerns and thoughts, and how they would like to be supported
- the concerns and thoughts of any carers.

Not all assessments are done face to face. It may be done through a self-assessment form: a questionnaire for the person to complete themselves. (This may also be done before a face-to-face assessment.) People with dementia can be assisted, for example by a social worker at home, when filling in self-assessment questionnaires, to ensure that all their needs are considered. Some local charities may also help with this.

Some local authorities may carry out phone assessments, but this is only appropriate when the person’s needs are not complex, or where the person is already known to the local authority and the assessment is a result of a change in needs. As people with dementia often have more complex needs, telephone assessments are generally not appropriate, and should not be used as the only method of assessing care needs.

Where the assessment takes place
A face-to-face assessment usually takes place in the person’s home. This gives a clearer picture of the care and support they need. If the assessment is arranged elsewhere, it should be somewhere convenient for the person and their carer.

Who carries out the assessment?
The local authority adult services department will carry out most assessments. This will normally be by a social worker. They may organise for other professionals to be involved if this is needed, for example the person’s doctor or a nurse.
The care needs assessment: tips for people with dementia
If you have dementia and are having a care needs assessment, there are a few things you can do to prepare, and things to do during the assessment. These suggestions will also be useful for someone caring for a person with dementia who is about to have an assessment.

Preparing for the assessment
- Look through the assessment questions you should have been given in advance and think about your answers. For example, you may be asked about what support you feel you need.
- Make notes outlining what needs you have, and what care and support you would like.
- Start a diary outlining what daily tasks you need support with.
- Consider what care and support you might need in the future as your condition progresses (this can include equipment).
- Collect any other supporting evidence. For example, the GP or other health or social care professionals may have a reason to comment on any medical needs that you have.
- Make a list of any medication you are taking and for what conditions.
- Make sure any carers or relatives that you wish to be present at the assessment are available.

During the assessment
- Be honest. Some people feel they need to hide their condition and the problems they are having from professionals. However, the purpose of the assessment is to see how your needs can be met, so it’s important that you are honest and get the most from the assessment.
- Outline the support you currently get from carers and family. This is important: even if your family will continue to do this for you, your care plan should cover what would happen if they could no longer provide this support.
Share your wishes and desired outcomes – what you want, for example to feel safer or to have more activity. If you (or your carer) have an idea of what care and support you would like, you should share this in the assessment. It doesn’t necessarily mean you will get it, but the assessment should consider what support you and your carer would like. As well as practical care, you should also think about equipment and other items.

Eligibility for support from the local authority
Once an assessment has been completed, the local authority will establish whether or not they will fund care and support for the person. In working this out, they will consider whether or not the person has what is called an ‘eligible care need’, and also their financial situation. For more information on the financial assessment see factsheet 532, Paying for care and support in England.

An eligible care need is the level of need that a person must have for the local authority to consider funding it. There are national eligibility criteria that apply across England; these are summarised below and on the following page.

Eligibility criteria
This box summarises the three main criteria (conditions) that someone must meet to be eligible for local authority funded care or support.

1. The person’s needs are due to a physical or mental impairment or illness (this includes dementia).

2. Due to the person’s dementia (or other illness) the person is unable to do any two of the items listed; or if they don’t have assistance will put themselves in pain, distress, anxiety or danger (or someone else in danger); or it takes significantly longer without assistance to:

   a) manage and maintain their nutrition – eg have access to food and drink and be able to prepare and eat or drink it
b) maintain their personal hygiene – eg be able to wash themselves and wash their own clothes

c) manage their own toilet needs – eg be able to access and use the toilet

d) be appropriately clothed – eg be able to dress themselves appropriately for the weather or to maintain health

e) safely make use of their home – eg move around (including steps and stairs), access the bathroom, use the kitchen safely and access the property safely

f) maintain a habitable home environment – eg be able to sufficiently clean their home and maintain amenities such as water, electricity and gas

g) develop and maintain family or other personal relationships – eg avoiding becoming isolated

h) access and engage in work, training, education or volunteering – eg be able to partake in these activities, taking into account physical access and support to participate

i) make use of necessary facilities or services in the local community including public transport and recreational facilities and services – eg public transport, shops or other services

j) carry out any caring responsibilities they may have.

3. Due to not being able to do at least two of the above there is, or is likely to be, a significant impact on the person’s wellbeing.

If someone is told that they do not have eligible care needs and they believe they do, they will need to put in a complaint (see ‘Complaints’ on page 18). They should outline why they believe their needs do meet the criteria.
Support for carers: carers’ assessments

Anyone who cares for a person with dementia is also entitled to an assessment of their needs as a carer. This is called a carer’s assessment. The aim is to work out exactly what the carer’s needs are, and the level and type of support required to meet these needs.

If the carer fulfils certain eligibility criteria, the local authority will pay for these needs to be met. Again, even if a carer is self-funding (paying for their own care), a carer’s assessment can help to work out what care and support they might need, and the local authority should not refuse to carry out a carer’s assessment because they think the carer will not be eligible for funded support.

Often a carer’s assessment is done at the same time as a care needs assessment for the person with dementia. This can be helpful, as the support needs for a carer might be best met by services that are actually provided to the person they care for. For example, replacement (respite) care or short breaks may be provided to the person with dementia and this enables the carer to have a break (and the person with dementia to have a break from their carer). Carers are entitled to a carer’s assessment even if the person with dementia refuses an assessment, or does not want care or support.
Accessing a carer’s assessment
A carer can request a carer’s assessment directly from their local authority’s social services department. There are other ways this may be arranged:

- as part of a care needs assessment for the person they care for
- a referral from a health or social care professional
- a referral from a relative.

If someone makes the referral for a carer, they must seek the carer’s consent. For a carer’s assessment to be carried out, the carer must agree to it.

What to expect
What to expect from a carer’s assessment may depend upon how it has been arranged. For example, if it is carried out at the same time as a care needs assessment, it is likely to be in the home of the person getting the care needs assessment – the two assessments will be linked. Alternatively, the carer’s assessment may be separate from the care needs assessment of the person with dementia, or the person with dementia may not be having an assessment themselves. In this case the assessment should take place somewhere that is convenient for the carer, for example in their own home. They should be given the list of assessment questions in advance; this can help carers to prepare.

The assessment will usually be carried out by a social worker. It may involve other health professionals, such as a GP if appropriate, but the social worker will arrange this if it is needed. It usually involves a series of questions. The carer will have the opportunity to outline the care and support they provide, and also what help and support they themselves would like. This information may be gathered through a self-assessment form.
Preparing for a carer’s assessment: tips for carers

If you are caring for a person with dementia and you are preparing for a carer’s assessment, there are a number of things you can do to help you prepare:

- Look over the assessment questions, which you should be given in advance, and think about or write down your answers.
- Write a list of the care and support that you provide to the person, including when, where and for how long. Include any time that you might spend checking that things are ok or being ‘on call’ in case of problems or because you are worried.
- Keep a diary for a few weeks detailing all the tasks that you do to support the person – include things that are involved in this, such as making several bus journeys across town or having to do a daily shop. Make a note of how your caring role may be difficult at times – possibly making you feel depressed or tearful.
- Take note of the things that you are unable to do as a result of caring, for example cleaning your home, childcare responsibilities, work or education, or even maintaining social activities.
- Think about and list what support would help you in your role. This may be care for the person you care for so you can have a break, or it could be some specific help for you, such as training or having some equipment, such as a tumble dryer, or items such as driving lessons so you would no longer need to use public transport.
- Think about what support you may need in the future as the person’s condition progresses.
During a carer’s assessment: tips for carers

- Be open and honest. This may be difficult, but for the assessment to work the person carrying out the assessment needs to understand your situation.
- If necessary, ask to speak to the assessor without the person you care for being present.
- Tell the assessor what outcome you would like from the assessment, for example you would like to know that the person you care for is clean and comfortable when you are not there.

Eligible care needs

Local authorities will only provide care and support to carers who meet certain eligibility and financial criteria. They can only consider this once the assessment has been concluded. For more information see ‘Financial assessments’ below, or factsheet 532, Paying for care and support in England.

An eligible care need is the level of need that a carer must have for the local authority to be responsible for that care, and therefore fund it. As with needs assessments, there are now national eligibility criteria that show the level of support required for a carer to be eligible. These are summarised in the box on page 13.

If a carer is told that they are not eligible as they do not meet these criteria, but they feel that they do, they will need to put in a complaint (see ‘Complaints’ on page 18). They should outline why they believe their needs do meet the criteria.
Financial assessments

Not everyone will be eligible to have care or support paid for by their local authority. This eligibility is determined through a financial assessment of the person receiving the care or support.

Unlike with assessing needs eligibility, the procedures for charging for care in the person’s own home, the time it takes to assess whether someone has to pay, and the amounts charged, all vary between local authorities. Charges should always be ‘reasonable’. Government guidance sets out a broad framework for local authorities to follow, so that people can afford to receive services.

The local authority will calculate the cost of the services to be provided (such as home care, frozen meals, transport or a person who is providing care who is directly employed by the person or the carer) and then financially assess the person using the local authority’s own charging policy. From this they will work out how much the person should contribute to the cost of these services. The local authority must provide a breakdown of how they worked out the charge.

If the person with dementia or their carer thinks the charge for community care services is unreasonable, or if the person with dementia is unable or unwilling to pay, they should ask the local authority whether it can reduce or waive the charge. A service cannot be discontinued simply because a person is unable to pay. However, a local authority can take the matter to court to recover the payment from the person.

If the person with dementia needs to move into a care home, the local authority will assess the person’s income and savings according to national rules. For further information see factsheet 532, Paying for care and support in England.
Carer’s eligibility criteria:

This box summarises the three main criteria that a carer must meet to be eligible for funded support.

1. The carer’s needs arise due to providing necessary care.

2. The effect of the carer’s needs result in either: the carer’s physical or mental health deteriorating (or being at risk of deteriorating); the carer is unable to achieve any of the following without assistance or where this causes pain, distress and anxiety, or they are putting themselves or others in danger:

   a) carry out caring responsibilities the carer has for a child
   b) provide care to other persons they provide care to
   c) maintain a habitual home environment – be able to keep their home safe and in an appropriate way to live and have essential amenities such as gas and water
   d) manage and maintain their own nutrition – have time to go shopping and prepare meals for themselves and their family
   e) develop and maintain family or other significant relationships
   f) engage in work, training, education or volunteering – be able to continue in their job or get a job; if not, be able to partake in education or volunteering (if they wish)
   g) make use of necessary facilities or services in the local community – have the opportunity to use local services, such as going to the gym or swimming pool
   h) engage in recreational activities – have leisure time, for example some free time to read a book, or engage in a hobby.

3. Due to the effect of the above there is, or is likely to be, a significant impact on the carer’s wellbeing.
Getting support
Once an assessment has been carried out, the next step is to organise the care and support.

Care and support plans
The outcome of both a care needs assessment and a carer’s assessment is a care and support plan. This states the care and support needs, and also outlines how these needs can be met. For example, it may show that a person with dementia needs prompting and support at mealtimes, and therefore that a care worker should visit the person in their home to help them at mealtimes, or that the person with dementia might wish for this support at a local day centre.

A carer’s care and support plan may be slightly different, as it may state things needed specifically for the carer, for example manual handling and lifting training or help with having a break. A carer’s assessment may also lead to changes in the care plan of the person they care for, as sometimes a carer’s need is best met by providing services to the person they care for. An example would be respite (replacement) care, such as a sitting service, which allows the carer to have a break. Although it is there to help the carer, it is actually provided to the person with dementia and therefore forms part of their care plan.

If someone is eligible to have their care needs met by the local authority, their care plan will also mention their ‘personal budget’, and how much they have been allocated to spend on meeting their needs. For more information see ‘Personal budgets and direct payments’ below.
How care and support are arranged
The main ways that care and support, including items and equipment, can be arranged are as follows:

- The local authority provides the support directly.
- The local authority arranges for a care provider, such as a home care agency to deliver the care.
- The local authority makes a direct payment to the person or their carer to purchase their own care and support.
- There may be a combination of the above.

In the past, local authorities would simply have arranged services for people who were eligible. This is still possible, but nowadays they encourage people to choose and organise their own care through a personal budget. For more information see ‘Personal budgets and direct payments’ below.

The local authority must provide a person with information about where to get care and support locally. This information is available for anyone, regardless of whether they are funding their own care or not and can include advice from an occupational therapist. Local care agencies and charities may also be able to provide this information. Some of these pay for a brokerage scheme to help people find the support they want (see section on brokerage below). The Care Quality Commission lists all registered domiciliary (home) care agencies (see ‘Other useful organisations’ on page 19).

Some services, such as community nursing, are arranged through the GP, either directly or after discussion with social services.
Personal budgets and direct payments
A personal budget is the amount that the local authority calculates as being necessary to meet someone’s needs. A financial assessment will be carried out to decide how much the person will contribute to their personal budget themselves.

The person or their carer may choose to be given a ‘direct payment’ from the local authority so they can arrange services themselves. Direct payments offer more choice and flexibility when choosing services to meet care needs. Managing them can sometimes be complicated, so the local authority must be satisfied that the person is willing and able to manage a direct payment, either alone or with assistance.

If necessary, the local authority must help the person managing the direct payment to find local support services. These support services may come from voluntary or charitable organisations. For people with dementia, a family carer can be the person who manages the direct payment – this option offers the same choice and flexibility. A personal budget might also be managed through an Individual Service Fund, a user-controlled trust or a suitable person. For more information on these see factsheet 473, Personal budgets.

Brokerage service
In some parts of the country, people with dementia and their carers may be able to seek assistance from organisations that provide an independent ‘brokerage service’. These services help people to take part in and understand the care planning process, and can also get involved in various aspects of this process, including the writing of the care plan and considering what is available.

For more information see factsheet 473, Personal budgets.
Reviews

People’s circumstances change, so the services they receive should be reviewed from time to time. Local authorities do this through review meetings to see whether the needs of the person with dementia or the carer have changed. There are different routes to getting a review:

- A planned review is where the date of the review was set out in the initial care plan.
- An unplanned review is normally the result of a change in circumstances, for example a fall or hospital admission.
- A requested review is where the person, their carer or a professional (such as their GP) requests a review. This may be due to a change in care needs, or where it is felt that different support is needed.

Where someone has been given a personal budget by the local authority, there should be a review within 6–8 weeks. This will not be as extensive as the original assessment. The purpose is to ensure that the support is meeting their care needs and to check that there is no unmet need. It should also ensure that if there are problems, they are dealt with quickly.
Complaints

If the person with dementia or their carer has a complaint relating to the processes, it is best to try to resolve it with the person they have contact with, such as the assessor or social worker. There may simply have been a breakdown in communication or a misunderstanding that can be easily put right. However, if this is not successful, the local authority will have a complaints procedure that you can follow. The local authority will explain how to use this. The complaints procedure might be useful if:

- there are problems arranging an assessment
- there is an unreasonably long wait for an assessment
- the required services are not provided, or are unsatisfactory
- there is a dispute about the amount of personal budget that is allocated
- someone is told that they are not eligible and they feel that they are.

If the local authority complaints procedure does not resolve the issue, someone can take their complaint to the Local Government Ombudsman (see ‘Other useful organisations’), but it may be helpful to talk to a local advice agency first, such as the Citizens Advice or other organisations listed on page 19.
Other useful organisations

Age UK
0800 169 8787 (general enquiries)
0800 678 1602 (advice line, 8am–7pm every day)
contact@ageuk.org.uk
www.ageuk.org.uk

Provides information and advice for older people in the UK.

Care Quality Commission
03000 616161
enquiries@cqc.org.uk
www.cqc.org.uk

Regulates, inspects and reviews all adult social care services in the public, private and voluntary sectors in England.

Carers Trust
0300 772 9600
info@carers.org
www.carers.org

Works to improve support, services and recognition for anyone living with the challenges of caring for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

Carers UK
0808 808 7777 (helpline, 10am–4pm Mondays and Tuesdays)
info@carersuk.org
www.carersuk.org
www.carersuk.org/forums (online discussion forum)

Provides information and advice to carers about their rights and how to access support.
GOV.UK website
www.gov.uk
www.gov.uk/find-your-local-council (site to find your local council)

Local Government Ombudsman
0300 061 0614
advice@lgo.org.uk
www.lgo.org.uk

Independent organisation that investigates complaints about councils and care providers and looks for a resolution.

Alzheimer’s Society is the UK’s leading dementia charity. We provide information and support, improve care, fund research, and create lasting change for people affected by dementia.

Alzheimer’s Society Dementia Helpline

England, Wales and Northern Ireland:

0300 222 1122

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