Many people with dementia and their carers will need care and support as the condition progresses. Whether from a carer, family, friends or professionals, all care should help people with dementia and those supporting them to live well. The types of care put in place will be different for everyone, because everyone’s needs are different. With the right information and support, you can understand your options and make the right decisions for yourself and the person you care for.

This factsheet is written for carers, however the information is also helpful for people with dementia. It explains what care assessments are and how people with dementia and their carers can access them.

This factsheet is for people living in England, as assessment for care and support is different in Wales and Northern Ireland. For information about Wales see factsheet W418, *Assessment for care and support in Wales*, and for Northern Ireland see factsheet NI418, *Assessment for care and support in Northern Ireland*. 
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Assessment for care and support in England

People with dementia and their carers will need care and support as the condition progresses. An assessment for care tells you what needs the person has, and what needs you may have. It also shows what care and support will meet these needs.

Some people with dementia and their carers have their care and support provided and paid for by the local authority (local council). For some people the local authority may only pay some money towards their care and support. Others may have to pay for their care and support themselves.

You have to meet certain criteria (conditions) to have your needs met by the local authority. If you wish to get care and support paid for by the local authority you must have either:

- a care needs assessment and financial assessment – for a person with dementia, or
- a carer’s assessment and financial assessment – for a carer.

Asking for information and advice as soon as possible will help you to plan ahead for care and support. This will help you and the person you care for to have more time to explore options and find out what is available locally. It will also help with planning for emergencies or preparing for times when you may not be able to care for them.
Support for people with dementia: a care needs assessment

Anyone with dementia is entitled to an assessment of their needs by the local authority. This is called a care needs assessment. It should identify what the person’s needs are, and what support would meet these needs. It also helps the local authority to decide whether or not they will pay towards meeting these needs.

The local authority cannot refuse to carry out an assessment, even if they think the person will have to pay for their own support and care. The information in the assessment will be helpful, even if the local authority does not pay towards the care and support. You can use the information to discuss care and support needs with other organisations and companies such as home care agencies.

For more information about paying for care see ‘Financial assessments’ on page 17 and 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 with dementia can ask for one themselves. You can also ask your local authority’s social services department for one on their behalf. This department may be called different things in different areas – for example, ‘adult services’. You can find their contact details:

- on a Council tax bill
- online
- at the GP surgery
- at the local library.
Other people can also arrange the assessment on behalf of the person, such as:

- the person’s GP, consultant or another health or social care professional such as an occupational therapist
- a carer or relative
- a hospital social worker (if the person is in hospital).

If you ask for an assessment on behalf of someone, you must get their consent first. Some people with dementia may lack the ability (mental capacity) to give this consent. You can still ask for an assessment, as long as it is in the person’s best interests. For more information on this see factsheet 460, *Mental Capacity Act 2005*.

**Who does the assessment?**
The local authority adult social services department will carry out most assessments. This will normally be done by a social worker or a care coordinator (they may be referred to as an assessor). They may ask for other professionals to be involved, for example the person’s doctor or a nurse.

**What to expect**
A care needs assessment will include answering questions, which should be given in advance. They will help the local authority to find out:

- where the person lives and what care they currently receive
- if the person has any health conditions, and what they can and cannot do for themselves
- the person’s views about their support, and how they would like to be supported. For example they might want to go to a day centre or have someone help them with shopping
- the carer’s views.
These questions and answers are then discussed together with those present at the assessment. However not all assessments are done face-to-face. They may be done through a self-assessment questionnaire.

**Self-assessment questionnaire**

Sometimes an assessment is done through a questionnaire which the person completes themselves. The person you care for might need help to fill out a self-assessment questionnaire. You or a social worker can help them at home, to make sure that all their needs are considered. You can ask the local authority for support if the person with dementia needs it. Some local charities may also help with this.

See ‘Other useful organisations’ on page 23.

**Telephone assessments**

Assessments can be carried out over the phone. However, this is only appropriate if the person is already known to the local authority and the assessment is a result of a change in their needs, or if their needs are not complex. People with dementia often have more complex needs, such as needs that can change on a daily basis. Therefore, telephone assessments should not be used as the only way of assessing their care needs.

If the person with dementia is offered a self-assessment questionnaire or telephone assessment, they can ask to have the assessment in person. They should explain why they need a face-to-face assessment. If a face-to-face assessment is still not offered they can make a complaint about the lack of support they are receiving in having their needs assessed. See ‘Complaints’ on page 22.

**Where the assessment takes place**

A face-to-face assessment usually takes place in the person’s home. This can help the assessor to know what care and support they need. If the assessment is arranged elsewhere, it should be somewhere convenient for the person and you, their carer.
The care needs assessment: tips

If the person with dementia is having a care needs assessment, there are some things that can help them to prepare for it. If the person has got the assessment questions it’s a good idea for them to look through them and think about their answers. If the person hasn’t been given the questions, contact the local authority and ask for a copy. It can help for the person to make notes so that they can tell the assessor what support they need.

It might seem like a lot for the person to think about, but even noting down some of the details listed below will help them to get more from the assessment. A carer can help the person prepare for an assessment and might also find these tips useful.
Preparing for the assessment

- A diary with details of what daily tasks the person needs help with can be helpful.

- What support does the person currently get from family and carers? This is important because even if the person continues to get care and support from others, the conversation should cover what would happen if they could no longer give this support.

- Is there any equipment or assistive technology that would help? For example, an automated pill dispenser, or ‘smart’ home systems that can be set up to turn off lights. For more information on assistive technology see factsheet 437, Using technology to help with everyday life.

- What care and support might the person need in the future as their condition gets worse? This can include equipment and assistive technology.

- Collect any letters from the GP or other professionals. This is called ‘supporting evidence’. For example, if the person has problems with getting about or walking, the GP might suggest ramps, grab rails, or help with shopping.

- Make a list of any medication the person is taking and what conditions they are for.

- Make sure any carers or relatives that the person would like to be at the assessment are available.

- Think about what care and support would help and share this in the assessment. It doesn’t necessarily mean the person will get it, but the assessment should consider it. As well as practical care, think about equipment and other items such as assistive technology devices.
During the assessment

- Be honest. Some people feel they need to hide the problems they are having from professionals. However, the point of the assessment is to see how the person’s needs can be met.
- Tell the assessor if there are things the person wants to do. For example:
  - be more active
  - stay living at home as long as possible
  - engage more with the community by attending social groups and events
  - have some help with shopping, going for walks or swimming.

Getting support from the local authority for people with dementia

Once a care needs assessment has been completed, the local authority will decide if it will pay for care and support for the person. They will consider whether the person has 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.

A person must have an eligible care need for the local authority to consider paying for their care and support. These care needs are organised into ‘criteria’ (conditions) which apply across England.

If the person you care for is told that they do not have eligible care needs and you believe they do, you will need to make a complaint (see ‘Complaints’ on page 22). You should explain why you think their needs do meet the criteria.
Eligibility criteria

There are three criteria (conditions) that someone must meet for the local authority to consider funding their care and support. The person will have eligible needs if:

1. They have care and support needs because they have a physical or mental condition (this includes dementia).

2. The person’s needs mean they are unable to do at least two of the following:
   - Manage and maintain nutrition – for example, buying and preparing food and eating and drinking.
   - Maintain personal hygiene – for example, washing themselves and their clothes.
   - Manage toilet needs – for example, getting to and using the toilet or changing incontinence pads.
   - Be appropriately clothed – for example, dressing themselves in clothes suitable for the weather and their needs.
   - Be able to make use of their home safely – for example, moving around the home safely (including going up and down stairs), using the kitchen, getting to and using the bathroom and being able to enter and leave the house safely.
   - Maintain a habitable home environment – for example, keeping the home clean and safe and being able to manage and pay the bills.
   - Develop and maintain family or other personal relationships – for example, staying in touch with others so they don’t become lonely or isolated.
   - Access and engage in work, training, education or volunteering – for example, attending a course or volunteering.
Make use of necessary facilities or services in the local community including public transport – for example, getting to doctors or other healthcare appointments, using public transport and local services or shops.

Carry out any caring responsibilities – for example, caring for any children or grandchildren they have.

The person is considered unable to do these things:

- if they cannot do them without help
- if they can do them without help, but it causes them pain, distress, anxiety or puts them (or someone else) in danger
- if it takes them much longer to do them than you would expect.

3. Because of not being able to do these things there is, or is likely to be, a significant impact on the person’s wellbeing.

Support for carers: carers’ assessments

Anyone who cares for a person with dementia is entitled to an assessment of their needs as a carer. This is called a carer’s assessment. It should identify what your needs are, and work out what type of support would meet your needs.

As a carer, the impact of dementia on your daily life can be challenging, and everyone needs support from time to time. Accessing care for yourself can help you to maintain your health and wellbeing and carry on caring for the person with dementia. For more information see factsheet 523, Carers – Looking after yourself and booklet 600, Caring for a person with dementia: A practical guide.
If you meet certain eligibility criteria (conditions), the local authority may pay for your support. Even if the person you are caring for is paying for their own care (self-funding), you may still be able to receive support. If the person you care for refuses an assessment, or does not want care or support, you can still have an assessment.

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 your needs might be best met by support that is provided to the person you care for. For example, if replacement (respite) care is provided to the person with dementia, this allows you both to have a break.

**Getting a carer’s assessment**

You can ask for a carer’s assessment directly from your local authority’s social services department. This department may be called different things in different areas – for example, ‘adult services’. You can find their contact details:

- on a Council tax bill
- online
- at the GP surgery
- at the local library.

There are other ways this may be arranged:

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

If someone makes the referral for you as a carer, they must have your consent. For a carer’s assessment to be carried out, you must agree to it.
What to expect

What to expect from a carer’s assessment depends on how it has been arranged.

The assessment will usually be carried out by a social worker or care coordinator. It may involve other health professionals, such as a GP, but the social worker will arrange this if it is needed. It involves a series of questions. You will have the opportunity to explain what you do as a carer, and also what help and support you would like.

Sometimes you may be asked to give this information through a self-assessment questionnaire. You can ask the local authority for support filling this out if you need it. Some local charities may also help with this.

If the carer’s assessment 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 carer’s assessment may take place separately 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 you, for example in your own home. You should be given the list of assessment questions in advance so you can think about your needs and prepare your answers.

Telephone assessments

Assessments can be carried out over the phone. However, this is only appropriate if you are already known to the local authority and the assessment is a result of a change in your needs, or if your needs are not complex.

If you are offered a self-assessment questionnaire or telephone assessment, you can ask to have the assessment in person. You should explain why you need a face-to-face assessment. If a face-to-face assessment is still not offered you can make a complaint about the lack of support you are receiving in having your needs assessed. See ‘Complaints’ on page 22.
A carer’s assessment: tips

If you are going to have a carer’s assessment, there are a few things you can do beforehand. Look through the assessment questions and take your time to think about your answers. You should have been given these questions before the assessment – ask for a copy if you have not. You may want to make notes, so you can tell the assessor what support you feel you need.

It might seem like a lot to prepare, but even thinking about some of the details listed below will help you to get more from the assessment.

- Make a note of what you want from the assessment. For example, that you want to stay in your job, or you want your relative to live nearer to you so that you can give care more easily.

- Write a list of the care and support that you give 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.

- Think about what care and support you can continue to provide. You should not feel pressured into providing care that you are not willing or able to give.

- Keep a diary for a few weeks with all the tasks that you do to support the person – for example, making several bus journeys, preparing their meals, or doing a daily shop.

- Make a note of how your caring role may be difficult at times – possibly making you feel irritable, stressed, depressed or tearful.

- Take note of the things that you are unable to do as a result of caring, for example cleaning your home, your childcare responsibilities, taking on extra hours at work or maintaining social activities and seeing your friends.
Think about and list what support would help you. This may be someone else providing care temporarily for the person so you can have a break, or it could be some specific help for you, such as equipment or training. For example – 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 gets worse.

If you’d feel more comfortable, ask for a separate carer’s assessment without the person you care for being present. 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.

Getting support from the local authority for carers

Local authorities will give care and support to carers who meet certain eligibility and financial criteria (conditions). They have to carry out a carer’s assessment first and then they can conduct a financial assessment. For more information see ‘Financial assessments’ on page 17 and factsheet 532, Paying for care and support in England.

A carer must have an ‘eligible care need’ for a local authority to consider paying and arranging for their care and support. These care needs are organised into ‘criteria’ which apply across England.

If you are told that you are not eligible because you do not meet these criteria, but you feel that you do, you will need to make a complaint (see ‘Complaints’ on page 22). You will need to explain why you believe your needs do meet the criteria.
Carer’s eligibility criteria

There are three criteria that a carer must meet for the local authority to consider funding their care and support.

1. The carer’s needs are due to providing care to the person with dementia to help them manage their everyday activities.

2. As a result of providing care the carer’s physical or mental health is getting worse (or is at risk of getting worse). Or they are putting themselves or others in danger. Or the carer is unable to achieve any of the following without assistance or where this causes pain, distress and anxiety:

- carry out caring responsibilities for a child – for example, having responsibilities for children and grandchildren
- provide care to another person or people – for example, caring for another friend or family member
- maintain a habitable home environment – for example, keeping the home clean and safe and being able to manage and pay the bills
- manage and maintain their own nutrition – for example, having time to go shopping and prepare meals for themselves and their family
- develop and maintain family or other personal relationships – for example, staying in touch with family and friends
- engage in work, training, education or volunteering – for example, continuing to work, attending a course or volunteering
- make use of necessary facilities or services in the local community and have the opportunity to use local resources – for example, going to the gym or cinema
- engage in recreational activities and have leisure time – for example, having some free time to read a book, or take part in hobbies.

3. Because of these needs there is, or is likely to be, a significant impact on the carer’s wellbeing.
Financial assessments

Not everyone will have their care and support paid for by their local authority. There will be a financial assessment to decide how much the person will pay and how much the local authority will pay, if anything.

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 more information on financial assessments see factsheet 532, *Paying for care and support in England*.

Care at home

Local authorities have different 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 they charge. These charges should always be ‘reasonable’ and leave the person with enough money to continue to run their home. If you or the person with dementia thinks the charge for care and support services is unreasonable, you should ask the local authority for a breakdown of costs and explanation of how the decision was made.

The Care Act 2014 provides guidance 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. Examples of these services could be:

- personal care at home
- frozen meals delivered to your home
- transport
- a personal assistant who provides care and is directly employed by the person or their carer.
The local authority will carry out the financial assessment. From this it will work out how much the person should pay towards the cost of these services, if anything. The local authority must provide you with a breakdown of how they worked out the charge.

For further information on paying for care at home and in a care home see factsheet 532, *Paying for care and support in England*.

**Organising care and support**

**Care and support plans**

If a person with dementia has eligible needs, they will get a care and support plan. If a carer is eligible, they will also get a support plan. These outline the person’s care and support needs, and how they can be met. For example, a person with dementia may need prompting and support at mealtimes. The support plan may say that a care worker should visit them in their home to help them at mealtimes.

A carer’s support plan outlines things that are specifically for the carer, for example manual lifting and handling training (which could help you to use a hoist), or having a temporary break from caring. A carer’s assessment may also lead to changes in the care plan of the person they care for. Sometimes a carer’s need is best met by giving services to the person they care for. An example is replacement (respite) care, such as a paid carer coming to spend time with the person, which allows the carer to take a break. Although it is there to help the carer, it is given to the person with dementia as 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 to spend on meeting their needs. For more information see ‘Personal budgets and direct payments’ on page 20.
How care and support are arranged
The main ways that care and support can be arranged are:

- The local authority gives the support directly.
- The local authority arranges for a care provider, such as a homecare agency, to give the care.
- The local authority makes a direct payment to the person or their carer to buy their own care and support.

You may have care and support arranged as a combination of these options. How the care will be arranged is usually discussed in the assessment, and should be in the care plan. The local authority must give you information about where to get care and support locally, even if they are not paying for the care. The information can include advice from professionals such as an occupational therapist or a social worker.

You can also get information from local care agencies and charities. Some of these run a brokerage scheme to help people find the support they want (see ‘Brokerage service’ on page 20). The Care Quality Commission lists all registered homecare agencies in each area of the country (see ‘Other useful organisations’ on page 23).

Some services, such as community nursing, are arranged through the GP, either directly or after discussion with social services (adult services).
Personal budgets and direct payments

A personal budget is the amount of money that the local authority calculates will meet someone’s needs. The local authority will use the financial assessment to decide how much the person will contribute to their personal budget themselves.

You or the person you care for may choose to be given a ‘direct payment’ from the local authority so you can arrange services yourselves. Direct payments can offer more choice and flexibility when choosing services to meet care needs. Managing direct payments 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 help. 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 manage 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

Brokerage is a service that helps you to set up your care and support by direct payment. To do this you might need help from a broker. They will help you to take part in and understand the care planning process, for example, to plan and organise tailored support. Professional brokers charge fees, but a broker can be anyone that you or the person with dementia trusts. Some voluntary organisations might also have a brokerage service.

For more information see factsheet 473, Personal budgets.
Reviews

Your circumstances change, so the services you get 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 yours as the carer have changed. There are different ways to get 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, such as a fall meaning the person is less able to do things, or hospital admission.
- A requested review is where the person, their carer or a professional (for example their GP) asks for a review. This may be due to a change in care needs, or where it is felt that different support is needed.

If you have been given a personal budget by the local authority, a review should be considered within six to eight weeks. This will not be as detailed as the original assessment. The point is to make sure that the support is meeting the care needs and to check that there is no unmet need. It should also make sure that if there are problems, they are dealt with quickly.
Complaints

It is best to try to resolve any complaints about the assessment process with the person you have contact with, such as the social worker. There may have been a breakdown in communication or a misunderstanding. However, if this is not successful, local authorities have complaints procedures 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
- where someone is told that they are not eligible and they feel that they are.

Contact the local authority to find out what the complaints procedure is.

If the local authority complaints procedure does not resolve the issue, you can take your complaint to the Local Government and Social Care Ombudsman. It may be helpful to talk to a local advice agency first – for example, Citizens Advice (see ‘Other useful organisations’ on page 23).
Other useful organisations

Age UK
0800 055 6112 (advice line, 8am–7pm)
www.ageuk.org.uk/contact-us/information-and-advice (contact form)
www.ageuk.org.uk

Age UK provides information and advice for older people in the UK.

Care Quality Commission (CQC)
03000 616161 (8.30am–5.30pm Monday–Friday)
enquiries@cqc.org.uk
www.cqc.org.uk

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

Carers UK
0808 808 7777 (helpline, 9am–6pm Monday–Friday)
advice@carersuk.org
www.carersuk.org

Carers UK gives advice, information and support about caring. This includes information on paying for care.

Citizens Advice
0800 144 8848 (for England, 9am–5pm Monday–Friday)
0800 702 2020 (for Wales)
www.citizensadvice.org.uk

Citizens Advice provides free, independent, confidential and impartial advice to everyone on their rights and responsibilities. Trained Citizens Advice advisers can offer information on finances in a way that is easy to understand. To find your nearest Citizens Advice, look in the phone book, ask at your local library or look on the website. Opening times vary.
Disability Rights UK
0330 995 0400 (general enquiries line)
enquiries@disabilityrightsuk.org
www.disabilityrightsuk.org

Disability Rights UK is an organisation of disabled people working for equal participation for all.

GOV.UK
www.gov.uk

GOV.UK is the website for information and services from the UK government, including information about paying for care.

Independent Age
0800 319 6789 (helpline, 8.30am–6.30pm Monday–Friday)
advice@independentage.org
www.independentage.org

Independent Age provides an information and advice service for older people, their families and carers, focusing on social care, welfare benefits and befriending services. It also offers local support, including one-to-one and group befriending schemes.

Local Government and Social Care Ombudsman
0300 061 0614 (10am–12pm Monday–Friday)
complaints.lgo.org.uk (complaints form)
www.lgo.org.uk

The Local Government and Social Care Ombudsman is an independent organisation that investigates complaints about councils and care providers and looks for a resolution.

Solicitors for the Elderly (SFE)
0844 567 6173
admin@sfe.legal
www.sfe.legal

Solicitors for the Elderly is a specialist group of lawyers who support older and vulnerable people.
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Factsheet 418LP

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Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

Reviewed by: Professor Jill Manthorpe, Professor of Social Work, King’s College London and Irene Chenery, Consultant, Harrison Drury Solicitors; member of Solicitors for the Elderly

This factsheet has also been reviewed by people affected by dementia.

To give feedback on this factsheet, or for a list of sources, please contact publications@alzheimers.org.uk

People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need.

To make a single or monthly donation, please call us on 0330 333 0804 or go to alzheimers.org.uk/donate

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.

For support and advice, call us on 0333 150 3456 or visit alzheimers.org.uk