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.

It can be difficult to know how to get this support. This factsheet outlines how people with dementia and their carers can access care and support at home, including day centres or short breaks. It will be useful both for people with dementia and anyone caring for a person with dementia.

This factsheet is for people living in Wales and is not intended for England and Northern Ireland, where the laws are different. For information about the laws in England see factsheet 418, Assessment for care and support in England, and for Northern Ireland see factsheet NI418, Community care assessment.

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Assessment for care and support in Wales

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).

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’ on page 13 or factsheet W532, Paying for care and support in Wales.
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 from 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 also a number of 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 else, the person making the referral must get the individual’s consent before contacting the local authority. Some people with dementia may lack the ability (known as ‘mental capacity’) to give this consent. For more information on this see factsheet 460, Mental Capacity Act 2005.

Assessments in Welsh
If the person needing the assessment would prefer that it is carried out in Welsh, they can request this. The local authority must then meet this request. This should not create any delay in the assessment process.
What to expect
A care needs assessment will usually involve a series of questions, often in the form of a discussion. The assessment is designed to find out the individual’s ‘personal outcomes’ – that is, what the person’s needs are and what support they want in order to achieve their aims. For example, the person might struggle with cooking and so want the support to be able to cook their own meals. To do this, the assessment considers five key elements:

- The person’s circumstances – for example, do they have any illnesses or mobility problems, and do they live alone?
- The person’s outcomes – what the person wants from the assessment, such as being able to go out shopping or seeing friends.
- Any barriers to the person achieving those outcomes – for example, any mobility problems.
- The risks to the person if the outcomes are not achieved – for example, they may wish to be able to go out and do their own shopping, and if they can’t there is a risk to their health and wellbeing.
- The person’s strengths and capabilities – the assessment should also focus on what someone can do, such as being good at organising their own budget or understanding their own diet.

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 the result of a change in needs. As people with dementia often have more complex needs, telephone assessments are generally not appropriate. They should not be used as the only method of assessing care needs.

Some local authorities may also expect the person to complete the assessment on their own and return it in the post. This is unacceptable and you should insist on a personal visit as set out above.
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
- Make notes outlining what needs you have, and what care and support you would like.
- Think about what you want the outcomes of the assessment to be.
- Consider whether there is any equipment or assistive technology that you may benefit from.
- 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, because 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.

A care needs assessment will usually involve a series of questions, often in the form of a discussion. The assessment is designed to find out the individual’s ‘personal outcomes’ – that is, what the person’s needs are and what support they want in order to achieve their aims.

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 W532, Paying for care and support in Wales.

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 Wales. These are summarised in the box on the next page.

If someone is told that they do not have eligible care needs, but they believe they do, they will need to put in a complaint (see ‘Complaints’ on page 17). They should outline why they believe their needs do meet the criteria.
Eligibility criteria

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

1. The person’s needs arise due to their physical or mental ill-health, age or disability (this includes dementia).

2. The person’s needs relate to at least one of the following:
   i. their ability to carry out self-care or domestic routines
   ii. their ability to communicate
   iii. protecting them from abuse or neglect
   iv. being involved in work, education, learning or in leisure activities
   v. maintaining or developing family or other significant personal relationships
   vi. maintaining and developing social relationships and involvement in the community
   vii. fulfilling caring responsibilities to a child.

3. The person cannot meet the needs:
   i. alone
   ii. with the care and support of someone willing to provide it
   iii. with assistance from services in the community that they can access.

4. The person is unlikely to achieve the outcomes shown in their assessment without:
   i. the local authority providing or arranging care and support
   ii. the local authority providing direct payments so the person can arrange support to meet their needs.
Support for carers: carers’ assessments

Anyone who cares for a person with dementia is also entitled to an assessment of their own 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. In short, a carer is entitled to a carer’s assessment regardless of their financial situation.

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, 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 regular 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.

If someone is told that they do not have eligible care needs, but they believe they do, they will need to put in a complaint (see ‘Complaints’ on page 17). They should outline why they believe their needs do meet the criteria.
Getting a carer’s assessment
A carer can request a carer’s assessment directly from their local authority’s social services department. There are also a number of 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.

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. The assessment 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.
Carer’s assessment: tips for carers

If you are caring for a person with dementia and are having a carer’s assessment, there are a number of things you can do to prepare, and things to do during the assessment.

Preparing for the assessment

- Consider what you want the outcomes of the assessment to be.
- 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.
- 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, irritable, stressed 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 and seeing your friends.
- Think about and list the support that 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 (for example a tumble dryer), or driving lessons so you no longer need to use public transport.
- Think about what support you may need in the future as the person’s condition progresses.
During the assessment

- 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’ on page 13 or factsheet W532, Paying for care and support in Wales.

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 the next page.

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 17). They should outline why they believe their needs do meet the criteria.
Carer’s eligibility criteria:

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

1. The carer has a need because they are providing care to a person with dementia.

2. The need the carer has relates to at least one of the following:
   i. their ability to care out self-care or domestic routines
   ii. their ability to communicate
   iii. to protect them from abuse or neglect
   iv. to be involved in work, education, learning or leisure activities
   v. maintaining or developing family or other significant personal relationships
   vi. maintaining or developing social relationships and involvement in the community
   vii. fulfilling caring responsibility to a child
   viii. if the carer is a child, then achieving their own developmental goals.

3. The carer cannot meet the needs:
   i. alone
   ii. with the care and support of someone willing to provide it
   iii. with assistance from services in the community that they can access.

4. The carer is unlikely to achieve the outcomes identified in their assessment without:
   i. the local authority providing or arranging care and support for the carer
   ii. the local authority providing or arranging care and support for the person the carer cares for
   iii. the local authority providing direct payments so that the carer can arrange services to meet their needs.
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 the process for assessing a person’s needs, 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 or a person who is providing care and 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.

Local authorities can charge a flat rate for low-level, low-cost care and support, or set a flat rate for care and support such as preparing meals or doing laundry. If a local authority charges a flat rate, it is not obliged to undertake a financial assessment.

There is a maximum weekly charge that any local authority can impose for services at home. For up-to-date figures see alzheimers.org.uk/benefitrates

If the person with dementia or their carer thinks the charge for these 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 W532, *Paying for care and support in Wales*.

**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 to eat, 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 care, such as a ‘sitting’ service, that 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 ‘Direct payments’ on the next page.
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 ‘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. 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 ‘Brokerage services’ on the next page). The Care and Social Services Inspectorate Wales (CSSIW) lists all registered domiciliary (home) care agencies (see ‘Other useful organisations’ on page 18).

Some services, such as community nursing, are arranged through the GP, either directly or after discussion with social services.

Direct payments
If a person’s care is funded by the local authority, they may choose to receive this funding in the form of a direct payment. A direct payment is money that a local authority gives to someone to spend on meeting their own eligible care needs. The money can be spent on a wide range of products and services. Direct payments allow people to make their own choices about their care.
The Social Services and Wellbeing (Wales) Act 2014 allows people to use direct payments to pay for long-term residential care as well as other services.

For more information on these see factsheet 473, **Personal budgets**. This mainly deals with the system in place in England, but the information on direct payments is still relevant for Wales.

**Brokerage services**

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, the writing of the care plan and considering how their direct payment can be used to meet their needs.

**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, such as 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 any part of the process, 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 to 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.

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

Age Cymru
Tŷ John Pathy
13/14 Neptune Court
Vanguard Way
Cardiff CF24 5PJ

08000 223 444
enquiries@agecymru.org.uk
www.ageuk.org.uk/cymru/

Provides information and advice for older people in Wales.

Citizens Advice
Various locations
www.citizensadvice.org.uk

Your local Citizens Advice can provide information and advice in confidence or point you to further sources of support. Trained Citizens Advice advisers can offer information on benefits 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.

Care and Social Services Inspectorate for Wales
Welsh Government Office
Rhydycar Business Park
Merthyr Tydfil CF48 1UZ

0300 7900 126
cssiw@wales.gsi.gov.uk
www.cssiw.org.uk/

Regulates, inspects and reviews all adult social care services in Wales.
Carers Trust Wales
3rd Floor, 33–35 Cathedral Road
Cardiff CF11 9HB

02920 090087
wales@carers.org
www.carers.org/wales

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
20 Great Dover Street
London SE1 4LX

0808 808 7777 (free carers’ line, 10am–4pm Monday–Friday)
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.

Public Services Ombudsman for Wales
1 Ffordd yr Hen Gae
Pencoed CF35 5LJ

0300 790 0203
www.ombudsman-wales.org.uk

Independent organisation that investigates complaints about public services and independent care providers and looks for a resolution.
Factsheet W418LP

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Reviewed by: Claire Davis, Partner, Howells Solicitors; member of Solicitors for the Elderly and Alison Tarrant, PhD Researcher, Cardiff Law School, Cardiff University
This factsheet has also been reviewed by people affected by dementia.
To give feedback on this factsheet, or for a list of sources, email publications@alzheimers.org.uk

Alzheimer’s Society National Dementia Helpline
England, Wales and Northern Ireland:
0300 222 1122
9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

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The Information Standard Certified Standard

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