Many people with dementia and their carers will need care and support as the condition progresses. All care should help people with dementia and those supporting them to live well whether this comes from a carer, family, friends or professionals. The types of care put in place will be different for everyone, because everyone’s needs are different.

The process can feel overwhelming, but you don’t have to do this alone. With the right information and support, you can understand your options and make the right decisions for you and the person you care for.

This factsheet is written for carers, but the information is also helpful for people with dementia. It explains what health and social care assessments (assessments of need) are and how people with dementia and their carers can access them.

This factsheet is for people living in Northern Ireland, as assessment for care and support is different in England and Wales. For information about England see factsheet 418, Assessment for care and support in England, and for Wales see factsheet W418, Assessment for care and support in Wales.
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Assessment for care and support in Northern Ireland

People with dementia and their carers will need care and support as the condition progresses. A health and social care assessment shows what needs the person with dementia has, and what needs you, as a carer may have. It also includes 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 health and social care (HSC) trust. For some people the local HSC trust 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 HSC trust. If you wish to get care and support paid for by the local HSC trust you must have either:

- an assessment of need and a financial assessment – for a person with dementia, or
- a carer’s assessment and financial assessment – for a carer.

Asking for information and advice as early 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 also helps with planning for emergencies or preparing for times when you may not be able to care for them.
Support for people with dementia: a health and social care assessment

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

Examples of the kinds of services someone could be assessed as needing include personal care, day care, equipment and adaptations, respite care or care in a care home.

You don’t need to wait for a diagnosis of dementia before requesting an assessment. The local HSC trust 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 HSC trust 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.

However, the HSC trust does not have a duty to arrange services unless an assessment has taken place, so it’s important to get an assessment.

For more information about paying for care see ‘Financial assessments’ on page 15 and factsheet NI532, Paying for care and support in Northern Ireland.

Getting a health and social care 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 social services at your HSC trust for one on their behalf. This department may be called different things in different areas – for example, ‘older person’s services’. You can find their contact details:

- 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 (known as ‘mental capacity’) to give this consent. You can still ask for an assessment, as long as it is in the person’s best interests.

**Potential problems with arranging an assessment**

A person should not be refused an assessment, even for any of the following reasons:

- The local HSC trust believes the person will not meet its criteria. Trusts must not refuse people without having enough information. If it can be shown that the person may need services, then an assessment must be carried out. They may refer the person to non-HSC trust services where appropriate.
- The trust does not have enough staff to carry out an assessment.
- The person has enough income or savings to pay for their own care services.

If the request for an assessment is refused, the person, their carer or relative should write to the trust to explain the circumstances in more detail. Or they can ask a professional or advice agency to write on their behalf. If they are still unsuccessful, they can make a complaint (see ‘Complaints’ on page 19).
Who does the assessment?
The local HSC trust’s social services department will carry out most assessments. This will normally be done by a social worker (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.

You and the person with dementia should be fully involved in the assessments and care planning. You play an important part in working out what services you need from the HSC trust and how your needs can be met.

What to expect
An assessment of need will include answering questions, which should be given in advance.

The Single assessment tool is used to carry out these assessments. This is the paperwork and guidance that professionals use to record the person’s information. It’s used to avoid or reduce repeat assessments, and so that the same questions aren’t asked by different professionals. These questions will help the local HSC trust to find out about the person’s:

- physical health
- mental health and emotional wellbeing
- awareness and ability to make their own decisions
- medicine management
- communication
- walking and movement
- personal care and daily tasks
- living arrangements
- relationships with friends and family and whether they provide care to anyone else
- finances and leisure activities
- quality of life, their goals, wishes and preferences for their future.
It will also cover:

- whether the person works or is in education or training
- whether there is a carer.

These questions and answers are then discussed together with those present at the assessment.

The assessment may be completed in one visit or, if there are more complex needs, spread over several weeks.

**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.

Assessments should not take place over the phone or via letter as needs must be properly assessed. 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 19.

It’s important to note that if there are lockdowns or restrictions due to coronavirus, it may not be safe for you or others to have a face-to-face assessment. If this happens, then speak to your assessor about how they can support you with your assessment at this time. For example, a phone assessment may be sufficient, or you may prefer a virtual assessment if this is something that is available in your area.

If the person being assessed is in hospital, the HSC trust may also arrange for an assessor to visit their home. This allows the assessor to get a better idea of their situation before they are discharged.
The health and social care assessment: tips

If the person with dementia is having an assessment of their needs, there are some things that can help them to prepare for it. They may want to make notes so they can take time to think about 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 here 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 care plan 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 see factsheet 429, Using equipment and making adaptations at home.
- What care and support might the person need in the future as their condition gets worse? This can include equipment and assistive technology. For more information see factsheet 437, Using technology to help with everyday life.
- 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. Some medicines might be for more than one condition – you could ask a GP or pharmacist for clarification if you are not sure.
- Make sure anyone who the person would like to be at the assessment, such as a carer or relative, is 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 devices that provide assistive technology.

**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 that 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 activities such as shopping, going for walks or swimming.

**Getting support from the local HSC trust for people with dementia**

Once an assessment of need has been completed, the local HSC trust will decide if it will pay for care and support for the person. They will consider whether the person’s needs match the criteria (conditions) for providing care and support, as well as looking at their financial situation. For more information on the financial assessment see ‘Financial assessments’ on page 15 and factsheet NI532, **Paying for care and support in Northern Ireland**.

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 19). You should explain why you think their needs do meet the criteria.
Eligibility criteria
The HSC trust will compare the person’s needs with eligibility criteria set by the Department of Health. These criteria consist of four bands of risk. The HSC trust will try to establish which risk band the person falls into. They will then use this to decide whether the person will receive services.

The bands of risk are:

**Critical** – when either:
- the person’s life is or may be threatened
- the person has significant health problems, or is likely to develop them
- the person has little or no control over their immediate environment
- serious abuse or neglect has occurred or is likely to occur
- the person is unable to carry out vital personal care or domestic routines
- the person is unable to carry out work, education or learning, or is likely to become unable to
- the person is unable to maintain relationships or social responsibilities, or is likely to become unable to
- the person’s hospital discharge is delayed, causing them a risk of infection or a loss of independence.

**Substantial** – when either:
- the person has only partial control over their immediate environment
- abuse or neglect has occurred or is likely to occur
- the person is unable to carry out the majority of personal care or domestic routines
- the person is unable to carry out many aspects of work, education or learning, or is likely to become unable to
- the person is unable to maintain the majority of relationships or social responsibilities, or is likely to become unable to
- the person is at significant risk of inappropriate admission to hospital or residential care.
Moderate – when either:
- the person is unable to carry out several personal care or domestic routines
- the person is unable to carry out several aspects of work, education or learning, or is likely to become unable to
- the person is unable to maintain several relationships or social responsibilities, or is likely to become unable to.

Low – when either:
- the person is unable to carry out several personal care or domestic routines
- the person is unable to carry out one or two aspects of work, education or learning, or is likely to become unable to
- the person is unable to maintain one or two relationships or social responsibilities, or is likely to become unable to.

HSC trusts must meet care needs that fall within the critical and substantial risk bands, and help for this cannot be sourced from elsewhere. They can choose to meet needs in the moderate and low risk bands, but legally they do not have to.

Support for carers: carer’s 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 own 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.
The Single assessment tool contains a carer’s assessment. This means that a carer’s assessment is often done at the same time as an 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 respite care is provided to the person with dementia, this allows you both to have a break.

If the person you care for refuses an assessment, or does not want care or support, you can still have a carer’s assessment.

**Getting a carer’s assessment**

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

- online
- at the GP surgery
- at the local library.

There are other ways this may be arranged:

- as part of an assessment of need 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.
If the carer’s assessment is carried out at the same time as the assessment of the person with dementia, it is likely to be done in the home of the person with dementia.

The carer’s assessment may take place separately from the 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 will have the opportunity to explain what you do as a carer, and also what help and support you would like. The assessment involves the following questions:

- how long you have been providing care and support
- when you provide care and support and how much you provide per week
- whether you assist with the person’s finances and if you have any legal authority, for example an Enduring power of attorney (EPA)
- whether there have been times you have been unable to fulfil your caring role
- whether anyone in the family shares the caring role with you
- whether there is a need to consider contingency care (if something was to happen to you, or you were unable to provide care for some reason, whether care and support will need to be provided and who can do this)
- whether your finances have been affected due to caring and if you are claiming anything you are entitled to, for example carers allowance
- your own health, including your physical and mental health and wellbeing
- any health problems that have been caused by or made worse by caring
- how you view your role, including what you find positive and most difficult and any concerns you have about the future.

Sometimes you may be asked to give this information through a self-assessment questionnaire. You can ask the local HSC trust for support filling this out if you need it. Some local charities may also help with this.
A carer’s assessment: tips

If you are going to have a carer’s assessment, there are a few things you can do beforehand. 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, tearful or alone.
- 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 could mean 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 HSC trust for carers

Once an assessment has been completed, the HSC trust will decide if it will pay for care and support for you. They will consider whether you are eligible and also your financial situation. For more information on the financial assessment see ‘Financial assessments’, or factsheet NI532, Paying for care and support in Northern Ireland.

Some types of support for carers, such as respite care, are given directly to the person with dementia (see ‘Care plans’ on page 16). For this to happen the person will then need to be assessed to work out whether they are eligible for services.

If you are not satisfied with the way an assessment was done, or with the outcome of an assessment, you can make a complaint (see ‘Complaints’ on page 19). You will need to explain why you are not satisfied, your reasons and what outcome you are seeking.

Financial assessments

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

If the person with dementia needs to move into a care home, the local HSC trust will assess the person’s income and savings according to national rules.

For more information on financial assessments see factsheet NI532, Paying for care and support in Northern Ireland.

Care at home

HSC trusts can charge for the services they arrange. They usually don’t charge for services provided in a person’s home, but there are some exceptions. These include the home help scheme and the meals on wheels service. There is a fixed charge for meals on wheels. There is a ‘means-tested’ charge for the home help service. This means that charges are based on a person’s ability to pay, taking into account their savings and investments. People over 75 are not charged for the home help service.
When a financial assessment is required, only the person receiving the services will be financially assessed. The HSC trust will calculate the cost of the services to be provided, then financially assess the person using the regional charging policy to see how much the person can contribute to this cost. The HSC trust must provide a breakdown of how they calculated the charge.

If the person with dementia needs to move into a care home, the HSC trust will assess the person's income and savings according to regional rules.

For further information on financial assessments see factsheet NI532, Paying for care and support in Northern Ireland.

Organising care and support

Once it is decided that someone has needs that make them eligible for support, the HSC trust has a duty to provide sufficient support to ensure that these are met.

Care plans

The person who carried out the assessment should write a ‘care plan’. This describes which services will be provided. The person with dementia and their carer should be closely involved in the development of the plan.

The care plan should include:

- the needs that have been identified
- the desired outcomes and how they can be met
- a risk assessment
- a plan for dealing with emergency changes
- the result of any financial assessment
- the support that carers are willing and able to provide
- the support to be provided to meet the assessed needs
- the date on which the plan will be reviewed.
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. The results of your carer’s assessment may also lead to changes in the care plan of the person you care for.

Sometimes a carer’s need is best met by giving services to the person they care for. An example is 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, the actual care is given to the person with dementia as part of their care plan.

For more information on respite care see factsheet NI462, Respite care in Northern Ireland.

**How care and support are arranged**

The main ways that care and support can be arranged are:

- The HSC trust gives the support directly.
- The HSC trust arranges for a care provider, such as a home care agency, to give the care.
- The HSC trust makes a direct payment to the person 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.

You can also get information from local care agencies and charities. The Regulation and Quality Improvement Authority (RQIA) lists all registered homecare agencies in each area of the country (see ‘Other useful organisations’ on page 20).

Some services, such as community nursing, are arranged through the GP, either directly or after discussion with social services (adult services).
How long do services take to arrange?
Once it has been agreed that a person needs services, the HSC trust must make sure these services are provided. In some cases, the HSC trust may provide a service straight away. However, there may sometimes be a wait while they are organised, though this shouldn’t take too long. If there is likely to be a delay, the HSC trust may find another way to meet the person’s needs until the service can be provided.

Even if an assessment has been agreed to, there may be a wait. If the wait seems unreasonable, you should complain to the HSC trust.

Direct payments
If a person’s care is funded by the HSC trust, they may choose to receive this funding in the form of a direct payment. A direct payment is an amount of money that the HSC trust 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 HSC trust must support people managing a direct payment – this could be through voluntary or charitable services.

The HSC trust must be satisfied that someone is willing and able to manage a direct payment, either alone or with assistance. If someone has been able to consent to receiving direct payments but is not able to manage them because they lose the capacity to do so, then the trust may continue to make direct payments. This is only if an ‘authorised person’ is prepared to handle them instead.

The authorised person must be prepared to manage the direct payments and care package on a day-to-day basis on behalf of the person and in their best interests. They must have the correct legal authority from the Office of Care and Protection – for example, the person’s attorney under an Enduring power of attorney.

For more information see factsheet NI431, Direct payments.
Reviews

Your circumstances change, so the services you get should be reviewed from time to time. HSC trusts have review meetings to see whether the needs of the person with dementia or yours as a carer have changed since they last had their needs assessed. Care plans should be reviewed at times or intervals specified in the care plan (for example, within the first six months and then annually), or as your needs change.

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 being admitted to hospital or having a fall, meaning the person is less able to do things.
- 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 there is a change in your situation or that of the person with dementia, you should contact the local HSC trust, whether or not a regular review is due. You should also contact them if you feel that you need more help, or different kinds of services.

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, the HSC trust will have a complaints procedure you can follow. The trust 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 services you need aren’t provided, or are unsatisfactory.
Contact the local HSC trust to find out what the complaints procedure is.

If the HSC trust’s complaints procedure does not resolve the issue, you can take your complaint to the Northern Ireland Ombudsman (see ‘Other useful organisations’ below).

**Other useful organisations**

**Age NI**
0808 808 7575 (advice line, 9am–5pm Monday–Friday)
advice@ageni.org
www.ageuk.org.uk/northern-ireland

Age NI provides information and advice for older people in Northern Ireland.

**Carers Northern Ireland**
0808 808 7777 (helpline, 9am–6pm Monday–Friday)
advice@carersni.org
www.carersuk.org/northernireland

Carers Northern Ireland gives information, advice and support about caring.

**Centre for Independent Living NI**
028 9064 8546 (9am–5pm Monday–Friday)
info@cilni.org
www.cilni.org

The Centre for Independent Living NI provides a range of services for people using or considering using direct payments and/or other self-directed support.

**Law Centre NI**
028 9024 4401
admin@lawcentreni.org
www.lawcentreni.org

Law Centre NI offers free legal advice and support on social security, health and social care issues and employment.
Northern Ireland Ombudsman
0800 34 34 24
nipso@nipso.org.uk
nipso.org.uk

The Northern Ireland Ombudsman is the Independent organisation that investigates complaints about government departments, agencies or public bodies and looks for a resolution.

Regulation and Quality Improvement Authority (RQIA)
028 9536 1111
info@rqia.org.uk
www.rqia.org.uk

The RQIA is an independent body responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland.

Rights 4 Seniors
028 9064 5919
rights4seniors@adviceni.net
www.rights4seniors.net

Rights 4 Seniors has information on health, social care, benefit and housing rights for older people in Northern Ireland.
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