



10B

What is social care and how does it work?

Information for people with or affected by motor neurone disease or Kennedy's disease

With motor neurone disease (MND), there may come a time when you need professional help with daily routines, personal care or equipment to prolong independence. This type of support is known as social care.

If you're living with Kennedy's disease, you may experience similar symptoms and also need social care support.

This information sheet looks at social care in England, Wales and Northern Ireland, from assessment of need through to delivery of services. If you live in Scotland, contact MND Scotland for advice (see section 6: *How do I find out more?* for contact details).

This sheet includes the following sections:

- 1: **What do the words mean?**
- 2: **What are my rights?**
- 3: **How do I get my needs assessed?**
- 4: **Who pays for social care?**
- 5: **Can I challenge a decision?**
- 6: **How do I find out more?**



This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.





This symbol is used to highlight **quotes** from other people with or affected by MND.

This information has been evidenced, user tested and reviewed by experts.

1: What do the words mean?

When accessing social care, you may come across the following terms:

advocate	Anyone who can help raise awareness of your needs in discussions about your treatment or care.
benefits	Various amounts of financial support are available as benefits from the Government, your local authority (England and Wales), or your local health and social care trust (Northern Ireland). You may qualify if you are disabled, a carer or have a low income. See <i>Further information</i> at the end of this sheet for relevant resources and details of our Benefits Advice Service. Disability benefits, such as Personal Independence Payment (PIP) are provided in addition to any social care services you qualify for through needs assessment.
carer's assessment	An assessment from adult social care services to work out if you qualify for their support in your role as an unpaid carer.
community care assessment	An assessment from adult social care services in Northern Ireland, to work out what your needs are, and whether you qualify for support. In England and Wales this is known as a needs assessment.
direct payments	You can receive your agreed amount of money for social care support (known as your personal budget in England), as direct payments into your bank account. This means you can select and buy services for yourself, rather than having services arranged for you. Find out more about direct payments in section 4: <i>Who pays for social care?</i>
Individual Service Fund (ISF) <i>England only</i>	Receiving your direct payments in England through a 'third party' organisation, agency or provider, is known as using an Individual Service Fund (ISF). The ISF then books and pays for services agreed in your support plan, in line with your wishes and the budget available. This option is not yet available in all areas of England. In Northern Ireland, the term 'Individual Service Fund' is not used, but you can still use a third party to manage your budget, with self directed support.
Integrated Personal Budget <i>England only</i>	Pilots are ongoing in England to use a combined budget for both healthcare and social care needs.

means test	A financial assessment that looks at your income and savings. For social care support, means testing in England and Wales works out what your local authority will pay towards agreed services, and how much you need to pay. In Northern Ireland you will not be means tested for care in your own home, but you will be for placement in a nursing home.
needs assessment	An assessment from adult social care services in England and Wales, to work out which support services you need, and whether you qualify for support. In Northern Ireland this is known as a community care assessment.
NHS continuing healthcare (CHC) <i>also known as continuing care</i>	<p>If you require a high level of support for complex medical needs, you may qualify for all your health and social care services to be paid by the NHS. There are strict guidelines during assessment. CHC is not available as a formal service in Northern Ireland – contact your local health and social care trust for guidance.</p> <p> See Information sheet 10D – <i>NHS Continuing Healthcare</i>.</p>
personal budget <i>England only</i>	An agreed and financially assessed amount of money from adult social care services, to provide you with social care support in England. You may need to pay towards this. It works the same in Wales and NI, but they don't use the term 'personal budget'.
personal health budget <i>England only</i>	<p>An amount of money to support your health and wellbeing needs. Your healthcare is still provided free, as normal, but you can use this amount to select services of your own choice, such as physiotherapy. You will be assessed for the services you need, but not financially assessed as the NHS pays for this funding.</p> <p> See information sheet 10F – <i>Personal health budgets</i>.</p>
personalisation	The government uses this word to describe how you should have full choice and control about how your needs are met, as everyone is different. Known in Northern Ireland as 'Self Directed Support'.

The approach to social care support can vary across England, Wales and Northern Ireland. We have noted differences where possible, but regions within each nation may also use varied approaches.

That means this sheet is intended for awareness only. Although we have checked the content with relevant experts, there may be different ways of achieving similar outcomes, depending on where you live.

We recommend that you use this sheet with your health and social care professionals to help you find out what is available in your area.

2: What are my rights?

Social care across the UK is under reform and budgets are controlled. Being aware of your rights can help you get an assessment, access support and find the information you need.



"You need to be as well informed as possible about how to access services."

Knowing your rights does not mean you will get social care support. You still need to be assessed to see if you qualify. See section 3: *How do I get assessed?*

Although the approach to assessment can vary across regions, you have the right to:

- information about social care (with assistance if you need this in another language or format)
- a needs assessment or carer's assessment as appropriate, resulting in a care and support plan
- agreed support services if you qualify (either arranged for you, self-selected using direct payments or a mix of both)
- a review of your care and support plan if your needs change
- challenge an assessment decision if you feel it is incorrect.

What about carers?

These rights also apply for unpaid or family carers. We provide separate information to help carers think about their own wellbeing, which includes carers' rights, carer's assessment and possible support, such as taking a break.



See our carer guide – *Caring and MND: support for you.*

What about financial support?

You also have the right to claim benefits, if you qualify for financial support (in addition to any social care you may qualify for). Your needs assessment may be an opportunity to ask about benefits, but you may need further support from a benefits adviser.

We offer a Benefits Advice Service that can help you identify relevant benefits. See *Further information* at the end of this sheet for contact details and related information resources.

How are my rights covered in law?

In England and Wales your local authority is legally responsible for assessment and provision of support – find your local authority at:
www.gov.uk/find-your-local-council

In Northern Ireland your local health and social care trust is legally responsible for assessment and provision of support – search for *health and social care trusts* at:
www.nidirect.gov

If you would like to read more, the following Acts cover your rights:

In England

Care Act 2014 – search for this Act at:
www.legislation.gov.uk

In Wales

Social Services and Well-being (Wales) Act 2014 – search for this Act at:
www.legislation.gov.uk

In Northern Ireland

Social care in Northern Ireland is based on a number of Acts and Orders. To find out more about guidance, search for *social services* at:
www.health-ni.gov.uk

3: How do I get my needs assessed?

Who provides the assessment?

In England and Wales contact your local authority to arrange an assessment with adult social care services – find your local authority at: **www.gov.uk/find-your-local-council**

In Northern Ireland contact your local health and social care trust to arrange an assessment with adult social care services. In law, the Trust where the person lives at that time has responsibility. For contact details, search for *health and social care trusts* at:
www.nidirect.gov.uk

If needed, a health professional can contact adult social care services on your behalf, with your permission.

If you have MND or Kennedy's disease and need care support, ask for a needs assessment. If you provide unpaid care support, ask for a carer's assessment. A needs assessment and a carer's assessment can happen at the same time or separately, as preferred. Assessments are usually carried out at your home, by a social worker or someone in a similar role, such as a care manager.

Other health and social care professionals may also be able to help prolong your independence. For example, a key contact is an occupational therapist (OT). You can ask an OT for a separate assessment of your needs for equipment, environmental controls or home adaptations.



“Planning ahead for equipment and adaptations is essential - a good occupational therapist can help hugely with this.”

If you have caring responsibilities for anyone else, such as an adult with care needs or a child, they may also qualify for assessment to ensure they continue to receive support.

The time it takes from asking for your assessment through to receiving services can vary. If your needs are urgent, stress this when asking for your assessment. This may help fast track the process.

Although this may work differently across England, Wales and Northern Ireland, the whole family should be considered in a needs assessment, where children live in the same household. This includes a young carer's needs assessment to explore the needs of children or young people involved in care tasks.

The rest of this sheet focuses on social care for someone with MND. If you're living with Kennedy's disease, you may be affected in a similar way and find this information useful.



See our carer guide – *Caring and MND: support for you* for information about carer's wellbeing and carer's assessment.

Being supported during assessment

You can have a partner, carer, relative or friend with you during the assessment, if you would like support.

You can also ask for a trained advocate to be present, but arrange this before the assessment date. An advocate is anyone who can help raise your needs in discussions about your treatment or care.

What does the assessment look for?

A needs assessment looks at how your disability or condition affects your daily life and independence. If you need support to complete activities in your daily life and your wellbeing is at risk, you should qualify for a needs assessment.



"We had no idea what MND is, what to expect or what equipment may help."

Does it take longer than it should to complete everyday tasks, such as washing, dressing or cooking? Are tasks painful, stressful or dangerous for you or other people? Are you unable to do certain tasks at all? If so, your wellbeing is at risk.

How wellbeing is defined can vary across England, Wales and Northern Ireland, but usually considers your:

- physical, mental and emotional health
- financial needs
- family and personal relationships
- ability to participate socially
- living accommodation and suitability for your needs
- sense of control over day to day life
- safety and protection from abuse and neglect.



"It's about finding solutions to problems to enable life to continue as positively and optimistically as possible."

Your assessment should consider both your needs and your wishes about what you want to happen. This means your views, beliefs, cultural background and personal support network may all play a part in the discussion.

In short, your assessment looks at whether you can manage certain daily tasks on your own or need help to:

- manage and maintain nutrition
- maintain personal hygiene, manage toilet needs and be appropriately clothed
- make use of your home safely and maintain a habitable home environment
- develop and maintain family or other personal relationships
- access and engage in work, training, education or volunteering
- make use of necessary community facilities or local services, including public transport and recreation
- carry out any caring responsibilities you have for a child.

What am I likely to receive if I qualify for support?

Each individual will have a different outcome from assessment, depending on their situation, symptoms and preferences. You may have to contribute to the costs of any agreed services, following a financial assessment. See section 4: *Who pays for social care?*



“Everyone’s situation is different, but your own social care professional will help sort out what’s applicable for you.”

Care support following needs assessment

Following a needs assessment with a social worker or a care manager, you will receive a care and support plan. This will show what support has been agreed with you. Depending on your needs, this might include:

- help from a professional care worker with personal care or household tasks
- respite care or access to day centres
- help to move into a residential or nursing care home, if needed
- help to identify services that can meet your needs.

For assistive equipment (such as mobility aids or a personal alarm) or changes to your home (such as a walk-in shower) a further assessment is required with an occupational therapist - see next heading *Assessment for equipment and home adaptations*.



“When supported, you feel less daunted about what lies ahead.”

If you have children or dependants living with you, then your needs assessment should take into consideration the whole family. For example, this could result in services such as day care for your child, if either you or they are disabled.

Where you live can affect the type of help or service you receive. Adult social care services may also offer different levels of help across regions. Your assessment is an opportunity to find out what is available.

Assessment for equipment and home adaptations

To prolong your independence within the home, you may be referred for a further assessment by an occupational therapist. This may be discussed during your needs assessment or ask your GP for guidance.

You can also self-refer to occupational therapy in England or Wales, by contacting adult social care services through your local authority. In Northern Ireland you usually have to be referred by a health or social care professional.



“We’ve asked for a home visit survey by an occupational therapist, for advice regarding adaptations to the home and wheelchairs, for future use.”

An occupational therapist can assess your needs and environment for assistive equipment, including environmental controls.

Some equipment can be provided free or on loan, some you may have to buy yourself. This assessment can help you avoid costly and frustrating mistakes, as not all equipment may be appropriate.

They can also provide guidance on home adaptations and whether you qualify for a Disabled Facilities Grant (DFG). Applying for a grant and adapting your home can take a long time, so try to think ahead, rather than waiting until point of need.



For more guidance, see information sheets:

10C – *Disabled Facilities Grants* and 11E – *Environmental controls*

Preparing for an assessment

When you ask for an assessment, find out if they have any guidance about the eligibility criteria they will use to measure your needs. This can help you understand the rules and use the words they use to describe your needs at your assessment. This can make the discussions easier.

The rules they follow should be based on the Acts covering your rights. See section 2: *What are my rights?*

They can only note down needs they are made aware of during the discussion. They may be unfamiliar with the condition and won't know the difficulties you face.

Make your needs known and pass on details of your MND care team if you can. With your permission, they may be able to add further information to the assessment, including how MND is likely to progress. A co-ordinated approach between health and social care can help to improve the level of care you receive.

The person doing the assessment is likely to be looking at your strengths. In other words, what you can do and your ability to adapt to any changes. You are the expert in how your condition or caring role is affecting you. Try not to make light of any problems and think about your needs on bad days.

When answering questions, provide as much detail as you can to help you get the right level of support.

Example of how to answer the questions:

Don't say:

'I find it difficult to get dressed.'

Do say:

'I cannot do up buttons or zips anymore. Even with assistance it can take over an hour to get dressed and I find it very tiring.'

Keep a diary

To help you answer questions with a good level of detail, try keeping a diary for a couple of weeks. Track what you do each day and try to record:

- the times of day or night you need support
- the tasks you need assistance with, such as getting washed or dressed
- how long each activity takes
- how tiring this might be and the recovery time you need
- any additional money you are spending due to being disabled.

Also note if it's more difficult to take part in things you enjoy. Include anything that has been a problem for you, even if it only happens now and then.



"Fatigue is very hard to accept, especially when you have been active in the past."

Make a note of how you would like to be supported – this may be discussed during your assessment or at a following visit, where your support is planned. The more thought you give to this, the better you can guide the assessment to achieve help that will suit you.

It's important to consider your needs in the near future, as well as now. While the assessment can only look at support to meet existing needs, let them know if your needs are changing rapidly. Your diary of daily tasks may help to demonstrate increasing care needs. Without this awareness, support may not be appropriate when it arrives. For example, equipment may no longer be fit for purpose.



"It's very important to think before buying lots of things."

As MND can progress quickly, it is important that your needs and support are reviewed regularly. A review date may be set but, if your needs change, you can ask for a review yourself. Keeping your diary going after assessment can help with review, to explain how needs have progressed.



"The problem with MND is that it is always moving on while you play catch up."

You will be asked questions at the assessment, but it's also an opportunity to ask questions in return. Make a list, so nothing gets forgotten.

Some local authorities send a self-assessment questionnaire in advance to help you prepare for the meeting. This includes topics you need to discuss. Give as much detail as possible, adding additional pages as needed.

Think about the following checklists to help you prepare. If you tick any of the following, you may want to make notes to help describe your needs at the assessment. Ask someone to help with notes if needed.

If your speech and communication ability has been affected, these notes can help the person assessing. It is vital they are aware of all the challenges you face.

Your physical health

- Do your symptoms make it more difficult to do tasks?
- Do you have any other ongoing medical or health problems?
- Do you have physical disabilities, such as problems getting around?
- Do you need any equipment to help you get around?
- Do you have sensory disabilities, such as sight or hearing impairment?
- Have you had any falls and do you need help to manage this?

Your emotional and mental health

- Do you feel your emotional wellbeing is at risk?
- Would you like emotional support or counselling?
- Would you like support with mental health, such as depression?
- Have you noticed changes to the way you process information?
- Have you or those close to you noticed any behaviour changes?
- Do you need help to remain involved in an interest, or find new ones?
- Do you need help to maintain your community involvement?
- Do you need help to maintain your relationships and intimacy?
- Are you safe from neglect and abuse?
- Do you need help to meet your spiritual or religious needs?

Daily living

- Do you have difficulties managing tasks from morning until going to bed?
- Do you have difficulties between going to bed until morning?
- Are there any household routines that are difficult, that you need help with?
- Do you need help with personal care, such as washing and dressing?
- Do you need help getting to or using the toilet?
- Do you need help with eating, drinking and food preparation?
- Do you need any equipment to help you with daily living?
- Can you get to the shops, appointments or other services if needed?
- Would you like guidance on finance, benefits or entitlements?
- Would it help to have support with household tasks?
- Do you have a carer or help from people close to you?
- Do you have backup if your main carer becomes unable to help?

Your environment

- Is your accommodation suitable or in need of adaptation now?
- Will your accommodation need adaptation as your symptoms progress?
- Would environmental controls help you work appliances by remote control?
- Would a personal alarm help you in an emergency situation?
- Do you feel safe in your home?

Where you live

Where you live and want to live is also classed as a need, so it's important to discuss this at your assessment. You may wish for all support to be given where you currently live.

However, if you need to consider a residential or nursing home at any stage, where would you want this to be?

For example, do you have family or friends to support you in your area? If not, would a residential or nursing home need to be in a certain area to maintain family relationships?

Other questions you can ask

- What aspects of care and wellbeing does social care cover in this region?
- How do I get urgent out of hours support, such as help from a crisis team?
- How do I get emergency care, if my main carer is unable to support me for any reason?
- Do any of the local services or nursing homes providing emergency care have experience of managing neurological conditions?
- Can I get extra help or funding if something unexpected happens, for example if I urgently need care cover?
- Do you have a directory of local services or care agencies that can assist with my daily care?
- How does a financial assessment work out the amount I need to contribute, for the social care services in my care and support plan?
- If I decide to have direct payments to select my own services, what guidelines do I follow and what records do I have to keep?
- Who can help me manage my direct payments, if I don't want to do this myself?
- How will you check that I'm spending my direct payments correctly?
- Can I change my mind with direct payments and have services arranged for me instead?

What happens during and after the assessment?

Your needs assessment is free, regardless of whether you qualify for services or not. This usually takes place in your home, so the person assessing can see your environment.

The person assessing will ask questions, guided by the assessment form. Ensure you have a way to take notes or record answers, so you can refer to them later. Ask someone to help with this if needed. Most phones and tablet devices can record audio, but tell the assessor you want to do this first.

Your assessment should cover all emotional, psychological and physical care needs. However, if the person carrying out the assessment forgets to ask something and you don't mention it either, it won't be included.

A financial assessment may also be arranged, either during your needs assessment or at a separate meeting. This works out how much you may need to contribute to any services and how much adult social care services will pay. See next section for details.

Following your needs assessment and financial assessment, your care and support plan will be agreed with you. You should be sent your care and support plan within a few weeks, and can request a copy if not. Again, make sure the person assessing your needs understands any urgency, as this can help fast track the process.

Your care and support plan sets out the support to meet your agreed needs and the amount of money to make this happen. It also shows how you want to receive services and how much you may need to pay. Everything can be arranged for you or you can receive direct payments to pay for services yourself. See the next section for details.

4: Who pays for social care?

You receive free healthcare through the NHS in England, Wales and Northern Ireland, but you may need to contribute to the cost of social care.

In England or Wales, your local authority will assess your finances to see how much they need to fund and how much you need to pay towards any agreed services. This is known as means testing. In Northern Ireland, means testing only applies if you are accepting a place in a nursing care home.

Where needed, financial assessment looks at your income and savings. If you have a partner, your share of joint savings will be included, but not their own income or savings.

If you own the property you live in, it will not be counted as capital in your financial assessment when receiving care at home. However, your property may be counted as capital if you move into a care home.

You need to pay for all your care or support services if your savings and capital are above:

- £23,250 in England
- £23,250 in Northern Ireland, when moving permanently into a nursing home for more than 12 weeks
- £50,000 for residential care or £24,000 for care at home in Wales.

These figures are correct at the time of print in 2019, but may change between revisions.

If your savings and capital are below this amount, your local authority or health and social care trust will pay for some or all of your care and support services.

How are services arranged and paid for?

In England

You can:

- have services arranged and managed for you by your local authority, in line with your care and support plan and your agreed 'personal budget' for these services (sometimes known as a 'managed budget')
- have services managed by a separate organisation, agency or provider (known as a 'third party' or 'broker'), who will organise and pay for the services agreed in your care and support plan, in line with your wishes (sometimes known as an 'Individual Service Fund' or 'third party managed budget')
- receive your agreed personal budget in the form of regular direct payments into your bank account, which you use to choose and pay for services yourself
- agree to use a mixture of the above.

In Wales

You can:

- have services arranged and managed for you by your local authority, in line with your care and support plan
- receive an agreed amount of money for services as regular direct payments into your bank account, which you use to organise and pay for services of your own choice
- agree to use a mixture of the above.

In Northern Ireland

You can:

- have services arranged and managed for you by your local health and social care trust, in line with your wishes and agreed care and support plan (sometimes known as a 'managed budget')
- have your direct payments managed by a separate organisation or provider (known as a 'third party' or 'broker'), who will organise and pay for the services agreed in your care and support plan, in line with your wishes (sometimes known as a 'third party managed budget')
- receive an agreed amount of money for services as regular direct payments into your bank account, which you use to organise and pay for services of your own choice
- agree to use a mixture of the above.

Contact your local authority or health and social care trust to find out more.

What happens if I want services arranged for me?

If you want your local authority or health and social care trust to select and organise services for you, let them know in your assessment.

If you are fully self-funding you may have to arrange your own services, but it is still worth asking if any help is available.

If they are paying or part-funding the services you receive, they can arrange services as agreed in your care and support plan.

In this case, your views and choices about how your needs can be best met should still guide the support planning process.

Depending on your needs and circumstances, your local authority or health and social care trust may feel it is in your best interest to arrange services for you.

What happens if I choose to have a third party managed budget?

This way of arranging services is currently only available in England and Northern Ireland. It is sometimes called an Individual Service Fund (ISF) or 'brokerage'.

With this approach, an independent organisation takes responsibility for arranging and paying services, in line with your care and support plan (and your wishes).

The money agreed in your budget is paid directly to the third party, rather than into your bank account – and they do all the record keeping. However, you don't pay for their assistance, as an amount for this is included in your care and support plan if you choose this option.

If you are interested in a third party managed budget, ask for information at your needs or carer's assessment.

What happens if I receive direct payments?

Accepting direct payments enables you to select and pay for services that you choose.



"It works very well for me. I have a very good care manager who helps me a lot and has known me for years now."

This can help you employ your own care staff and have the same helpers, or control the times services are provided, when you most need help.



"If I had different help all the time, they wouldn't get used to what I need."

What do I need to think about with direct payments?

Ask about the amount of work involved with direct payments at your assessment, or when you receive information about your budget. This may help you decide whether direct payments are right for you.

You can ask a trusted family member or a friend to help you manage direct payments. Discuss this during your assessment, as adult social care services need to be aware of anyone involved. They can also advise on the best way to approach this.

You may want to think about the following questions before choosing direct payments:

- Will I be able to manage all the arrangements if my needs change rapidly?
- Am I likely to be spending time in hospital for treatment and how will this affect any arrangements I make?
- Do I feel confident about managing records, receipts or employer responsibilities?
- Do I trust a family member or friend to do this on my behalf and would they be confident or willing to take this on?
- Am I happy to use a third party organisation or a broker to manage my payments?
- Will it be easy to find services for myself, in my area?
- Am I happy for my local authority to arrange and manage my care?



"We have a problem recruiting as we are in a rural area...with social services carers we knew we would always have cover."

If you choose direct payments and then change your mind, contact adult social care services to have your services managed in a different way.

How do I manage direct payments?

Once your care and support plan has been agreed, you need to set up a separate account that adult social care services can transfer the money into each month. It can only be used for your direct payments and must be a:

- bank or building society account
- national savings account
- or post office account.

You will need to:

- keep records, receipts and forms supplied by adult social care services, for them to check you're spending the money correctly (you will be shown how to do this)
- take on the role and responsibility of an employer if you want to employ a carer to help you on a regular basis (known as a 'personal assistant').

If you become an employer, you will have certain legal responsibilities, particularly with:

- pay, holiday pay and statutory sick pay
- terms and conditions
- tax and national insurance
- notice.

You will also need to set up and pay into a pension for anyone you employ who works in the UK and:

- earns more than £10,000 a year
- is aged between 22 and the current state retirement age.

Find more detailed information about your responsibilities as an employer at: **www.gov.uk/contract-types-and-employer-responsibilities**

And more on employing personal assistants, and a toolkit with template job descriptions, contracts and application forms at: **www.employingpersonalassistants.co.uk**

For Northern Ireland, see: **www.nidirect.gov.uk/articles/employing-a-professional-carer-or-personal-assistant** or contact the Northern Ireland centre for Independent Living: **www.cilni.org**

How can the money be used?

“Being supported by a care company brings its stresses and challenges, but provision of committed compassionate care workers can help families immensely.”

Your personal budget in England, or agreed amount in Wales and Northern Ireland, can only be spent on services agreed in your care and support plan.

Among others, these services might include:

- personal care, such as help with bathing and dressing
- support with food preparation, and eating and drinking
- respite care to support you and help your main carer get a break
- complementary therapies
- help to pay for a hobby or social activity to support your well-being, such as going to the cinema.



For more about complementary therapies, see:
Information sheet 6B – *Complementary therapies*



For information on prolonging hobbies and interests with MND, see our guide:
Making the most of life with MND

Your budget cannot be spent on:

- cigarettes, alcohol or gambling
- help, care or equipment that should be provided by adult social care services or the NHS (statutory services) – although these may still be covered in your care and support plan
- everyday costs that your own money or other benefits should pay for, like food, transport or rent
- care in a care home, unless this is for short term respite care (this may be allowed in Wales – contact your local authority for more information)
- employing a family member who lives in the same household as you (there may be times when this is allowed, depending on your local authority or health and social care trusts guidelines)
- anything illegal.

Your personal budget will be regularly reviewed. If your needs change, the amount of money allocated to you will be adjusted to help meet them.



“Your financial support needs change as the illness progresses.”

Carers can also only spend the budget or agreed amount on services shown in their support plan. These might include:

- help with housework or gardening
- training courses
- a leisure course or gym membership.

A carer’s assessment should also explore ways for a carer to take a break, including respite care to support you in their absence.

There is normally a charge for respite care, but you and your carer may receive help towards this, depending on the outcome of your assessments.

There may also be local funding schemes to help with carer breaks, but this varies across regions. Voluntary organisations can often help.



“As a carer, time off would be good, even just for half a day.”

We offer support grants for people with MND or Kennedy’s disease. We also provide carer grants and grants for children and young people. See our web page at:
www.mndassociation.org/financialsupport

Or contact our MND Connect helpline for guidance. See *Further information* at the end of this sheet for contact details.

Can I add my own money to top up my budget?

Following the means test, you may be asked to pay towards your personal budget or agreed amount. You can add more money as a top up if you wish. However, if you feel your budget is not enough to pay for the care or support you need, ask to be reassessed. (See next section.)

5: Can I challenge a decision?

Yes. If you feel unhappy about the result of an assessment, you can challenge the decision. This is known as making an appeal.

You can appeal if you have been refused an agreed budget for support or think a decision about an agreed budget is wrong. There are three areas you can appeal against:

- the final decision response on one or more questions in the assessment
- the total amount of money agreed to meet your needs
- the way the money for each care need has been calculated and what you have been told you can use this for.

If you wish to make an appeal, contact your social worker from adult social care services. Let them know why you want to appeal, with clear details to support your case. You can do this by writing, email or phone.

If you are still unhappy following their response to your appeal, you can make a complaint to the:

- Local Government and Social Care Ombudsman in England: www.lgo.org.uk
- Public Services Ombudsman in Wales: www.ombudsman-wales.org.uk
- Northern Ireland Public Services Ombudsman: <https://nipso.org.uk>

See *Useful organisations* in section 6: *How do I find out more?* for more contact details.

NICE guideline on MND

You may find the NICE guideline on MND helpful. This set of recommendations is provided by the National Institute for Health and Care Excellence.

While not legally binding, health and social care professionals are expected to follow the recommendations in the guideline, wherever feasible and appropriate to do so.

Being informed about the guideline can help you open discussions about your care with health and social care professionals and providers. This may help you access more suitable support.



“Whilst the NICE guidelines are not statutorily enforceable, they do pack a punch especially when dealing with the NHS and the local authority. These agencies will have to provide good reason if they choose to depart from the recommendations in the guideline...The full guideline provides a massive bank of essential information for patients, as well as the professionals caring for them.”

We provide resources about the guideline – see *Further information* for details. You can also find the full *NICE guideline on MND* at: www.nice.org.uk/guidance/ng42 and the *NICE quality standard for MND* at: www.nice.org.uk/guidance/qs126

6: How do I find out more?

Useful organisations

We do not endorse organisations, but the following may help you search for further information.

Contact details can change between revisions, but our MND Connect helpline can help (see *Further information* at the end of this sheet for contact details).

Advicenow

Online information on rights and legal issues.

Website: www.advicenow.org.uk

Age UK

Guidance for older people, including how to access benefits and social care.

Address: Tavis House, 1-6 Tavistock Square, London WC1H 9NA

Telephone: 0800 678 1602 (England)

08000 223 444 (Wales)

0808 808 7575 (Northern Ireland)

Email: through the relevant website contact pages

Website: www.ageuk.org.uk (England)

www.ageuk.org.uk/cymru (Wales)

www.ageuk.org.uk/northern-ireland (Northern Ireland)

Citizens Advice

Free, confidential advice to help resolve legal, money and other problems.

Telephone: 03444 111 444 (England, or contact your local Citizens Advice)

0344 477 2020 (Wales)

Website: www.citizensadvice.org.uk (England)

www.citizensadvice.org.uk/wales (Wales)

www.citizensadvice.org.uk/nireland (Northern Ireland)

Disability Law Service

Legal advice and information.

Address: The Foundry, 17 Oval Way London SE11 5RR

Telephone: 020 7791 9800

Email: advice@dls.org.uk

Website: www.dls.org.uk

Disability Rights UK

Information, products and services developed by and for disabled people.

Address: Plexal, 14 East Bay Lane, Here East, Queen Elizabeth Olympic Park, Stratford, London E20 3BS

Telephone: 0330 995 0400

0330 995 0404 (Personal budgets helpline)

Email: enquiries@disabilityrightsuk.org

personalbudgets@disabilityrightsuk.org

Website: www.disabilityrightsuk.org

Employing Personal Assistants

A toolkit to help you employ your own personal assistants.

Website: www.employingpersonalassistants.co.uk

GOV.UK

Online government information about benefits and support in England or Wales.

Website: www.gov.uk

Health and social care trusts (Northern Ireland)

Find contact details for your local health and social care trust in Northern Ireland at:

Website: search for *health and social care trusts* at: www.nidirect.gov.uk

In Control

A national charity to improve personalisation.

Address: Carillon House, Chapel Lane, Wythall, West Midlands B47 6JX

Telephone: 0121 474 5900

Email: admin@in-control.org.uk

Website: www.in-control.org.uk

Local Government and Social Care Ombudsman

Free, independent help with complaints about councils and social care providers.

Telephone: 0300 061 0614

Website: www.lgo.org.uk

MND Scotland

Care, information and research funding for people affected by MND in Scotland.

Address: 2nd Floor, City View, 6 Eagle Street, Glasgow, G4 9XA

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

Website: www.mndscotland.org.uk

NHS

For health advice and NHS online information.

Telephone: 111 for urgent, but non-emergency medical advice 24 hours a day, 365 days a year, in England and some parts of Wales

Website: www.nhs.uk

NHS Northern Ireland (Health and Social Care in Northern Ireland)

Online information about health and social care services in Northern Ireland.

Website: <http://online.hscni.net>

NI Direct

Online government information on benefits and support in Northern Ireland.

Website: www.nidirect.gov.uk

Northern Ireland Public Services Ombudsman

Investigates complaints about public services and care providers in Northern Ireland.

Address: Progressive House, 33 Wellington Place, Belfast, BT1 6HN

Telephone: 0800 34 34 24

Email: nipso@nipso.org.uk

Website: <https://nipso.org.uk>

Patient Advice and Liaisons Service (PALS)

Confidential support about health care in England, including making complaints.

Website: search for PALS at www.nhs.uk
or find officers from PALS at your local hospital.

Public Services Ombudsman for Wales

Investigates complaints about public services and care providers in Wales.

Address: 1 Ffordd yr Hen Gae, Pencoed CF35 5LJ

Telephone: 0300 790 0203

Email: ask@ombudsman.wales

Website: www.ombudsman-wales.org.uk

Regulation and Quality Improvement Authority (RQIA)

Contact RQIA to find out or complain about care providers in Northern Ireland.

Address: 9th Floor Riverside Tower, 5 Lanyon Place, Belfast, BT1 3BT

Telephone: 028 9536 1111

Email: info@rqia.org.uk

Website: www.rqia.org.uk

References

References used to support this document are available on request from:

Email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ

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Further information

You may find the following information sheets helpful:

1A – *About the NICE guideline on motor neurone disease*

6A – *Physiotherapy*

6B – *Complementary therapies*

10A – *Benefits and entitlements*

10C – *Disabled Facilities Grants*

10D – *NHS Continuing Healthcare*

10E – *Work and MND*

10F – *Personal health budgets*

10G – *Support for families with children*

11C – *Equipment and wheelchairs*

11E – *Environmental controls*

You can also refer to our guides:

What you should expect from your care – our pocket booklet featuring the main points from the NICE guideline on MND, to help open conversations with health and social care professionals.

Living with motor neurone disease – our guide to MND and how to manage its impact.

Caring and MND: support for you – comprehensive information for family carers, who are supporting someone living with MND.

Caring and MND: quick guide – the summary version of our information for carers.

You can download most of our publications from our website at:

www.mndassociation.org/publications or order in print from our helpline MND Connect, who can provide additional information and support:

MND Connect

Telephone: 0808 808 6262

Email: mndconnect@mndassociation.org

MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park,
Northampton NN3 6BJ

MND Association website and online forum

Website: **www.mndassociation.org**

Online forum: **<https://forum.mndassociation.org>** or through the website

MND Association Benefits Advice Service:

Our trained advisers can help you identify benefits you may be able to claim if living with MND or Kennedy's disease. This service is provided by Citizens Advice Cardiff and the Vale, and Advice NI. The service is available by telephone or email for people living in England, Wales or Northern Ireland. There is a web chat facility in England or Wales. We may be able to arrange for an interpreter to join your call with an adviser if you struggle with English and have nobody to speak on your behalf.

Telephone: 0808 801 0620 (England and Wales)
0808 802 0020 (Northern Ireland)

Website: **www.mndassociation.org/benefitsadvice**

MND Support Grants and equipment loan

Telephone: 0808 802 6262

Email: support.services@mndassociation.org

Website: **www.mndassociation.org/getting-support**

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with or affected by MND, or Kennedy's disease. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

To feedback on any of our information sheets, access our online form at:

www.smartsurvey.co.uk/s/infosheets_1-25

You can request a paper version of the form or provide direct feedback by email:

infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ

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