

10B

What is social care and how does it work?

Information for people with or affected by Motor Neurone Disease (MND) or Kennedy's disease

With motor neurone disease (MND), there may come a time when you need professional support with daily routines, personal care or equipment to help maintain independence. This type of support is known as social care and explored in this information sheet. If you're living with Kennedy's disease, you may experience similar symptoms and also need support. The content includes:

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?



Patient Information Forum

This content has been evidenced, user tested and reviewed by experts. See: piftick.org.uk



This symbol highlights quotes from people living with or affected by MND or Kennedy's disease.



This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in section 6: **How do I find out more?**

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	If you are disabled, a carer or on a low income, financial support may be available from the Government in the form of benefits. This is sometimes through local authorities (England and Wales) or health and social care trusts (Northern Ireland). Disability benefits such as Personal Independence Payment (PIP) are paid separately from any social care support you receive.
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 (Northern Ireland)	An assessment from adult social care services to work out your needs and if 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: Who pays for social care?
Individual Service Fund (ISF) (England only)	In England, using a third party to receive and manage your direct payments is called an Individual Service Fund (ISF). The third party arranges and pays for services agreed in your support plan, within your budget and preferences. In Northern Ireland, the term ISF is not used, but a third party can still manage your budget through self-directed support.
Integrated Personal Budget (England only)	A combined budget to be used for both health 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 what support you need, and whether you qualify for support. In Northern Ireland this is known as a community care assessment.
NHS continuing healthcare (CHC)	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, but a similar package of support may be offered – contact your local health and social care trust for guidance. CHC is also known as continuing care.
personal budget (England only)	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 (England only)	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.
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.



See our resources:

- information sheet: **10A Benefits and entitlements**
- information sheet: **10F Personal health budgets**
- information sheet: **10D NHS Continuing Healthcare**
- animation: **What is NHS Continuing Healthcare (CHC)?**

Nations and regions may use varied approaches to social care. This sheet provides an overview and we have noted differences where possible with expert review. However, we recommend using this sheet with your health and social care professionals to help you find out what is available in your area.



Watch our animation called **What is Social Care?** at: mndassociation.org/animations for a quick summary with subtitles and voice over.

2. What are my rights?

Being aware of your rights can help you get an assessment, access support and find the information you need.

Knowing your rights does not mean you will get social care support. You still need to be assessed to see if you qualify.



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

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

- information about social care, such as 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.



See section 3: **How do I get assessed?**

What about carers?

These rights also apply for unpaid or family carers.

We provide more resources to help carers think about their own wellbeing, including content about carers' rights, carer's assessment and possible support, such as help to take a break.



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

What about financial support?

Whether or not you qualify for social care, you may qualify for benefits. Seek support from a benefits adviser or call our MND Association benefits advice service.



See section 6: **How do I find out more?** for contact details and other resources.

How are my rights covered in law?

In England and Wales your local authority is legally responsible for assessment and provision of support. See: **[gov.uk/find-your-local-council](https://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: **nidirect.gov.uk**

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

In England

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

In Wales

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

In Northern Ireland

Social care in Northern Ireland is based on a number of Acts and Orders. Find out more by searching for: social services, at: **health-ni.gov.uk**

3. How do I get my needs assessed?

Who provides the assessment?

Adult social care services usually arrange and carry out your needs assessment or carer's assessment.

In England and Wales contact your local authority to arrange this. Find your local authority at: [gov.uk/find-your-local-council](https://www.gov.uk/find-your-local-council)

In Northern Ireland contact your local health and social care trust to arrange this. In law, the Trust where the person lives at that time has responsibility. Search for: health and social care trusts, at: 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.

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 speed up the process.

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.



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

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. Sometimes an OT is present at your social care assessment, ask about this before your assessment.



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

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.

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. You can ask a family member, friend or other trusted person to support you as an advocate.

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."

With MND or Kennedy's disease, you may find it takes longer to complete routine tasks. You may even need help with activities like washing, dressing or cooking. Without support, your wellbeing or safety may be 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 should 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?



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

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.

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, household or daily tasks, and taking prescribed medication
- 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.



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

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 needed with an occupational therapist. This may be arranged as part of your social care assessment, or separately.

If you have children or dependants living with you, then your needs assessment should take into consideration the whole family. For example, any children living with you may benefit from additional care and support being put in place.

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.



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

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.

An occupational therapist (OT) 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. An OT can advise on likely future needs too.

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.



See information sheet: **10C Disabled Facilities Grants and home accessibility.**

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.

They can only note down needs they are made aware of during the discussion. As they may be unfamiliar with MND or Kennedy's disease, they may not know the type of challenges you face or the level of impact.

Make your needs known and give the 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 support 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 give you most benefit.

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.

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 'yes' to any of the following, 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?



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

Where you live

Where you live and want to live is also classed as a need, so 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 a family member, friend or trusted person 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 speed up 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.

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.

What is meant by means testing?

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, the 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.

It is important to give them information about any additional costs you face due to your disability. For example, purchasing additional clothing, hiring a gardener or cleaner and purchasing aids, known as disability-related expenditure.

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 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, who may use a supporting organisation, in line with your care and support plan and agreed with you
- 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'.

If you live in Wales, local authorities can help you manage your direct payment if needed. They may use a support organisation for this. You may be able to choose which organisation helps. Search for the direct payments page on your local authority website to find out more.

With a third party managed budget, an independent organisation takes responsibility for arranging and paying for your 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 to pay for this is included in your care and support plan if you choose this option.



"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."

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



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

What happens if I receive direct payments?

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

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.



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

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.

Think about the following before choosing direct payments:

- Will I be able to manage all the arrangements if my needs change rapidly?
- Am I likely to need time in hospital for treatment and will this affect any plans?
- 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?

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



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

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 legal responsibilities, such as:

- 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:

[gov.uk/contract-types-and-employer-responsibilities](https://www.gov.uk/contract-types-and-employer-responsibilities)

For Northern Ireland, see:

nidirect.gov.uk/articles/employing-a-professional-carer-or-personal-assistant

Or contact the Northern Ireland centre for Independent Living: **cilni.org**

How can the money be used?

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
- support to take part in social activities and hobbies for your wellbeing, such as going to the cinema.



See information sheet: **6B Complementary therapies** and 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 financial support needs change as the illness progresses.”

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.

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 financial support for people with MND or Kennedy's disease, their carers and children and young people who are affected by a diagnosis in their family. See our web page at: mndassociation.org/financialsupport

Or contact our MND Connect helpline for guidance.



See section 6: **How do I find out more?** for contact details and more about our services.

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, make a complaint to the:

- Local Government and Social Care Ombudsman in England: **lgo.org.uk**
- Public Services Ombudsman in Wales: **ombudsman-wales.org.uk**
- Northern Ireland Public Services Ombudsman: **nipso.org.uk**



See section 6: **How do I find out more?** for more on other organisations.

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.



“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.”

While not legally binding, health and social care professionals are expected to follow the guideline recommendations, wherever feasible and appropriate to do so. This means that being informed about the guideline can help you open discussions about suitable care and support with health and social care professionals, and providers.



See section 6: **How do I find out more?** for our resources in further information, including publications based on the NICE guideline for MND. See the full NICE guideline at: **nice.org.uk/guidance/ng42**

6. How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

Advicenow

Online information on rights and legal issues.

Website: **[advicenow.org.uk](https://www.advicenow.org.uk)**

Age UK

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

Website: **[ageuk.org.uk](https://www.ageuk.org.uk)** (England)
[ageuk.org.uk/cymru](https://www.ageuk.org.uk/cymru) (Wales)
[ageuk.org.uk/northern-ireland](https://www.ageuk.org.uk/northern-ireland) (Northern Ireland)

Citizens Advice

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

Tel: 0800 144 8848 (England)
0344 477 2020 (Wales)
Website: **[citizensadvice.org.uk](https://www.citizensadvice.org.uk)** (England)
[citizensadvice.org.uk/wales](https://www.citizensadvice.org.uk/wales) (Wales)
[citizensadvice.org.uk/nireland](https://www.citizensadvice.org.uk/nireland) (Northern Ireland)

Disability Law Service

Legal advice and information.

Tel: 020 7791 9800
Email: advice@dls.org.uk
Website: **[dls.org.uk](https://www.dls.org.uk)**

Disability Rights UK

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

Tel: 0330 995 0400
Email: enquiries@disabilityrightsuk.org
Website: **[disabilityrightsuk.org](https://www.disabilityrightsuk.org)**

Government information

Online government information about benefits and support.

Website: **[gov.uk](https://www.gov.uk)** (England and Wales)
[nidirect.gov.uk](https://www.nidirect.gov.uk) (Northern Ireland)
[gov.scot](https://www.gov.scot) (Scotland)

In Control

A national charity to improve personalisation.

Tel: 0121 474 5900
Email: admin@in-control.org.uk
Website: **[in-control.org.uk](https://www.in-control.org.uk)**

Local Government and Social Care Ombudsman

Investigates complaints about councils and other relevant public bodies in England.

Tel: 0300 061 0614

Website: **lgo.org.uk**

MND Scotland

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

Tel: 0141 332 3903

Email: info@mndscotland.org.uk

Website: **mndscotland.org.uk**

NHS and UK healthcare

Information about NHS services and healthcare across the UK.

Te: 111 (England, Wales and Scotland)
for Northern Ireland, see individual trust contact page

Website: **111.nhs.uk** (For England)
111.wales.nhs.uk (For Wales)
hscni.net (For Northern Ireland)
nhs24.scot (For Scotland)

Northern Ireland Public Services Ombudsman

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

Tel: 0800 34 34 24

Email: nipso@nipso.org.uk

Website: **nipso.org.uk**

Patient Advice and Liaisons Service (PALS)

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

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

Public Services Ombudsman for Wales

Investigates complaints on public services and independent care providers in Wales.

Tel: 0300 790 0203

Email: ask@ombudsman.wales.org.uk

Website: **ombudsman.wales**

Regulation and Quality Improvement Authority (RQIA)

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

Tel: 028 9536 1111

Email: info@rqia.org.uk

Website: **rqia.org.uk**

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Gillian Thomas	WH SCT Macmillan Specialist Palliative Care Social Worker, Hospital and Primary Care Complex, Omagh, Northern Ireland.
Ingrid Unsworth	Specialist Occupational Therapist, Betsi Cadwaladr University, Health Board, Wales.

References

References used to support this resource are available on request:

Email: infofeedback@mndassociation.org

Or write to:

Information feedback,
Motor Neurone Disease Association
Francis Crick House
6 Summerhouse Road
Moulton Park
Northampton NN3 6BJ

Further information

We offer a wide range of information about MND and Kennedy's disease. You may find the following resources helpful, relating to this sheet.

Information sheets

- 1A About the NICE guideline on motor neurone disease
- 6A Physiotherapy
- 6B Complementary therapies
- 10A Benefits and entitlements
- 10C Disabled Facilities Grants and home accessibility
- 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

Booklets

What you should expect from your care (NICE guideline tool)
Caring and MND - quick guide

Large guides

Living with MND
Caring and MND - support for you

Animation

What is Social Care? at: mndassociation.org/animations

Search for information by need at: mndassociation.org/careinfofinder

Find information for professionals at: mndassociation.org/professionals

Download our information at: mndassociation.org/publications

Find information in other languages at: mndassociation.org/languages

Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

MND Connect

Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: **mndassociation.org/mndconnect**

Tel: 0808 802 6262

Email: mndconnect@mndassociation.org

Support services

Find out about our support services at: **mndassociation.org/our-services**

Local and regional support

Find out about our branches and groups at: **mndassociation.org/local-support**

MND Association Benefits Advice Service

For help to identify claims and how to apply, visit: **mndassociation.org/benefitsadvice** or call our MND Connect helpline.

Tel: 0808 802 6262

MND Association website and online forum

Website: **mndassociation.org**

Online forum: **forum.mndassociation.org**

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 MND or Kennedy's disease, their families and carers.

Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns, and applications for funding.

To give feedback on this or any of our information sheets, access our online form at: **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
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton NN3 6BJ

Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or you are a carer, contact us at: **infofeedback@mndassociation.org**

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