

# Living alone

**with motor neurone disease (MND)  
or Kennedy's disease**





**“It’s crossed my mind that many others with MND or Kennedy’s disease may be ‘flying solo’, like myself. It didn’t seem to be addressed, but this booklet will support people like me.”**

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*Patient Information Forum*

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## How can this booklet help me?

With motor neurone disease (MND) or Kennedy's disease, daily life changes and you need help as your symptoms progress. If you live alone, help may not be nearby, so planning ahead becomes essential. But where to begin?

This booklet explores the likely challenges when living alone with either condition and offers information resources that can help. We have a range of guidance about symptoms and care.

The MND Association supports people affected by either MND or Kennedy's disease, their families and carers.



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

## How do I download or order your information resources?

Download our information resources, as listed in this booklet, at: **[www.mndassociation.org/publications](http://www.mndassociation.org/publications)** or search by need using our *Care information finder* at: **[www.mndassociation.org/careinfofinder](http://www.mndassociation.org/careinfofinder)**

You don't have to read everything at once. If you would like help to find information resources to meet your needs, ask our MND Connect helpline. You can also order printed copies through MND Connect:

Telephone: **0808 802 6262**

Email: **[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)**



See also section 5 *How do I find out more?* for a list of suggested resources.

# 1: How do I manage the impact of living alone with MND or Kennedy's disease?

With MND or Kennedy's disease, guidance on care and treatment is the same when living alone, as when living with a partner, family or friends. However, you may need to make earlier decisions about support without help at hand.

Finding out that you have a life-changing condition takes its toll. Your life plans, career, emotional wellbeing, relationships and social life may all feel shaken. If you're looking for help on how to think ahead, this booklet may be a useful starting point.

There could be many reasons why you live alone. You may be:

- living independently as your preference
- living with someone who is dependent on you
- sharing accommodation, but without support
- going through a separation or widowed
- living with family members about to leave home (for example, a young person going to university)
- living far away from family or friendship connections.



**"I have always had to do things on my own with no family. Others may have that, but I don't."**

You may even be living with someone, but some relationships have problems. Whatever your situation, we are here to provide guidance and support.

Take time to adjust to the shock of the diagnosis. When ready, find out as much as you can about the likely challenges ahead. There is a lot of help available if you know who to contact.

How you move, walk, talk, eat, drink and breathe can change with MND or Kennedy's disease. For some people with MND, thinking and behaviour may also be affected.

With MND, you may have a different form to someone else with the condition, such as amyotrophic lateral sclerosis (ALS), primary lateral sclerosis (PLS), progressive muscular atrophy (PMA) or bulbar onset MND, known as progressive bulbar palsy (PBP).

The speed at which symptoms progress varies between the forms. For example, PLS and PMA tend to be slower, compared to ALS and PBP. Kennedy's disease is also a very slow progressing condition.

Not all symptoms happen to everyone, but you are likely to experience multiple affects. Finding different ways of doing things and advance planning are key to well-timed care solutions.



**"I have been thinking what I have learned since the onset of my illness, being alone and coping with it."**

Neurological disease may feel as though it's always 'a step ahead' of you, as symptoms keep progressing. Discuss your needs as soon as you can with your health and social care professionals. Trustworthy information can help you make choices that feel right for you.

Exploring choices helps you find out where you have control over treatment and future care. This won't feel easy, but it can reduce fear of the unknown, help you adapt and make life more comfortable.

When you know what to expect, you'll know what you want to put in place and who to ask when you do need support.



**"When living alone with this condition, it can be hard to ask for help. I needed to go to hospital one night... but I 'winged it' to the next morning because I didn't want to bother anyone. When you're on your own, that can be an issue, even if you have friends."**



For helpful guidance, see:

- section 4 *How can the MND Association help me?*
- section 2 *What big decisions am I likely to face?* including our *MND Checklist* to help you think about your needs.

## How do I deal with the emotional impact?

Your diagnosis may have been a huge shock, but if it took a long time, it can bring relief to finally know what's happening. MND and Kennedy's disease may even be confused with each other, but once confirmed, you can find appropriate help.



**"It took some time to get a formal diagnosis. On the 1 February my neurologist told me I possibly had MND. On the 8 July that changed to probably MND. After a long drawn-out process and many tests, MND was definitely confirmed in June of the following year."**

You are likely to face challenging emotions, from anger, resentment and fear, to a sense of isolation and ongoing loss. It can be even more difficult to manage mixed emotions when living alone.



**"Dealing with a diagnosis like this isn't easy..."**





See our booklet *Emotional and psychological support* for guidance on therapies that can help.

If you find it difficult to accept the diagnosis, or feel in a constant low mood, seek guidance.

It can also help to find a sense of purpose, especially if you decide to stop working or can no longer be as active physically.



**“When I became wheelchair bound at home, I needed to find something that would occupy me and finished my Economics Degree. The satisfaction and feeling of self worth was so powerful...”**

You may have people you can easily turn to for emotional support, but if not, ask for help from:

- your health and social care professionals
- your GP, if you would like a referral to specialists in emotional wellbeing, neuropsychology or palliative care
- someone you trust, such as a faith or spiritual lead
- our helpline team, MND Connect: **0808 802 6262** or **mndconnect@mndassociation.org** to help you contact services, our regional staff, and our branches and groups
- Samaritans 24-hour support service on **116 123**.



**“A multidisciplinary team is equally as important for people with Kennedy’s disease as for people with MND.”**

With Kennedy’s disease, you can also contact the Kennedy’s disease clinic (based in London) for multidisciplinary support, which means you’ll be helped by a range of specialists: **020 3448 3517** (Enquiries) or **uclh.referrals.mnd.care@nhs.net**



## Who needs to know and how do I communicate my needs?



**“I gradually told other people what was happening. I’d just said it was stress-related before that.”**

Who you tell is your choice, but your symptoms will become visible.



**“My legs started ‘freezing’... I had problems with my speech if I became anxious... my muscles were sometimes visually twitching and my strength in my right arm diminishing. Working at the pub, I could no longer carry a bar meal in each hand. I was falling on occasions. (Not drink induced!)”**

At some point, you will need to explain your needs to family, friends and colleagues, or health and social care professionals. Depending on your situation, you may also need to tell some organisations, for practical or legal reasons.



**“I had to report my illness to the DVLA and car insurance company. I’m still able to drive, but only short distances.”**

If you have speech and communication problems, you may need help from your bank to manage your account. Explain to them before trying to make any account changes, so your needs are known.



**“I failed a bank security check on the phone as they wouldn’t accept mine or my friend’s explanation that I had MND. After complaining, I now have it flagged on my account.”**

If your speech, communication, expression or ability to gesture have been affected, much can be done to help, including communication aids and voice banking (recording your voice for future use on mobile devices or computers). Ask your GP for referral to a speech and language therapist to assess your needs.



See section 4 *How can the MND Association help me?* for details about our Communications Aids Service and find more guidance in information sheets:

- 7C - *Speech and communication support*
- 7D - *Voicebanking and message banking.*

If you find it difficult to manage lengthy conversations and get very tired, it helps to have someone speak on your behalf (known as an advocate). This can be a trusted friend or a professional advocate.



**“If you live alone with MND, ask someone to go with you to major appointments... even an external advocate. I find it helps with my speech and tiredness. Go over things before you arrive, so they know how you feel and can be your voice if needed.”**



See our booklet *Telling people about MND*, which includes guidance about advocacy, where someone helps communicate your needs.



**“I loved talking to anyone in my former life... My speech varies and I tell people why, as it helps. In general, they’re really good about it.”**

## **Will my relationships change?**

With a huge shift in life, it can affect how we relate to others and how they relate to us, but there is no right or wrong path. Take time to deal with the changes in a way that feels right for you.



**“Of course, my sense of who I am has altered a bit, but I don’t want my condition to do that... or allow it to define me. While I can, I want to use what I have.”**

You may find it helps to employ techniques like mindfulness, where you focus on how you feel in the moment. This can be calming and helps you explore what's most important to you, without judgement.



See our booklet *Emotional and psychological support* for more about approaches to help you adjust.

Other people may not respond to you in quite the same way as before your diagnosis. This could show a lack of understanding about your condition. They may also be wary of upsetting you or hiding their own emotions about what's happening.

Being open about any changes can really help other people feel less wary, whether they are wider family members, friends or colleagues.



**"I don't hide from it, but make a joke instead. If I'm friendly and relaxed when I go out, people relax with me. I tell them what's wrong and that it makes me wobbly, but I can still listen and understand. It seems to avoid them becoming worried."**



Openness can also help you communicate changing needs in intimate relationships. If you are seeking guidance about sex and intimacy, ask your health and social care team for help or referral to someone with expertise in this area.

We provide information to help, whether you are in a sexual relationship or single and seeking intimacy, and regardless of gender or sexual preferences.



See our booklet *Sex and relationships with MND*.

With Kennedy's disease, you may also need guidance from your professionals about hormonal changes, which can affect you sexually.



See our booklet *Kennedy's disease*.

With both conditions, you'll meet a range of health and social care professionals. Being open lets them know you're willing to discuss certain subjects. They can also help discussions between you and those close to you, even if those people don't live with you.



**"Try and build up a relationship with your professionals, especially if you see a multidisciplinary team (MDT). I really like my gang and enjoy seeing them, so my appointments aren't intimidating now... more like a social event."**



See section 3 *Who can help me?* for more about professionals.



**"Recently, I managed the step into a cafe without taking a tumble. I was so pleased with myself, I promptly tripped and fell flat on my face inside. As I hit the floor, everyone turned to stare, so I popped my head up and said as loudly as I could "I've arrived!" They all roared with laughter and helped me. Helping others relax can help you cope..."**

## How do I manage social events and interests?

As your condition can affect movement, mobility, speech and communication, you may get frustrated if it impacts on your social life and hobbies. Energy levels can also drop if you have fatigue or constant tiredness.

Your diagnosis brings change, but learning to do things in a different way can be of huge benefit to your sense of wellbeing. There may come a time when you have to adapt how you take part in activities.



**“My most effective tactic is my sense of humour. I tend to laugh at my condition. I may not be able to control my body all the time, but I can control how I think about it.”**





**"I loved playing netball when young, badminton and swimming as I aged. I've also loved walking and rambling, particularly long-distance walks. I've never liked sitting around at home and always made an effort to get out and about doing things, achieving things."**

It can feel as though social options become limited more quickly when living alone with a challenging condition. You don't have immediate company, but there are ways to adapt and find help.



**"So I can't play any sport anymore? Then I shall watch others play and go to the pub after."**



See our booklet *Making the most of life with MND*, which looks at ways to approach your interests, including examples from other people with the condition.

Getting out and about to do things you enjoy is of huge benefit. It can take a bit more planning, such as finding the right transport or adapted holiday accommodation.



**"I've always been independent and accustomed to going places on my own, but I find being prepared helps. You do get anxious (and more quickly with MND)... I ask a friend and use my Blue Badge. They love that they can park anywhere. It's like we have Willy Wonka's golden ticket!"**



See our booklet *Getting around*, which explores transport, driving and travel, including help from taxi services and guidance on assisted holidays.

You may also find your diagnosis leads you to new interests, groups and relationships, that fulfil you in unexpected ways.



See section 4 *How can the MND Association help me?* for more details about our regional support.

## What is emotional lability?

Emotional lability (known as pseudobulbar affect) can affect some people with MND. It's more common if there are problems with swallowing and speech. With this symptom, you may laugh or cry at inappropriate times, or in an exaggerated way. This can be distressing and difficult to stop.

If you can, it helps to explain or show a written message to let others know it's a symptom. These outbursts are usually short and in most cases emotional lability reduces over time.

Ask your GP or neurologist for guidance.



See our booklet *Emotional and psychological support* for more about ways to manage mixed emotions, therapies and emotional lability.

## Will there be changes to the way I think or behave?

Some people with MND have changes in the way they process information or behave with others. You may not be aware of this happening, but others may notice. It can help to make more complex decisions early on, but these effects are usually mild and don't impact on daily living.

In some cases, the changes are more severe and more support is needed. Ask your healthcare team if you are worried about this. You can be referred to a neuropsychologist or other specialist for screening to assess if you're affected.



See our booklet *Changes to thinking and behaviour with MND* for more information.

## 2: What big decisions am I likely to face?

In this section, we explore the following questions:

- **How do I know what to think about when diagnosed?**
- **What are the likely challenges I'll face?**
- **How can I plan for the unexpected?**
- **Can my healthcare team help me plan for the unexpected?**
- **Do I need to adapt my home or move into residential care?**
- **What if I'm discharged from a stay in hospital?**
- **What if I look after someone else?**
- **What if I have a pet?**

### How do I know what to think about when diagnosed?

Although not all symptoms of MND or Kennedy's disease happen to everyone who is diagnosed, existing symptoms do get worse. Kennedy's disease progresses very slowly, and some people have a slower form of MND, but your healthcare team can provide guidance.



**“Professionals want you to visualise what's ahead, and think and plan... I understand why, but I do find that hard.”**

Planning ahead can help you prepare, make decisions about treatments and arrange the support you prefer. Choices are easier to provide if thought about in advance.

Planning can also help prolong independence, with timely equipment, home adaptations and environmental controls.



You may find our *MND Checklist* helpful, as it asks questions about your possible future needs, with options to think about. This cannot replace discussion with your health and social care professionals, but the *MND Checklist* can help you work out what you want to ask them.

Open conversations with your professionals can help with decision making and how to maintain the best quality of life possible.



Our *MND Checklist* is available in print or online at: [www.mndassociation.org/mndchecklist](http://www.mndassociation.org/mndchecklist) See also section 3 *Who can help me?* for more about professionals.



**“We have been using the MND Checklist at diagnosis for a while and every patient independently came back and told us how useful, easy to use and helpful it has been... some felt more empowered and less overwhelmed... One reported that it made them feel less nervous and steered them to think about things they otherwise wouldn’t have done.”** Anthony Hanratty, Advanced Nurse Specialist – Middlesbrough MND Care Centre



## What are the likely challenges I'll face?

Adapting to disability can feel overwhelming. When living alone, making choices may feel daunting. Group things you need to tackle to help you focus on your most urgent needs.

If you need help with any of this, ask your health and social care professionals or contact our MND Connect helpline team, who can also put you in touch with our local branches and groups for support.



See section 4 *How can the MND Association help me?* and section 5 *How do I find out more?*



**“Recognise the fact you can’t do what you used to do. Don’t be too proud to admit this and ask for help.”**

Think about your support network, which may be a mix of family, friends, colleagues and professionals, or just one or two of those groups. Work out who can help and how, and don’t be afraid to ask. Most people want to help but don’t know what you need.

As well as the emotional impact, challenges usually fall into the following four areas.

### 1) **Practical**

You’ll find different ways to do things, but support becomes essential, especially if you live alone. Adapting your environment can help, but as symptoms progress, you’ll need personal support.



**“I haven’t had a needs assessment. I haven’t reached that point yet... A friend helps me change bedding, as I no longer have the strength for that.”**

Contact adult social care services, at your local authority or health and social care trust, for a needs assessment. Find out about choices, create a care plan and ask for a review if things change.

Explore options as early as you can. Services and equipment take time to arrange and it can be frustrating and costly if solutions no longer meet your needs by the time they arrive.



**“When adapting your life, home and transport, try to picture the worst case scenario, even if it’s daunting. Or you may have to start again when the condition worsens.”**

Ensure you tell your GP and local surgery that you live alone with your condition. This will help them better understand your needs and they may have practical advice as well as medical.



See our *Care information finder* search facility at: **[www.mndassociation.org/careinfofinder](http://www.mndassociation.org/careinfofinder)** then select:

- *Personal care* for guidance on assessment and social care
- *Mobility* for getting around
- *Speech and communication* to communicate your needs.

See also our *Kennedy’s disease* booklet, and our *Living with motor neurone disease* guide at:

**[www.mndassociation.org/lwmnd](http://www.mndassociation.org/lwmnd)**

## 2) Financial

Any condition with disability means extra costs for equipment, home adaptations and more.

If you work, you may need to think about adjustments and flexible hours, or options for leaving employment.

All of this can impact on your standard of living. When living alone, you may not have any shared income. It’s worth finding out whether you qualify for any financial support.



See our *Care information finder* search facility at:

**[www.mndassociation.org/careinfofinder](http://www.mndassociation.org/careinfofinder)** and select the option *Social care and financial support*, to explore guidance about benefits, grants, social care, employment and more.

### 3) Medical

Although neither MND or Kennedy's disease can be cured, there are therapies, medications and equipment to ease symptoms. This can improve comfort and may help energy levels, so you can do more. You are likely to face healthcare decisions about:

- breathing support and assisted ventilation
- support for swallowing problems, such as tube feeding
- medications for symptom control.

If living alone, you may need help with any medical support provided. For example, if you use ventilation, you may need help with the mask. With a feeding tube, you may need help to use the feeds.

At some point, you will likely need part-time or full-time care support. With equipment and care workers, much can be done to help you stay at home. However, if 24-hour medical care is needed, you may be asked to think about a move into nursing care. This can feel emotional, but in case it happens, planning ahead gives you time to find a choice that feels right, rather than waiting until it's needed.



See the heading *Do I need to adapt my home or move into residential care?* later in this section.

See also our *Care information finder* search facility at:

**[www.mndassociation.org/careinfofinder](http://www.mndassociation.org/careinfofinder)** and explore:

- *Swallowing, eating and drinking*
- *Breathing problems*
- *Treatments and medication.*

With MND, you may be offered riluzole, which may have a moderate impact on survival of several months. More drugs are likely to emerge soon from clinical trials.



See more about the latest discoveries and information on clinical trials at: **[www.mndassociation.org/research](http://www.mndassociation.org/research)**

#### 4) Legal

Even if you don't feel ready at first, you may want to get your affairs in order, such as your will. This also includes planning ahead for your future care and advance decisions about treatments. It can help reduce worry to get these things sorted before they are needed.



**"I have a will, but it was done before MND, so needs updating. With family bereavements since, it's no longer correct but on my to-do list."**

When living alone, it may be worth exploring options such as power of attorney. This enables you to legally appoint someone you trust to make choices on your behalf, if you become unable to do so.



**"I have now got power of attorney set up, so my medical needs can be looked after by my friend."**



See our *Care information finder* search facility at: **[www.mndassociation.org/careinfofinder](http://www.mndassociation.org/careinfofinder)** and explore *Planning ahead* for information about advance decisions, including how power of attorney works in different nations.



# How can I plan for the unexpected?

Tackle planning ahead when you feel ready, as this can be emotional. However, waiting until point of need risks frustration and wellbeing. Support takes time to arrange, so early planning helps avoid the need for emergency requests or support. The following may help:

- **Needs assessment:** when having your needs assessed by adult social care services, ask about out of hours support and urgent care, then keep contact details to hand.
- **MND alerts:** use our alerts to raise awareness of your condition (see following pages).
- **Advance care planning:** record your needs, wishes and preferences to help professionals support you in the way you want (see following pages). Your healthcare team can help.
- **Waiting lists:** some health and social care services are stretched, but with treatment, equipment, support or palliative care, it's better to be on the list as early as you can.
- **Home assessment:** ask your GP to refer you to an occupational therapist for a home assessment, equipment, advice on safety and how to prolong independence.
- **Equipment:** you may not want assistive equipment at first, but it can improve quality of life and comfort, and help prolong independence.
- **Environmental controls:** using adapted switches and remote controls can help you operate things in your home, such as doors, curtains, heating, lights and items such as your television. Ask your occupational therapist for guidance.
- **Personal alarm systems:** wearing a personal alarm ensures help if you fall or need emergency support.



**“I have a call alarm, which is very sensitive. If it goes off, the company always contacts me to check if I’m okay. Even if it wasn’t needed, they’re great about it and better to be safe.”**

Planning ahead is useful for everyone, but may be more time sensitive with MND. Being as prepared as you can for your future needs helps reduce anxiety as things progress.



See our *Care information finder* search facility at: **[www.mndassociation.org/careinfofinder](http://www.mndassociation.org/careinfofinder)** with options on *Social care and financial support* including needs assessment and *Planning ahead*, for help on advance decision making.

Keep any medical documents secure, but easy to find if needed in an emergency. Locking them away can make them difficult to access and paramedics need to see these to carry out your wishes.

Advance care planning, providing guidance about your care, and advance decisions about possible withdrawal of treatments (known as an ADRT), can feel daunting.

Your health and social care team can help you through the process, but having the right information and resources gives you the tools to do this.



The MND Association provides the following tools to raise awareness of your condition and communicate your needs:

**Understanding my needs:** a form to record your needs to guide hospital staff or care workers.

**Information sheet 14A - Advance Decision to Refuse Treatment (ADRT) and advance care planning:** guidance on advance planning, advance decisions and power of attorney, with a completed sample ADRT form and a blank form to use if wished.

**MND Alert Card:** a small card to keep in your purse, wallet or pocket, to alert healthcare staff that you have MND. It includes space for you to record key contacts and warns that you may be at risk with oxygen.

**MND Alert Wristband:** a wristband that can be worn at all times to alert medical teams that you have MND and may be at risk with oxygen. A web address also helps professionals find more about urgent support for MND.

You may also find the following resources useful:

**Message in a bottle:** a sticker on your fridge and the inside of your front door tells medical professionals that an information bottle is inside your fridge. The bottle is designed to contain essential personal and medical details, and is free of charge from your local chemist.

**MedicAlert:** a registered charity where you can buy identity bracelets or necklets, to include medical alerts. The system is supported by a 24-hour emergency telephone service. Find details at:  
**[www.medicalert.org.uk](http://www.medicalert.org.uk)**

**Digital Alerts:** search for *Medical ID:ICE* in your app store for alerts 'in case of emergency'. The apps show essential details on the locked front screen of your phone, so emergency responders can see key health information or contacts, even if you are unconscious.



## Can healthcare also help me plan for the unexpected?

Ask your GP for advice about local systems. For example, some ambulance services may hold copies of ADRTs so that paramedics know about your wishes. Local healthcare teams also use other records to record your needs and preferences. These include:

**Summary Care Record:** an electronic record of your basic health information, for healthcare professionals involved in your care. You can add details to your *Summary Care Record*, such as your preferences for future care and advance care planning.

**Electronic Palliative Care Co-ordination Systems (EPaCCS):** these systems exist in some areas to enable end of life and palliative care records to be shared by healthcare professionals.

**Recommended Summary Plan for Emergency Care and Treatment (ReSPECT):** a form to help you and your healthcare professionals agree recommendations for your care in emergency situations, if you become unable to make or communicate decisions. Find out more at [www.resus.org.uk/respect](http://www.resus.org.uk/respect)



## Do I need to adapt my home or move into residential care?



**“There’s just too much going on, but I do need to think about my home.”**

Deciding to move into supported living can feel emotional, but they can offer appropriate support if you need a lot of care. This will depend on your situation, but you are likely to face this if living alone with MND, as symptoms may progress quickly. You may also need to think about this if you need ongoing help with Kennedy’s disease.

Adapting your home or moving into more accessible accommodation may be all you need at first. Ask your GP or social worker for referral to an occupational therapist, who can assess your needs at home.



**“I have two grab rails, one at the front door and one at the back, and a new stair rail that’s easier to grip. I also use a card to get in, rather than fiddling with keys.”**



Think whether you'll need larger installations, like an accessible bathroom, through-floor lift or adaptations to live on the ground floor. Explore what's needed for larger projects as early as possible, as they can take time to fund and for building work to complete.



See our *Care information finder* search facility at: [www.mndassociation.org/careinfocfinder](http://www.mndassociation.org/careinfocfinder) and select:

- *Social care and financial support*, to explore guidance about Disabled Facilities Grants and social care
- *Personal care*, to explore equipment, environmental controls and more.



**“If you can't change something you just have to do your best... I still see it all as a challenge and I'm fighting it. I won't give in and keep going. I'm very stubborn.”**

If living without support, you'll start to need help. At some point with MND, you're likely to need one of the following options:

- a full-time care worker at home, including night care
- residential care, including nursing care
- NHS continuing healthcare, a fully funded package of health and social care delivered at home or in a nursing care home (your health needs must be complex and urgent to qualify).

Find out as much as you can about these options for care, including where costs might apply.



See our resources to help:

- our booklet *Types of care*
- our information sheet 10B *What is social care?*
- our information sheet 10D *NHS Continuing Healthcare*
- our animations *What is social care?* and *What is NHS Continuing Healthcare* at:

[www.mndassociation.org/animations](http://www.mndassociation.org/animations)

Deciding how to receive full-time care can be an emotional process and you may need support to do this.

Start by asking about care options during your needs assessment with adult social care services.

They can listen to your wishes and needs, provide information about local services and options, with guidance on costs and what to expect. Contact your local authority or your health and social care trust to arrange the assessment.



**“When the time comes, I’ll find a nursing home locally. Then friends can still pop in to see me.”**

Your view on when to accept full-time care may be different to others in similar situations, but timing is more urgent when living alone.

For some, accepting more care feels right when mobility prevents independent movement. For others, it’s when they need ongoing breathing support through assisted ventilation.

Thinking about your views on this can help you plan effectively, with lead time to make choices that feel right for you.

If you choose to move into residential care for general support and company, select a dual purpose home that also provides nursing care when needed. This avoids having to move again to access medical support as MND symptoms progress.



See our guidance about *Getting the right treatment or care with MND* at: **[www.mndassociation.org/mycare](http://www.mndassociation.org/mycare)**

This covers what to do if your needs are not being met, but also how to find ratings for nursing homes which can help your decision making.

## What if I'm discharged from a stay in hospital?

You may need follow-on care after an admission to hospital. After discussion with the discharge team, all of the arrangements should be sorted before leaving the ward.

Let the team know if you are worried about going home alone while recovering. If you feel ongoing support may be needed from this point, ask for help to arrange a needs assessment with adult social care services.

If you only need short-term support, you may be offered a stay in a care facility, known as intermediate or reablement care. This type of care usually lasts for a maximum of six weeks.

This can help you recover from any treatment, but your symptoms will still progress, especially with MND. However, they can help you think about your care options during intermediate care.

If you are on any benefits, check if they will be affected during intermediate care. As this type of care is provided free of charge, it may impact on the financial support you receive.



Contact our Benefits Advice Service for guidance:

**[www.mndassociation.org/benefitsadvice](http://www.mndassociation.org/benefitsadvice)**

And see our information sheet 10A *Benefits and entitlements*.

If you know you have a planned hospital treatment, it helps to think about what you might need afterwards and explore possible care options before your admission. This gives time for arrangements to be made and enables more choice because of the lead time.



See our booklet *Types of care* for more about care options.



## What if I look after someone else?

You may have dependents and worry about their needs. They could be children, or adults who need support. You may be in a parental role or helping them as a carer.



**“I was caring for Mum and Dad at the time and didn’t want them to know and worry. So, I kept the diagnosis hidden.”**

If they need supervision or care, contact adult social care services as soon as you can at your local authority or health and social care trust. Even if you don’t need help right now, they can support you all to make choices and arrange support, when necessary. This includes help for young carers if a child or young person gives you support.



Find information to support children and young people affected by MND at: [www.mndassociation.org/cyp](http://www.mndassociation.org/cyp)

## What if I have a pet?

If you have one or more pets, you may need help to care for them. For example, you may need a dog walking service.

If you don't have anyone who can support you or you're worried about future care for your pets, contact the team at Cinnamon Trust: <https://cinnamon.org.uk>

They provide guidance and support for people with pets during life-shortening conditions.



### 3: Who can help me?

Depending on your needs, your health and social care team may be wide, and could include the following or more:

**Neurologist:** for diagnosis and symptom management.

**MND specialist nurse:** for guidance on services.

**MND care co-ordinator:** for linking to points of care.

**GP:** for local care and check ups.

**District or community nurse:** for home visits to monitor your needs.

**Dietitian:** for guidance on nutrition, eating and drinking.

**Speech and language therapist (SLT):** for guidance on swallowing difficulties, and speech and communication support.

**Physiotherapist:** for physical assessment and guidance on exercise.

**Respiratory physiotherapist:** for breathing therapies.

**Pharmacist:** for guidance on medications and ways to take them.

**Occupational therapist (OT):** for support with daily living, assistive equipment and assessment of your needs if adapting your home.

**Orthotist:** for access to orthotics service to be fitted for limb braces and splints, or head and neck supports.

**Neuropsychologist:** for emotional and psychological support.

**Palliative care specialist:** for symptom management, practical guidance, and emotional or spiritual support.

**Social worker:** for assessment of your care needs, help to arrange care services and guidance. Some work through hospices and palliative care, providing emotional as well as practical support.

**Benefits adviser:** for guidance on claims and where you qualify.

**Care worker:** for care support at home.



# What does a multidisciplinary team (MDT) do?

An MDT is where specialists work together in a co-ordinated way, where you usually see several specialists at once.

This helps save you time and energy, but it helps to know what this will be like.



**“It was like a panel interview and so unexpected... If on your own, check what to expect before appointments.”**

For access to an MDT, ask your GP to refer you to an MND care centre or network, a neurological service or the Kennedy's Disease Clinic, which is based in London.



See *Useful organisations* in section 5 for the clinic details and more in our booklet *Kennedy's disease*.

Record discussions on your phone, so you can listen again later and avoid missing something important.



**“Have someone with you at appointments or for phone consultations... having a friend by my side helps greatly.”**



For more about how to get appropriate care, see:

- our booklet *Types of care*
- our pocket booklet *What you should expect from your care*, based on the NICE guideline for MND
- our webpage on getting the right care, [www.mndassociation.org/mycare](http://www.mndassociation.org/mycare)



**“There is a lot of help out there. You are not alone if you are prepared to ‘open the door’ to support.”**

## How can I get information in the format I need?

Your health and social care professionals have a duty of care to support you when making informed decisions. This could mean using communication aids, a different format or language, or an advocate (someone to help you communicate a concern in the way you wish).



Use our Care information finder to find content by need at: [www.mndassociation.org/careinfofinder](http://www.mndassociation.org/careinfofinder) and see:

- our guide *Telling people about MND* for advocacy
- information sheet 1B - *Health information in other languages and formats*
- information sheet 7C - *Speech and communication support*



**“Be honest and say how you are feeling: everyone is different and one size doesn’t fit all.”**

Try not to ‘put on a brave face’ when being assessed. Give clear details of your needs, especially if you live alone without immediate support.

You will probably feel more relaxed with some of your professionals than others. This helps if you need to ask something sensitive. Asking questions tells professionals you’re ready to discuss that subject.



See section 5 *How to find out more* for details about our resources and how to order printed items.

## What if I can’t get to an appointment?

Telephone and video consultations are more common now, but you can ask your GP surgery about home visits from specialists, your community or district nurse, or how to access hospital transport.



**“Find out about home visits, as this reduces stress and anxiety, and reduces dependency on friends for transport.”**

## 4: How can the MND Association help me?

Find our service details in section 5 *How to find out more*, but our support may be of particular value if you live alone with MND or Kennedy's disease. We are here to help with guidance, grants and emotional support.



**“Any way that the MND Association can draw you in and offer support is useful. Reaching out is a two-way process. If they reach out, grab their hand, together is better. I’ve learned this myself and I hope you do also. Go for it.”**



Your first point of contact is through our MND Connect helpline:  
**0808 802 6262** or **mndconnect@mndassociation.org**

The helpline team can:

- provide guidance, information and answer questions
- explain our financial support and services, or direct you to external services
- link you to our regional staff, volunteers, and local branches and groups (where you can meet others affected by MND or Kennedy's disease)
- help explain our MND care centres and networks - see a list at: **[www.mndassociation.org/carecentres](http://www.mndassociation.org/carecentres)**



**“There is a great benefit to be able to talk to someone... someone with whom you can share all your hopes and fears without worrying about the impact this might have.”**

They offer chances to share experiences, tips and contact through social events and support meetings. If this doesn't feel right for you now, you can join at any time.



**“Draw on other people's experience and knowledge with the condition. Over time you become the person with experience to share and that is potentially a boost to your own wellbeing. Maintaining purpose in life is especially important if you live alone.”**

Our online forum is another safe place to share peer support, at: **<https://forum.mndassociation.org>**

You are also welcome to take part in our fundraising, campaigning and volunteering at: **[www.mndassociation.org/getinvolved](http://www.mndassociation.org/getinvolved)**

There is no pressure to do this, but many people living with MND or Kennedy's disease ask for these details. There are lots of opportunities if you do wish to get involved and your needs will be understood.

## 5: How do I find out more?

### Useful 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 *Further information* later in this section).

#### Adult social care services

To arrange a needs assessment or carer's assessment, contact adult social care services.

In England and Wales: search for *find your local council* at  
**[www.gov.uk](http://www.gov.uk)**

In Northern Ireland: search for *health and social care trusts* at  
**[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

In Scotland: search for *find my council* at  
**[www.careinfoscotland.scot](http://www.careinfoscotland.scot)**

#### Aging Without Children (AWOC)

Find local groups if you don't have the support of children as you age.

Website: **[www.awwoc.org](http://www.awwoc.org)**

#### Care Quality Commission (CQC) (England)

Search for care service ratings in England on their website

Telephone: 03000 616161

Website: **[www.cqc.org.uk](http://www.cqc.org.uk)**

#### Care and Social Services Inspectorate Wales (CSSIW)

Search for care service ratings in Wales on their website.

Telephone: 0300 7900 126

Website: **[www.careinspectorate.wales](http://www.careinspectorate.wales)**

## **Health and social care online (Northern Ireland)**

Health and social care online information for Northern Ireland.

Email: through the website contact page

Website: [www.hscni.net](http://www.hscni.net)

## **Health in Wales**

Online information on NHS services in Wales.

Website: [www.wales.nhs.uk](http://www.wales.nhs.uk)

## **Hospice UK**

Guidance about hospice care in the UK.

Telephone: 020 7520 8200

Email: through the website contact page

Website: [www.hospiceuk.org](http://www.hospiceuk.org)

## **Kennedy's disease clinic (based in London)**

The only Kennedy's disease specialist clinic in the UK.

Telephone: 020 3448 3517 (general enquiries)

Email: [uclh.referrals.mnd.care@nhs.net](mailto:uclh.referrals.mnd.care@nhs.net)

Website: [www.uclh.nhs.uk/our-services/find-service/neurology-and-neurosurgery/motor-neuron-diseases](http://www.uclh.nhs.uk/our-services/find-service/neurology-and-neurosurgery/motor-neuron-diseases)

## **Kennedy's Disease UK**

Charity run by volunteers and people with Kennedy's disease.

Email: through the website contact page

Website: <https://kd-uk.com>

## **MND Scotland**

MND care, information and research funding for Scotland.

Telephone: 0141 332 3903

Email: [info@mndscotland.org.uk](mailto:info@mndscotland.org.uk)

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

## **National Institute for Health and Care Excellence**

Provides national guidelines on treatment and care, including MND.

Telephone: 0300 323 0140

Website: [www.nice.org.uk](http://www.nice.org.uk)

## **NHS 111**

NHS help if you need urgent, but not life-threatening medical help or advice. Available 24-hours a day, 365 days a year.

Telephone: 111 (England and some areas of Wales)

Website: <https://111.nhs.uk>

## **NHS online**

The main online reference for the NHS.

Website: [www.nhs.uk](http://www.nhs.uk)

## **National Institute for Health and Care Research (NIHR) and DeNPRU Exeter**

The NIHR with DeNPRU is running a national project on supporting people who live alone with dementia or neurological disease. Find details through this web page:

Website: <https://denpruexeter.nihr.ac.uk/projects/supporting-people-who-live-alone>

## **The Regulation and Quality Improvement Authority (RQIA)**

Search for care service ratings in Northern Ireland.

Telephone: 028 9536 1111

Website: [www.rqia.org.uk](http://www.rqia.org.uk)

## **Samaritans**

A 24-hour confidential emotional support service.

Telephone: 116 123

Email: [jo@samaritans.org](mailto:jo@samaritans.org)

Website: [www.samaritans.org](http://www.samaritans.org)

## References

References for this document are available on request from:  
**infofeedback@mndassociation.org** Or write to:

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

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## Further information

### Resources relevant to this booklet:

*Telling other people about MND* – ways to communicate about the  
condition with family, friends, colleagues and professionals.

*Types of care* – an overview of the services available.

*Making the most of life with MND* – suggestions to help you maintain  
your hobbies and interests.



*Emotional and psychological support* – types of support.

*Changes to thinking and behaviour with MND* - how thinking and behaviour may be affected for some people with MND.

*What you should expect from your care* – a pocket guide to help guide discussions at appointments, about your care needs.

*Living with motor neurone disease* – guidance to help manage MND.

*Kennedy's disease* – guidance to help manage Kennedy's disease.

Our *Care information finder* helps you search for our content by need:

**[www.mndassociation.org/careinfofinder](http://www.mndassociation.org/careinfofinder)** or download our resources at: **[www.mndassociation.org/publications](http://www.mndassociation.org/publications)**

Order printed copies from our MND Connect helpline (see below).

They can also help you select information to meet your needs.

We provide introductory information in languages other than English.

Contact MND Connect or ask someone to contact them on your behalf. Find out more at: **[www.mndassociation.org/languages](http://www.mndassociation.org/languages)**

Find our information for health and social care professionals at:

**[www.mndassociation.org/professionals](http://www.mndassociation.org/professionals)**

## **Our services**

### **MND Connect**

Our helpline team can provide emotional support, guidance and information. They can help you search for organisations, our local branches, groups and volunteers, and explain our services and grants.

Telephone: **0808 802 6262**

Email: **[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)**

## **Benefits Advice Service**

The MND Association Benefits Advice Service can help you identify available benefits and how to claim them. Find details at: **[www.mndassociation.org/benefitsadvice](http://www.mndassociation.org/benefitsadvice)** for England, Wales and Northern Ireland, or contact our MND Connect helpline for guidance.

## **Support services and financial support**

We provide selected services and financial support to help people with MND or Kennedy's disease, their carers and younger family members. Some applications must be made by a relevant health or social care professional.

Telephone: **0808 802 6262**

Email: **[support.services@mndassociation.org](mailto:support.services@mndassociation.org)**

Website: **[www.mndassociation.org/support-and-information](http://www.mndassociation.org/support-and-information)**

## **Communication Aids Service**

Contact our service with queries about communication aids or possible financial support for aids.

Telephone: **0808 802 6262**

Email: **[communicationaids@mndassociation.org](mailto:communicationaids@mndassociation.org)**

## **Local and regional support**

Find out about our branches and groups, at: **[www.mndassociation.org/local-support](http://www.mndassociation.org/local-support)** or ask MND Connect as shown in this section.

## **MND Association website**

Find support and information about membership, fundraising, campaigning, research and news at: **[www.mndassociation.org](http://www.mndassociation.org)**

## **MND Association online forum**

Our online forum is a safe place to share experiences with other people living with or affected by MND. You can just view if you wish or join the online chats. You can access the forum at:

**<https://forum.mndassociation.org>**

**“Don’t wait. Prepare what you need to do in the early stages, then enjoy every precious moment, in whatever way you want, with whoever you want, doing things you enjoy best of all.”**

## **We welcome your views**

Let us know what you think of this booklet. We’d love to hear what you feel we did well and how we can improve this content for people with or affected by MND or Kennedy’s disease.

Your anonymous comments may also be used to support and influence, as they help us share real MND experiences and raise awareness in our resources, campaigns and applications for funding.

Find our feedback form at: **[www.smartsurvey.co.uk/s/living-alone](http://www.smartsurvey.co.uk/s/living-alone)**  
Or email comments to: **[infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)**  
or write to *Information feedback* at the following address.

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

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**Patient Information Forum**

