



## **Guide to supportive activities and therapies for people living with MND**

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“ My attitude is that you should do what you can today and worry about tomorrow when it comes. This is the card I've been dealt so I've just got to crack on.

**Doddie**

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## A note from Doddie

MND is a tough diagnosis to receive. If you're anything like me, you might well have 'googled' your symptoms long before that, and already have had your own suspicions. But that doesn't make it any easier for you or your family to accept the diagnosis when it comes.

So, we find out pretty quickly what might be ahead and that we don't have a cure. And that's it, you're on your own... Or that's how it felt to me at the time.

My approach was, and still is, "Well, here we are. Now, what can I do to keep myself as healthy and active as possible, for as long as possible?" I've been lucky — I've been able to access specialists who have given me tips on complementary therapies, exercise, diet and the like. From this combination of sources — and my own trial and error — I feel that I have slowed the impact of MND on my life, and it gives me positivity and purpose to be doing something to help myself. We've put together the best of what I've learned in this booklet, and I hope you and your family find it useful.

So — until we do find that cure — take care, stay strong and live every day.

Doddie Weir



## INTRODUCTION TO THIS GUIDE

Being diagnosed with motor neuron disease (MND), which is often called amyotrophic lateral sclerosis (ALS), can be an overwhelming experience. You may feel like you have not been provided with enough information, or perhaps that you have been provided with too much information. This guide contains a summary of suggestions and tips that can help you following your diagnosis.

Currently, the only drug that has been shown to slow the progression of MND is riluzole (your doctor may also call it Teglutik® or Rilutek®), but it is not suitable or effective for everyone. However, people with MND have reported that other things have been beneficial, such as:

- Exercises
- Changes in lifestyle and diet
- Complementary therapies
- Managing mental health
- Using adaptive equipment

This guide contains suggestions and thoughts based on the experiences of people with MND, Doddie's experience and other anecdotal feedback. Although some of these suggestions could make you feel better, **none of these have been shown to slow the rate of MND progression**. Therefore, it is up to you to investigate whether these suggestions help your symptoms. It is important that you consult your doctor before trying any of the suggestions in this guide.

You can find out more information about nutrition, complementary and other potential therapies for MND at [alsuntangled.com](http://alsuntangled.com).





# Diet and nutrition

## DIET

Weight loss is a common side effect of MND. Additionally, MND may affect how you chew and swallow your food. As well as it being important that you eat enough to stay healthy, a high-calorie diet may be particularly beneficial for those with MND.

To ensure you are eating enough energy-rich foods, it is important that your diet consists of:

- High-calorie, easy-to-eat food
- Foods that you enjoy

Energy-rich foods that you should consider eating include:

- Full-fat foods, such as cream, butter and coconut milk
- Thick fluid foods, such as protein shakes, soup, purées, yoghurts, mousses and jelly
- Healthy oils from nuts and seeds, such as flax seed oil, which can be added to soups, dips and yoghurts

People with MND often require feeding tubes to ensure that they continue to get adequate nutrition. You should talk to your doctor about when this is appropriate for you. However, in the meantime, there are things you can do to make foods easier to eat. You may find that it helps to:

- Mash food with a fork
- Blend or purée food
- Pipe food into shapes
- Cook food so that it is soft and tender

If you are concerned about your weight, please talk to your doctor or dietician.

Choking is a potential risk when eating. If you are experiencing difficulties swallowing, you should talk to your doctor, and you may be referred to a speech and language therapist. A speech and language therapist will advise you on how to swallow food safely. You may be prescribed medication to alleviate distress if choking occurs.

**Doddie** “ I use lots of mayonnaise, ketchup or gravy with my meals, to add calories and reduce the chance of choking on dry foods. ”

## DRINK

As well as eating enough calories, it is important to stay well hydrated, as it may become more difficult to swallow liquids. Below are a few tips that you can follow to help you stay hydrated:

- Drink around six glasses of fluid a day
- You may find it easier to drink thicker fluids such as smoothies
  - A thickener can be added to your drinks (a speech and language therapist will determine if you need this)
- Some people with MND find drinking through one-way suction straws helpful
  - Talk to your doctor, physiotherapist or speech and language therapist about obtaining a one-way suction straw
- Drink alcohol in moderation as it can cause dehydration

## NUTRITION

As well as ensuring that you are eating enough calories and staying hydrated, it is important that you are meeting your nutritional needs. You should aim to eat a range of foods that contain a variety of vitamins and other useful nutrients. Examples of vitamin-rich foods are listed below:

### Vitamin A

- Carrots, spinach, sweet potato, apricots, broccoli, red pepper, kale, peach

### Vitamin C

- Yellow peppers, strawberries, kiwi, broccoli, Brussels sprouts, papaya, orange juice, grapefruit
- Additionally, you may wish to take a vitamin C supplement of 500 mg a day

### Vitamin E

- Wheatgerm oil, sunflower seeds, hazelnuts, avocado, peanuts, sunflower oil, almonds

### Selenium

- Brazil nuts, seafood, oatmeal, liver, whole grains

Some foods and supplements are being investigated to see if they might be beneficial to those with MND. You may want to include the following in your diet:

- Tauroursodeoxycholic acid supplement (also known as TUDCA)
- Cumin

You may find it helpful to juice some fruits and vegetables to try to increase your vitamin intake. Additionally, there is only one multivitamin that can be prescribed on the NHS: this is known as Forceval®; you will need to talk to your GP about a Forceval prescription.

Though there is little evidence on this topic, you may wish to **avoid foods** that contain the flavour enhancer monosodium glutamate (MSG). MSG contains glutamate, which acts as a nerve transmitter in the body. Riluzole (the only approved treatment for MND) aims to reduce the level of glutamate; therefore, it may be wise to try to reduce MSG in the diet as far as possible.

MSG may be found in:

- Crisps and other seasoned snacks
- Instant noodles
- Soups
- Seasoning/spice mixes or condiments
- Takeaways
- Yeast extracts

*Talk to your doctor or nutritionist before making any significant changes to your diet.*

### Antioxidants

- Onions, shallots, tea, chocolate, red wine, blackberries, rosemary, green tea, camomile tea, celery, parsley, tomato, watermelon

### Vitamin B

- Whole grains, soya beans, dairy products, green vegetables, fish, chicken

### Omega-3

- Oily fish
- You may wish to try a supplement that contains over 200 mg of docosahexaenoic acid (DHA); this is a type of omega-3 fat



# Exercise

## EXERCISE

Exercise may be helpful for maintaining mobility and function. There are different types of exercise that you may want to try.

### Aerobic exercise

- These are exercises that increase your breathing and heart rate
- Examples are walking, cross training, rowing and swimming
  - Swimming is an exercise that some people with MND find beneficial due to the support from the water
- Although aerobic exercise has its benefits, it is important that you do not overexert yourself when doing these exercises
  - A good measure of this is to check whether you can have a conversation while doing the exercise

### Resistance training

- This is a type of exercise that uses weight, such as your own body weight or equipment such as dumbbells
- This can help to strengthen your muscles
- It is important that you avoid exercising weak muscles

### Other exercises

- You may find it beneficial to do some gentle stretches, which can reduce joint stiffness
- Singing could be a fun alternative to exercise that has been recommended to improve lung health

You must not overwork your muscles. You should consult a doctor or a physiotherapist before starting a new exercise, and you should check in periodically to make sure that your exercise needs have not changed. Your doctor or physiotherapist will be able to advise you on what and when to eat before and after exercise.

“ Use it or lose it: mentally or physically — stay as active as possible! ”  
**Doddie**



# physiotherapy

## PHYSIOTHERAPY

Physiotherapists can help in numerous ways, ranging from advice on exercises to small movement and lifestyle modifications that you may find beneficial. Some of the ways that physiotherapists may help you are outlined below.

### Assisted exercise

- Your physiotherapists can teach you exercises to perform with support from a friend or family member
- These types of exercises can be useful to maintain joint mobility

### Breathing exercises

- Your physiotherapist can recommend breathing exercises that are useful for maintaining your lung health — *it is important to get your lung capacity measured regularly by your doctor*

### Increase your comfort

- Your physiotherapist can suggest exercises that may help with issues that cause discomfort, such as poor circulation or cramping
- They may also be able to suggest changes to your body position and the way you move, and show you how to rub areas of your body to decrease discomfort

### Help with day-to-day activities

- This might involve advice on balancing and moving around your home
- Your physiotherapist may suggest practical solutions for any mobility issues that you may be having

### Restoring movement

- You may wish to seek help from a qualified soft tissue therapist who is well versed in the restoration of functional movement
- They might be able to help you by identifying the affected area and treating it with recognised soft tissue techniques, with the objective of reducing your pain levels and helping with movement difficulties

**Ask your doctor about access to physiotherapy services in your area. Alternatively, you may be able to access physiotherapy services through:**

- Referral by your MND care network or local neurological centre (where available), or self-referral to an NHS physiotherapist
- Physiotherapy services provided by MND charities or your local hospice
- Private treatment via your employer's occupational health scheme, private medical insurance or by self-funding



# Speech and communication

## SPEECH AND COMMUNICATION

You may find that MND eventually changes the way that you communicate verbally or in writing (handwriting or typing). Below are some suggestions that may help you to communicate clearly.

### Verbal communication

The way that you talk may change as MND progresses. If you feel like your speech is changing, there are some techniques that you can use to make the most out of your voice. Try to:

- Speak slowly
- Pause frequently to breathe
- Use short sentences
- Emphasise the syllables of the words
- Clear your mouth of saliva before talking

### Speech alternatives

You may gradually find that it becomes difficult to talk as a result of MND. This symptom can be worrying; however, there are other alternatives to speech that you can use to keep communicating.

Below are some alternatives to speech that people with MND have found helpful. Your healthcare team may be able to suggest providers of software and/or equipment to help with some of the suggestions below:

- Texting or voice texting on your smartphone
- Typing emails
- Writing by hand
- Using letter frames
- Using picture charts
- Signalling in sign language
- Using a voice amplifier
- Using keyboard or touch screen devices for word and/or symbol communication
- Using a downloadable software that can be used to read text from documents on a computer
- Typing on a computer using chin switches if your hands and arms are too weak or tire easily

People with MND find different ways of communicating helpful, and there is no best method. You will need to find what works best for you. When choosing a speech alternative, you should think about your own communication needs. *Do you still want to be heard?* If so, maybe texting is not the choice for you. *Do you prefer to type and spend a lot of time on the internet?* Consider typing and using email. *Do your arms often feel tired?* Perhaps a chin switch or voice amplifier could be useful.

You do not have to pick just one option. You may find it useful to try different ways of communicating in different situations to find the best solution for you.

### Alternatives to writing and typing

If you like to communicate through text but are finding it difficult or tiring to do so, you may want to consider using voice recognition software.

Some people with MND have said that voice recognition software can work well even when using ventilation masks. Specialised software that you can download or purchase allows you to do things such as delete sections of text in a document and spell out words, and allows you to programme frequently used pieces of text to add to a document or email, such as your address.

### Speech and language therapy

If you are having difficulty communicating or would like further advice, you should ask your doctor for a referral to a speech and language therapist. They will be able to offer you guidance and equipment to help you to communicate. Even if your speech has not yet changed, you may want to talk to a speech and language therapist so that they can address your future communication needs.

### Voice banking

Before your speech severely declines, you may wish to consider voice banking. Voice banking will allow you to create a synthetic voice similar to your own that can say any sentence input into a speech device. To do this, you will need to record between 600–3,500 sentences that will then be used to create your synthetic voice. There are numerous voice banking services available, at a range of prices. The earlier the process is started, the easier it will be; however, even if your speech has already mildly declined, it may still be possible to create a synthetic voice.



“ When I was diagnosed with MND, voice banking was a priority for me.  
**Doddie** ”



# Complementary therapies

## COMPLEMENTARY THERAPIES

There are many different complementary therapies available. These have not been proven to affect MND, but they may help to provide some relief from your symptoms.

*Before trying any of these therapies, it is important for you to check with your doctor.*

Some therapies that may be useful in providing **relief from physical discomfort** include:

- **Massage therapy:** massages performed by trained massage therapists to increase blood circulation and ease muscle pain and cramping
- **Acupuncture:** the use of fine needles under the skin and in the muscles to stimulate nerves and release natural chemicals such as pain-relieving endorphins (Western medical acupuncture) or believed to restore energy flow through the body (traditional Chinese acupuncture)
- **Reflexology:** a therapy based on the theory that massaging specific points on the feet, lower leg, hands, face or ears can relax and rebalance corresponding areas of the body
- **Chiropractic therapy:** the manipulation of bones, muscles and joints, mainly used to relieve pain
  - Unlike most complementary therapy practitioners, chiropractors must be registered with the General Chiropractic Council (GCC)
- **Indian head massage:** head massage to induce deep relaxation that may improve blood circulation, and relieve muscle tension, fatigue and headaches

Other therapies may provide **emotional relief**, such as:

- **Hypnotherapy**: use of a deeply relaxed state to alleviate emotional distress, treat sleep problems and change habits
- **Reiki**: an energy-healing technique based on the idea that energy can be channelled by means of touch to activate natural healing and restore emotional well-being
- **Aromatherapy**: use of plant-based aromatherapy oils on the skin, or to inhale, with the aim of relaxing and stimulating to improve well-being. This can be performed at home or during a consultation with an aromatherapist
  - You should check with your doctor before using aromatherapy because it is possible that the oils may interact with medicine that you are taking
- **Art therapy**: the practice of using art to express yourself emotionally
- **Music therapy**: the practice of using music to express yourself emotionally
- **Meditation**: a practice to train the mind to focus, which can result in stress relief. This can be practised through classes, or using free mobile apps and free online videos
- Additionally, **massage therapy** and **Indian head massages** may provide emotional relief and relaxation, as well as relief from physical symptoms

Although you can pay for most of these services privately, some of these may be available on the NHS, through MND charities, or from your local hospice or palliative care team.



“ I've found complementary therapies have a positive impact on my body and mind.  
**Doddie** ”



# Medical management of pain and discomfort

## MEDICAL MANAGEMENT OF PAIN AND DISCOMFORT

MND itself does not usually cause pain; however, painful symptoms may occur due to a reduced ability to move. Before taking medications for your pain, you may want to try to manage your pain using other therapies, as discussed earlier in this guide. Some common painful symptoms and suggested treatments are listed below.

You must talk to your doctor before trying any of the following. Please be aware that your doctor may not be able to prescribe medication due to side effects or interactions with other medications, or if you have underlying health conditions that could mean they should not be used.

### For joint and muscle pain

- Non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen
- NSAID gels
- Paracetamol
- Heat packs
- Transcutaneous electrical nerve stimulation (from a physiotherapist)
- If these do not work, your doctor may be able to prescribe you stronger alternatives

### For muscle cramps

- Your doctor may be able to prescribe you medicines such as quinine, tizanidine, dantrolene or gabapentin

### For muscle spasticity and stiffness

- Your doctor may prescribe you medicines such as baclofen, tizanidine, dantrolene or gabapentin
- Your doctor may also suggest botulinum toxin injections (also known as Botox)
- Some patients report that transcutaneous electrical nerve stimulation relieves muscle stiffness
- It may be possible to obtain medical cannabis from the NHS, which might help to alleviate muscle spasticity



# Day-to-day living

## DAY-TO-DAY LIVING

You may find that you need additional support with activities such as moving around the house or dressing in certain items of clothing. Below you can find some advice and suggestions for improvements to make your day-to-day life a little bit simpler. These are examples of the types of adaptations available, but there are many more that can be implemented.

### For moving about in your home

- Installing handrails, ramps, widened doorways, hoists, stair lifts, and through floor lifts can help make your home more accessible
- Using splints, walking sticks and wheelchairs can help you to move about more easily

### For maintaining your personal hygiene

- Adding non-slip mats and shower rails to your bathroom to avoid falls
- Using hoists or mechanical baths for access to the bath
- Installing a walk-in shower or wet room
- Adding a frame or rails to the toilet
- Installing a toilet with a self-washing feature, such as a Closomat toilet, or similar alternatives

### For clothing and personal care

- Shoehorns, sock aids and leg lifters
- Adapted clothing
- Long-handled hairbrushes

### Additionally, the following may help you to feel more comfortable

- Reclining bed and seats so that you can easily adjust your position
- Cushions to prop yourself up with and to alleviate points of pressure
- Head support for if your neck becomes tired
- Adapted cutlery may make it easier and more comfortable to eat

## **Who to talk to for more information about adaptive equipment**

It is worth talking to an occupational therapist or physiotherapist about your home environment, your lifestyle and any mobility issues that you have, so they can help you to make the right decisions on your equipment needs.

## **Where to find adaptive equipment**

Although you may need to purchase some of this equipment, you should see what equipment is available through your local social services, the NHS or MND charities, such as the MND Association and MND Scotland, who receive grants from the My Name'5 Doddie Foundation to help with practical issues facing those with MND.

Online shops such as Complete Care Shop, or similar alternatives, have lots of ideas to help you adapt and stay independent.



**“** Don't be afraid to use adaptations to make your life easier.  
**Doddie** **”**



# Other supportive care

## OTHER SUPPORTIVE CARE

MND requires care from many different specialists. Within this guide, you have been introduced to the role of your doctor, physiotherapists, speech and language therapists, dieticians, psychologists and counsellors, complementary therapists and occupational therapists.

However, there are also **other specialists** who may be involved in your care, and other professionals who you may find it beneficial to talk to. You should talk to your doctor to find out more information about these specialists, including how to access their services. These can include:

- Social care workers, who can help with tasks such as organising support, managing housing issues and mediating work-related issues
- Respite carers, who can provide care while your primary carer takes a short break
- MND specialist nurses, who can help with tasks such as providing advice, reviewing your condition and coordinating care with other medical professionals
- Respiratory specialist nurses, who will assess your lung health and provide further breathing support when needed, such as a ventilation tube. It may be useful to work with your care team to plan for this early on
- Respiratory physiotherapists, who will advise on breathing techniques
- A gastrointestinal team, who will be able to provide further support for any ongoing feeding or swallowing issues
- Dieticians, who will be able to advise and support dietary requirements
- NHS wheelchair services, who will assess your mobility needs and provide wheelchairs if needed
- Residential and care homes, where care can be provided if the management of care at home becomes too difficult



# Emotional well-being

## EMOTIONAL WELL-BEING

It is normal to feel a range of emotions, such as shock, anger, grief and anxiety following a diagnosis of MND. During this time, it is important that you take care of your emotional well-being, and there are steps you can take to improve your mood.

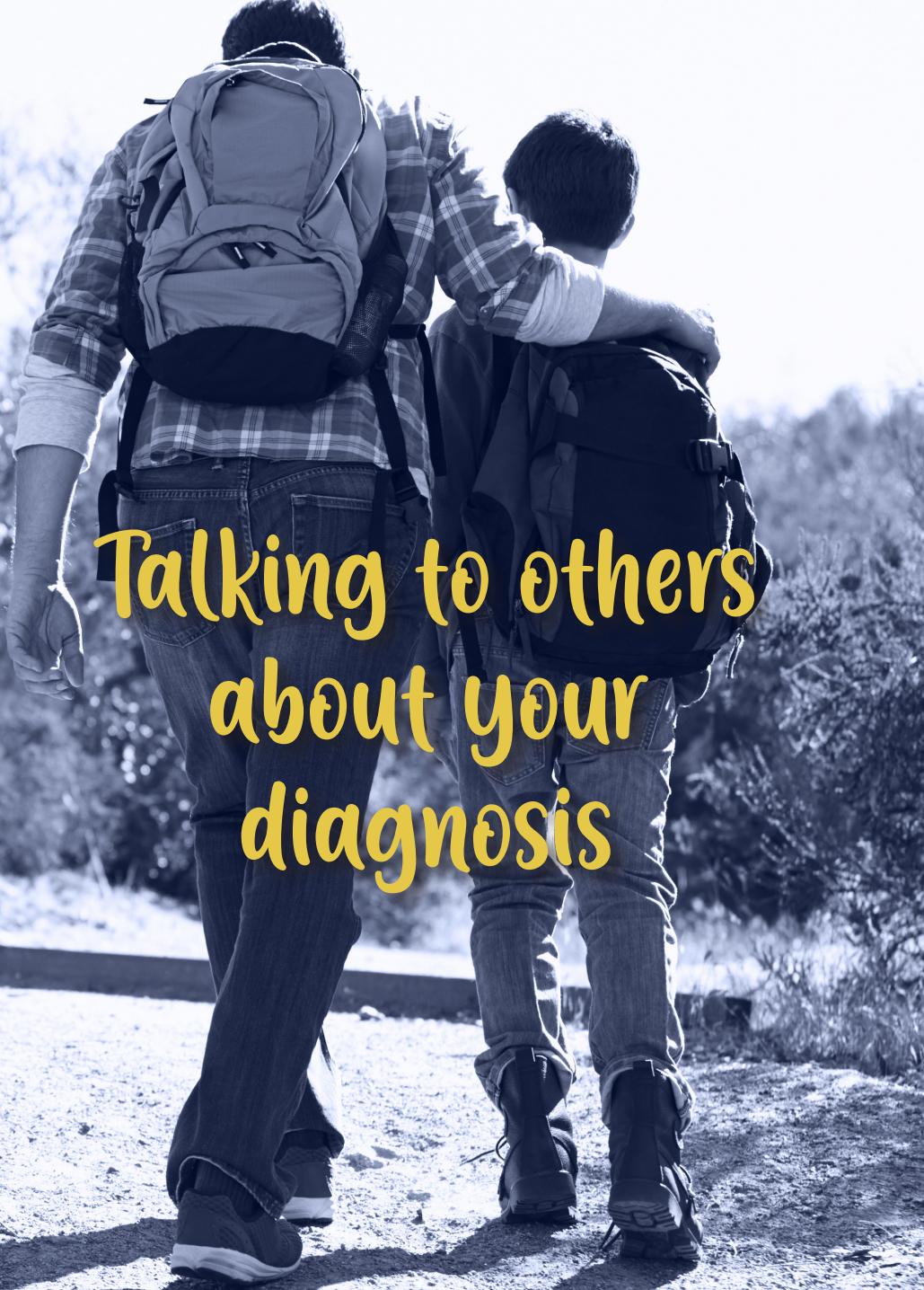
### Suggestions for improving your mood

- Talking to a counsellor or psychologist
- Talking to trusted friends and family members, charities that provide emotional support, NHS advisors, your local hospice, or religious or spiritual leaders
- Learning relaxation techniques, such as deep breathing or meditation
- Trying complementary therapies that can improve your mood (outlined previously in this guide)
- Receiving a prescription for a mood enhancer from your doctor

Additionally, some people with MND report sudden changes in their mood, such as laughing or crying episodes that may not reflect how they are currently feeling. This symptom is known as *emotional lability*. These outbursts typically only last a few seconds, but if you find that this bothers you, there are some steps that you can take.

- Talk to a doctor who is familiar with neurological conditions and may be able to prescribe you medicine to regulate emotional lability
- Let people know that you may laugh or cry spontaneously due to MND; if it helps, you can carry a card with this information on to show others

“ Even a silly cartoon can make me cry these days!  
**Doddie** ”



# Talking to others about your diagnosis

## TALKING TO OTHERS ABOUT YOUR DIAGNOSIS

Deciding when and how to tell people about your diagnosis can be a difficult and emotional process, and it may seem hard to start these conversations.

Your care team can advise on professional services that can support you through this process.

### Tips for talking to people about MND

- Wait until you feel ready to talk to people about your diagnosis
- Decide who you are ready to tell — you do not need to tell all your friends, family and co-workers at the same time
- If you feel that it will help, keep the conversation simple
- Encourage an open conversation about your feelings
- You may find that it helps to have a friend or family member with you to help explain the news and to support you
- If you are dealing with children, you may want to protect them from the truth; however, explaining the situation may help them to emotionally process what is happening

It is important for you to know that there is no correct way to talk to people about your diagnosis. If you are not comfortable with telling people about your diagnosis through a conversation, you can try a different approach that is easier or more personal to you. You may find it easier to write a letter or perhaps to have a friend send an email on your behalf.

It may also be helpful for you to tell your care team and family and friends what you wish to happen if you were to suddenly become unwell, so they are able to plan for this.





# Managing MND for loved ones and carers

## MANAGING MND FOR LOVED ONES AND CARERS

MND may change your relationships with others. Your partner or family members may find the transition to a carer role upsetting, and you may find it difficult to see how MND affects those close to you.

### Advice for managing romantic relationships while living with MND

- It is possible for MND to strengthen the relationship between partners when a couple share their emotional strength and spend more time together
- As MND can affect how you interact with your partner, you may need to physically adapt the way that you and your partner cuddle and share physical intimacy
  - Equipment is available to aid this, such as adjustable beds or positioning pillows
- Although relationships can break down as a result of MND, you do not need to give up on love — some people with MND start new relationships after their diagnosis

### Advice for carers of those with MND

- Consider the best way to communicate with the person with MND when you are in different rooms or outside of the house — some carers use tools like two-way radios to help stay in touch
- Staying in your current job and participating in activities outside of being a carer may help you to maintain your social life and independence
- You may find that you are angry, stressed or sad about the diagnosis — it is important that you take care of your own emotional well-being as well as the person with MND
  - You may find it helpful to talk to a doctor about these feelings or join a carers' support group
- You may find it inspiring to involve other friends, family, neighbours or community members in the care of the person with MND
- As a carer, you may be entitled to support and consideration from your employer and the local council
  - These include benefits such as flexible working, financial support, and emotional and well-being support

**ABOUT US:** [myname5doddie.co.uk](http://myname5doddie.co.uk)

**KEEP IN TOUCH:**  [@MNDoddie5](https://twitter.com/MNDoddie5)

The Foundation is committed to helping improve the lives of those affected by motor neuron disease. We can help through grants for individuals and families administered by our friends at the MND Association and MND Scotland.

[www.mndassociation.org](http://www.mndassociation.org)   [www.mndscotland.org.uk](http://www.mndscotland.org.uk)



Many thanks to all who contributed to this source of information, including OPEN Health Medical Communications who kindly offered their time and expertise as part of their Corporate Social Responsibility programme.