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# Managing emotions

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## Information for people with or affected by motor neurone disease


Living with motor neurone disease (MND) can involve a range of emotional challenges and changes that may be difficult to cope with.


If you begin to feel overwhelmed, identifying feelings and likely causes can help you find ways to manage them and feel more in control.

This information sheet includes the following sections:

- 1: **How do I adjust to a diagnosis of MND?**
- 2: **What can I expect?**
- 3: **How can I manage my emotions?**
- 4: **What is emotional lability?**
- 5: **Who can help me?**
- 6: **How do I find out more?**

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

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

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

# 1: How do I adjust to a diagnosis of MND?

For most people, a diagnosis of MND can feel devastating and you may need time to cope with the shock. For some there can also be a sense of relief after a period of great uncertainty. Once you know what is happening, you can take action to make life as comfortable as possible.

Every individual is different and your response to diagnosis will be influenced by your own circumstances, culture and beliefs. Whatever you feel in the weeks and months following, it is important to remember that you are not alone and that help and support is available.

As you begin to deal with the diagnosis and what it will mean, the range of emotions can feel confusing. It is common to experience more than one distinct feeling at a time, such as anger and guilt.

You may experience:

- shock at diagnosis
- fear for the future
- disbelief and denial
- anxiety for family, children and friends
- grief for the loss of the future you expected
- anger at the medical profession or family and friends
- isolation because you feel different from others
- intense sadness
- guilt that you may be the cause of stress for others
- relief that you finally know what is happening to you.



*"You grieve on diagnosis. I was inconsolable for about a month, but then it got much better."*

Some or all of these reactions may feel overwhelming for a while and it is important to feel able to work through them at your own pace.

Trying to maintain a positive mental attitude while accepting you have a life-shortening illness can feel very difficult, but support is available to help you through this. However, you may need to get the situation straight in your own mind before seeking help or information.

Gradually though, you may wish to review your life and plans. You may feel determined to face the disease head on or you may prefer to deal with it one day at a time.

## How do I tell people about my diagnosis?

How and when you tell others about your diagnosis is up to you. Do what feels right for you. You may feel you:

- need time to adjust before telling anyone else
- want only your immediate family to know while you adjust
- want all close contacts to be aware.

MND is progressive and the effects will be visible to others. The more people know, the easier it is for them to adjust too. It can help them understand how to offer support that suits you.



*"My way of telling my workmates was to use a humorous approach with the 'good news, bad news' idea. The good news is we finally know what's wrong and the bad news is there's no cure yet. I found it broke the ice nicely."*

You may not want to explain the situation over and over again if this feels stressful. This may also be true for your partner or those closest to you. A close friend may be prepared to communicate on your behalf to reach a wider circle. There are many ways they can do this, perhaps by email including information about MND or links to our accredited information resources at: **[www.mndassociation.org/publications](http://www.mndassociation.org/publications)**

It may help to keep initial conversations simple in case people feel overwhelmed. As time goes on, you can give more detail about how the disease is affecting you, so that others know how to support you.

## What should I say to my family and friends?

Maintaining relationships with family and friends can be an important part of maintaining your own emotional wellbeing. Discussing and acknowledging your feelings with those close to you is vital. MND affects them too and sharing highs and lows means you can support each other.

If you have a difficult relationship with a family member, or MND is creating a barrier between you, ask your health and social care professionals for guidance. They may be able to facilitate a joint discussion and help you to resolve these issues. You can ask your GP for a referral to a professional relationships counsellor, however they may not necessarily have experience of MND or the challenges it brings.

If your partner or a family member helps support you, we have information for family or unpaid carers. This includes emotional and practical guidance to help them face the challenges of the caring role.



For detailed information for family carers see our guide:  
*Caring and MND: support for you*


## How can I talk to children and young people about MND?


It is natural for any parent or guardian to want to protect their children from distress or worry, yet children notice far more than we realise.

Sharing feelings, such as sadness with your child, can help them to understand their own. You may be worried about getting upset in front of them, but this can give children and young people permission to release some of their own emotions. By talking about MND you are clearly demonstrating it is not a taboo subject, but one that is safe to discuss. Encouraging openness will help them seek you out when they feel troubled.

When communicating sensitive issues to children, start with things the child will already have noticed. For example, if facial muscles have been affected, explain that it may be difficult to smile, but this does not mean you are angry.

There is no need to give all the information at once. How much and how often you should talk to children will depend on their age and how quickly the disease is progressing. However, it is important to avoid confusion or misunderstanding.

 For more information about conversations with children and young people see:  
*4A – Communicating about MND to children and young people*


 For information to share with children and young people see:  
*When someone close has MND - a workbook for children aged four to ten*  
*So what is MND anyway? – a guide for teenagers*

## Can other symptoms of MND affect my mood?

MND symptoms can affect emotions in various ways, such as making you feel low, irritable or angry. Advice about symptom management may help reduce these effects by improving your sense of wellbeing.

Ask your GP or health and social care team for guidance if you experience:

- extreme tiredness
- disturbed sleep
- shortness of breath
- pain
- swallowing difficulties
- stiffness or cramps
- speech difficulties
- changes to your thinking and behaviour.

 See the following information sheets for more information:  
*7A – Swallowing difficulties*  
*8A – Support for breathing problems*  
*9A – Will my thinking be affected?*

## 2: What can I expect?

With MND, you may experience difficult emotions that can feel very challenging. You are not alone in this. Even though everyone's experience is individual, many will share your feelings. These are normal responses to the shock and ongoing changes the disease brings.

This section explores some of the ways that MND can affect relationships, social networks and your sense of purpose, all of which can have a strong emotional impact on you and those close to you.

### Feelings of isolation

People with MND, and their main carers, often talk about a sense of growing isolation, for various reasons. Social networks may grow smaller. Physical hobbies and certain types of employment may become difficult as the disease progresses.

There may be ways to do things differently, if you wish to remain involved. This can help to maintain relationships based on these activities. For example, you might continue to go fishing, but ask a friend to cast the line out for you, or continue gardening by using assistive equipment.

Speech and communication may become affected by MND. This can make social interaction more difficult.

There are therapies and communication aids to assist, but you may need to explain to others how to listen and respond to you in different ways.

Some friends may retreat. There could be many reasons for this, including fear of saying or doing the wrong thing. It is also possible they lack understanding about the disease and its symptoms.

Where people do visit and maintain contact:

- keep them informed of changes so they know what to expect (MND is rare and they may not fully appreciate the impact of the disease)
- let them know the best times of day to visit, as your routines may change and you may feel more energised at certain times
- let them know how long to stay, to help you avoid fatigue
- make a list of tasks that others might be able to help with (people like to offer practical support and a ready list gives them choice and saves you trying to think of instant tasks)
- open difficult conversations to give them 'permission' to ask about things that may concern them
- encourage your inclusion at social gatherings for as long as you feel this is right for you.

You may find new ways to develop social contacts by exploring different types of social activity. This could include new hobbies, or joining a local branch or group of the MND Association. Meeting other people in a similar situation and sharing experiences can help to remove the feeling of isolation for both you and your carer.

Not everyone feels this is appropriate for them at first, but you can join a branch or group at any point. Contact MND Connect for information about branches and groups in your area. See section 6: *How do I find out more?* for contact details.



*"I have had a one-to-one conversation with someone else with MND. This was very helpful at a low time."*

Association Visitors are volunteers who provide free and confidential personal support to people living with MND, their carers, their family and close friends. An AV can help you to identify problems as they arise and discuss your choices for how these might be managed.

Contact MND Connect for more information if you would like support from an AV. See section 6. *How do I find out more?* for contact details.

The MND Association online forum also provides a safe place for you to communicate openly with other people who are living with or affected by the disease. You can also view the forum conversations without joining if you prefer. This can help to reduce isolation. Although your particular experience of MND is unique to you, there will be many examples of shared issues and practical tips. You can access the forum at <http://forum.mndassociation.org>

## **Anticipatory grief**

MND can cause emotional upheaval for you, your partner, relations and friends. You may all experience anticipatory grief, where you grieve for losses to come and feel a sense of dread.

The progressive nature of MND means that physical independence, expression, communication and activity may all be affected, and you are likely to grieve for each limitation that MND may bring.

Being open with those around you can help to reduce some of the anxiety that anticipatory grief may cause. This is important for everyone involved, as the grieving process can affect all those in your close circle. If you have a main carer who provides ongoing support, it can be particularly intense for them. They may also find their relationship with you changing to meet the challenges of the caring role.

## Changing roles

Living with MND can affect your normal routines and lifestyle. This can lead to significant emotional challenges for everyone in your immediate circle. Tasks that were traditionally yours may be taken on by someone else, careers may be put on hold and money worries can increase. Your own sense of purpose may need to adapt rapidly, and family roles can all change, and this is not always easy.

If your main carer is also your partner, some people find it strengthens their relationship, however for others it may cause strain. However, it cannot be emphasised enough how important it is for your carer to consider their own wellbeing, as MND is progressive and your need for support will increase.

People close to you may try to hide their own feelings to protect you and it may take time to develop open communication. Try to recognise when people close to you need to share their feelings and encourage this to help open conversations. This will enable understanding and help you to develop better ways of coping as a team.

Accepting external support for some of your care can be very beneficial. This may help you to hold on to what was unique about close relationships before you had MND. It can also provide a rest for your main carer, as their wellbeing can come under pressure through worry and fatigue. Appropriate external support will become particularly important if you live on your own.

## Inappropriate emotional responses

If you are experiencing uncontrollable laughing or crying that does not reflect how you are feeling, you may be experiencing a symptom of MND known as emotional lability. See section 4: *What is emotional lability?* for more information.

## Intimacy and sexuality

For many of us, physical intimacy is very important. Touch and being close to your partner can be an essential part of showing affection and sharing emotional support.



*"It is easy for the person with MND to withdraw and for the carer to be preoccupied with caring. It is important to take time to remember to show the other that you still care. I can't stress how important this is."*

Intimacy does not necessarily always include sex, but sex may be a significant part of your emotional life. Many people affected by MND worry about the impact of the disease on sexual expression.

MND does not affect sexual function, but impaired movement can make sexual expression more difficult. However, open discussion with your partner can be very helpful. You may also find it useful to talk to someone from your health and social care team for guidance if you have specific questions.

You and your partner may have questions about how MND will affect intimacy and how you can solve these issues. We provide helpful and candid information if you have concerns.



For more information about sex and relationships with MND, see:

13A – *Sex and relationships for people living with MND*

13B – *Sex and relationships for partners of people living with MND*

### 3: How can I manage my emotions?

If you do begin to feel overwhelmed, identifying your emotions can help you to work out ways to cope with your feelings:

**Anger:** You may feel anger against the world, where other people are still having fun and getting on with their life. You may feel angry at feeling alone or because other people don't seem to understand how you are feeling. If it helps, take your anger out in a way that does not hurt anyone. Venting your anger to someone who will listen can sometimes help to reduce destructive feelings.

**Anxiety/Panic:** Anxiety can cause physical symptoms, such as an increased heart rate, sweating and muscular tension. It can be difficult to think clearly when you are anxious. Take time out to help you calm down. Distract yourself for a while by doing something you find relaxing. Take a moment to close your eyes and imagine a place of safety and calm. Taking five slow breaths may also help. When you have calmed down, you may feel more able to cope.

**Denial:** In some cases, initial denial can give you time to adjust to a painful or stressful situation, as you might need time to work through what is happening and adjust. However, being in denial can hold you back from dealing with the issues. Facing up to the situation will allow you to be more proactive.

**Fear:** You may have fears about the future. Not knowing exactly what will happen to you, or those you care about can feel very distressing. You may be able to make it feel less so by thinking about the future as smaller 'pieces'. You can still think about bigger issues, but don't feel that you have to tackle everything at once. Putting plans in place in advance might help to ease some of your fears.

**Frustration:** Living with MND can lead to many frustrations. This could be due to the impact of the disease on your communication, mobility and independence. Ensuring that your needs are well met can help to reduce this frustration. Equipment, advice and support are available to assist with many aspects of daily living. See section 5: *Who can help me?*

**Grief:** You may have feelings of grief due to the loss of the future you expected. The grieving process takes time. Healing happens gradually and can't be forced or hurried and there is no 'normal' timetable for grieving. It's important to be patient with yourself and allow the process to naturally unfold.



**Isolation:** You may feel a sense of isolation due to the impact of MND on your social networks as activities such as hobbies or work become more difficult. Making contact with people you care about can be a useful first step in helping you feel less alone and remind you that there are people in your life. If your speech has been affected by MND, therapies and aids can assist, but you may need to explain to others how to listen and respond to you in different ways.

You may find it helpful to meet others in a similar situation, for example on The MND Association's online forum. See section 5: *Who can help me?*

**Sadness:** Sadness is often not a constant feeling and may come and go. It can be helpful to distract yourself with activities you enjoy and spending time with others. Talk about your feelings with those close to you and don't hold back from expressing your sadness. It can also help people close to you to open up about the way they are feeling and help open conversation.

**Shock:** Sometimes shock can cause a physical reaction, including feelings of nausea or shaking. You may experience difficulty in sleeping, heart palpitations or physical exhaustion. You may also be more susceptible to illness or infection. It can take a while to overcome this. Be kind and look after yourself. Don't take on too much. These powerful emotions will eventually subside.

## What positive steps can I take?

Often, it is the sense of losing independence and control to MND that takes its toll. Many people with the disease have said that taking positive action can help you feel more in command. This can help to reduce frustration and lift your mood.

MND may alter the direction you expected your life to take, but it should not stop you making new plans. Some people living with MND have found the following helpful:

- doing something physical if you are able to, like gardening with assistive equipment to help you stay active for as long as possible
- planning a trip, event or holiday
- seeking out experiences with family and friends that will provide lasting memories
- using speech and communication aids to help maintain social contacts if your speech has been affected
- listening to music or going to music therapy sessions
- having physiotherapy, with a qualified physiotherapist who has experience of MND
- having hydrotherapy, where exercise is assisted and supported in water to help you move and flex joints safely
- trying one of the many complementary therapies with a qualified and registered practitioner.



See the following Information sheets for more information:

6B - *Complementary therapies*

6A - *Physiotherapy for people with MND*

12D - *Planning a holiday*

## **How can I manage extreme emotions?**

Living with MND can create fear about what may happen in the future. However, many people with MND find an unexpected ability to adapt to the challenges and your views can change over time.

If you feel particularly distressed and find the challenges of MND are more than you can cope with, do seek help. Often extreme feelings are due to the wider pressures the disease can create and through fear of becoming a burden to others.

With the right support, many problems can be solved or reduced to help you and those close to you achieve a better quality of life. This may help you feel calmer and consider ways to manage the demands of the disease.

You could talk to:

- a friend, family member or someone you trust
- your GP or a specialist palliative care professional
- our MND Association helpline, MND Connect on 0808 802 6262
- an adviser through the NHS helpline, NHS 111
- Samaritans 24-hour support service on 116 123 or other appropriate helplines
- a local hospice, as many have 24 hour helplines
- a religious or spiritual leader.

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

## **Am I depressed?**

If you feel very low and these feelings do not pass, it could be a sign that you are depressed.

If you are experiencing these signs, and they are not due to the physical symptoms of MND mentioned above, ask your GP for guidance:

- feeling persistently sad or anxious
- feeling worthless
- loss of interest and pleasure in things.

Experiencing strong emotions is natural and to be expected, but can become particularly distressing if you feel overwhelmed. You will probably discover various ways to deal with emotional overload. If you find it difficult to show your feelings, give yourself permission to express anger, irritation, tears or laughter, as these can all help relieve tension.

## 4: What is emotional lability?

Emotional lability (also known as pseudo-bulbar affect) is a symptom of MND, where some people tend to laugh or cry at inappropriate times. It is not experienced by everyone with the disease and is more common in MND where people have difficulty swallowing and speaking.

Emotional responses due to emotional lability can be difficult to stop and you may feel out of control. This may be distressing for you, but also for those close to you, who may not understand.

Emotional lability can be mistaken for depression or a reaction to being diagnosed with MND. Unlike depression, reactions due to emotional lability are sudden, unpredictable, and may not reflect how you feel. Depression lasts for weeks or months, but outbursts due to emotional lability usually only last seconds or minutes.

### What causes emotional lability?

It is an abnormal motor response caused by the effects of MND on the pathway between the outer layer of the brain and the brain stem. This means your responses may not match how you feel. For example, you may laugh uncontrollably, but feel sad, or you may cry, but feel happy. The symptom of uncontrolled crying is more common than uncontrolled laughing.

Some people with MND experience changes to their thinking and behaviour. In these instances, it is more common to experience emotional lability. However, it is very important to be aware that emotional lability is not in itself a sign of other changes to thinking and behaviour.




For more information about changes to thinking linked to MND, see: [9A - Will the way I think be affected?](#)


### How can I cope with emotional lability?

In many cases this is a temporary symptom that reduces over time, but if the responses are persistent and causing distress, talk to your GP. If your GP is not familiar with emotional lability, try to talk to an appropriate member of your health and social care team with experience of neurological conditions. Medication is available that may help.


You may find that understanding the symptom is enough to help you and your family manage the impact. Others find emotional lability limits where they go and what they do, and that medication or other assistance helps.

 *“The more people that know this problem is due to my disease, the less of a problem it feels to me.”*

Let people know that you cannot always control your laughing or crying. This will help them not to worry or feel like they have upset you. Tell them how you would like to be supported during these episodes. For example, you may prefer that they ignore it, or that they distract you from the situation. Some people find that being comforted can make it harder to stop control the response.

 *“The best way to help me is to quickly transport me away for people and after five or ten minutes I will regain my composure.”*

Some people carry information about emotional lability with them to show people if they have an outburst. If you choose to do this, explain how you are affected and how best people can support you at these times.

 *“Emotional lability has been something that has affected me from an early stage and still affects what I do now. I have an advice sheet with me that I can give to people if I break down, as when this happens I cannot speak or communicate.”*

## 5: Who can help me?

MND may affect your independence and ability to participate in everyday activities that other people take for granted. This may cause frustration and affect you emotionally. There are ways to minimise the impact of some of these difficulties and cope with the changes that are happening.

 We produce a wide range of publications that you may find helpful. See *Further information* in section 5: *How do I find out more?*

For professional guidance, contact your GP and your health and social care team. They can offer a range of assistance, from how to manage difficult emotions, to medication for specific symptoms. The following health and social care professionals can help:

### **Counselling and psychology services**

Counselling is a type of talking therapy that allows you to talk about your problems and feelings with someone who has been trained to listen with empathy. Counselling can help you deal with negative thoughts and feelings you have. Your GP can refer you to an appropriate service, but there may be a waiting list. Many hospices offer counselling as part of their palliative care support.

Psychological therapy, such as cognitive behaviour therapy (CBT) is a more in-depth form of therapy than counselling, and it can be used to address a wider range of issues. A psychologist can help you explore your thoughts, feelings, past experiences and beliefs to help you challenge your negative thoughts.

Neuropsychology focuses on the relationship between the physical brain and behaviour. A referral to a neuropsychologist can be helpful if you think you may be experiencing changes to your thinking and behaviour

 For more information about changes to thinking linked to MND, see: 9A - *Will the way I think be affected?*

### **Occupational therapy (OT)**

Occupational therapists support people to remain as independent as possible through equipment for daily living, adapting the home environment and showing people different ways to do everyday activities. Ask a health or social care professional for a referral.

### **Speech and language therapy**

Speech and language therapists can assess your needs and give you advice about swallowing, speech and communication aids. Ask a health or social care professional for a referral.

### **Care services**

Support and care services are available from your local Adult Social Care Services or health and social care trust if you live in Northern Ireland.


They can support you to access support to meet your care needs including care at home, respite care and day care centres. They can also refer you to other local services that can assist you.

If you are not currently receiving a care package, contact Adult Social Care Services or your health and social care trust for an assessment. See section 6: *How do I find out more?* for contact details.

### **Palliative care services**

When you have a serious and potentially life shortening illness, palliative care services can be provided to achieve the best quality of life and access to a wide range of health and social care support.

If you have not been referred to a palliative care team or hospice, ask your GP if it can be considered. Many hospices and palliative care services will allow you to refer yourself. This support may provide access to wider services that can support you and those close to you manage the emotional impact of MND. Many hospices have day centre services that you can access, counselling, spiritual or religious guidance, access to complementary therapies and support with difficult family discussions.

 *"It really can't be emphasised enough to listen to professionals who have helped people go through this before... Please listen, I know it is hard, but it could save you pain and keep you well that bit longer."*

## Who else can I talk to?

Although health and social care professionals can help, they may only be available through appointments.

The MND Association can help you through:

**MND Connect:** our helpline team can direct you to our services, external support or just provide a listening ear if you need to talk.

**Association visitors:** our voluntary visitors (where available), can provide support, guidance and information by telephone, email or through face to face visits.

**Regional staff:** our regional staff members can support and guide when your needs are complex, and help to co-ordinate services on your behalf.

**MND Association branches and groups:** where informal support meetings are arranged for people living with MND or their carers. This enables you to share ideas and experiences with other people affected by the disease.

**Our online forum:** This provides a safe place for you to communicate openly with other people affected by MND. You can view the forum conversations without joining if you prefer. For contact details for The MND Association, see section 6: *How do I find out more?*

## 6: How do I find out more?

### Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information.

The contact details are correct at the time of print, but may change between revisions. If you need help to find an organisation, contact our MND Connect helpline (see *Further information* at the end of this sheet for details).

#### Adult social care services (often known as social services)

These services can be contacted through your local authority. You can find details for your local authority on the following website:

Website: [www.gov.uk/find-your-local-council](http://www.gov.uk/find-your-local-council)

For Northern Ireland, search for health and social care trusts at:

Website: [www.nidirect.gov.uk](http://www.nidirect.gov.uk)

### **British Association for Counselling and Psychotherapy**

Advice on how to seek counselling and psychotherapy support, with directions to trained practitioners.

Address: BACP House, 15 St John's Business Park, Lutterworth LE17 4HB  
Telephone: 01455 883300  
Email: [bacp@bacp.co.uk](mailto:bacp@bacp.co.uk)  
Website: [www.bacp.co.uk](http://www.bacp.co.uk)

### **GOV.UK**

The main government online information service, including help about benefits and government support schemes.

Email: different contacts are given on the website for various subjects  
Website: [www.gov.uk](http://www.gov.uk) (England and Wales)  
[www.nidirect.gov.uk](http://www.nidirect.gov.uk) (Northern Ireland)

### **Hospice UK**

Hospice UK is the national charity for hospice care. They support the work of more than 200 member organisations which provide hospice care.

Address: 34-44 Britannia Street, London, WC1X 9JG  
Telephone: 020 7520 8200  
Email: [info@hospiceuk.org](mailto:info@hospiceuk.org)  
Website: [www.hospiceuk.org](http://www.hospiceuk.org)

### **Mind**

Provide advice and support on a range of topics including types of mental health problems and where to get help in your local area. Lines are open 9am to 6pm, Monday to Friday.

Address: PO Box 277, Manchester M60 3XN  
Telephone: 0300 123 3393  
Text: 86463  
Email: [info@mind.org.uk](mailto:info@mind.org.uk)  
Website: [www.mind.org](http://www.mind.org)

### **MND Scotland**

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

Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA  
Telephone: 0141 332 3903  
Email: [info@mndscotland.org.uk](mailto:info@mndscotland.org.uk)  
Website: [www.mndscotland.org.uk](http://www.mndscotland.org.uk)

### **NHS 111**

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

Telephone: 111

### **NHS Direct Wales**

Health information and advice for Wales.

Telephone: 0845 4647

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

### **NHS Northern Ireland**

Information on NHS services in Northern Ireland. This is an online service only.

Email: through the website contact page

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

### **NHS UK**

The main online reference for the NHS, including information on continuing healthcare.

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

### **NI Direct**

Government online information for Northern Ireland.

Website: **[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

### **Samaritans**

Confidential non-judgmental emotional support, 24 hours a day, for people experiencing feelings of despair. Contact your local branch or:

Address: Freepost RSRB-KKBY-CYJK, Chris, PO Box 9090, Stirling, FK8 2SA

Telephone: 116 123

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

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

## **References**

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

email: [infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

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## Further information

We have related information sheets you may find helpful:

4A - *Communicating about MND with children and young people*

7A - *Swallowing difficulties*

8A - *Support for breathing problems*

6A - *Physiotherapy*

6B - *Complementary therapies*

9A - *Will the way I think be affected?*

9B - *How do I support someone if the way they think is affected?*

12D - *Planning a holiday*

13A - *Sex and relationships for people with MND*

13B - *Sex and relationships for partners of people with MND*

You can also refer to our main guides:

*Living with motor neurone disease* – our guide to MND and how to manage its impact, including guidance about your finances

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

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

*When someone close has MND: a workbook for children aged four to ten* - an interactive booklet to help children understand about the disease and develop ways to cope, with guidance from a trusted adult

*So what is MND anyway?* - A publication informing young people about MND from the point of someone's diagnosis and throughout their journey. This resource was developed with contributions from young carers affected by MND in their family. You can download most of our publications from our website at:

**[www.mndassociation.org/publications](http://www.mndassociation.org/publications)** or order in print from the MND Connect team, who can provide additional information and support.

MND Connect can also help locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional MND Association staff.



**MND Connect**

Telephone: 0808 802 6262

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

MND Association, PO Box 246, Northampton NN1 2PR

**MND Association website and online forum**

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

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

## **We welcome your views**

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them.

If you would like to provide feedback on any of our information sheets, you can access an online form at: **[www.smartsurvey.co.uk/s/infosheets\\_1-25](http://www.smartsurvey.co.uk/s/infosheets_1-25)**

Or request a paper version by email: [infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR



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