



13A


Sex and relationships

Information for people living with motor neurone disease

This information sheet offers suggestions to concerns you might have about sex and intimacy when living with MND, whether or not you are in a relationship. It includes the following sections:

- 1: How might MND affect sex and intimacy?**
- 2: How can sex and intimacy be maintained?**
- 3: Are there other ways we can be close?**
- 4: How can my sexual needs be met if I don't have a partner?**
- 5: Where can I get support if I have experienced sexual violence or abuse?**
- 6: How do I find out more?**

When used, the term 'partner' refers to anyone with whom you have a sexual relationship.

 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 might MND affect sex and intimacy?

It can be reassuring to know that MND has no direct effect on fertility, libido, sexual arousal, the ability to have an erection or orgasm. If you do experience changes to your sexual function, it is helpful to discuss any concerns you have with your GP, as these changes won't necessarily be related to MND.

Depending on how your symptoms progress, you may find MND has an impact on your sexual expression and confidence. The following information considers concerns you may have.



For information for your partner, see:
Information sheet 13B – *Sex and relationships for partners of people with MND*

Why has my sex drive changed since diagnosis?

An MND diagnosis can cause strong emotions, and you are likely to need time to adjust. Illness or disability of any kind can change how we feel about ourselves. Anxiety, fear and depression can reduce arousal and interest in sex. You may also experience fatigue with MND, and this can affect your sex drive.

For more information about managing the impact of fatigue, see later heading *How can I manage the effect of fatigue on my sexual relationship?* in section 2: *How can sex and intimacy be maintained?*

For some couples, the sexual side of a relationship becomes less important, while shared activities and time together become more valuable. For others, there might be an increase in sexual arousal. Love-making could be very important to you and, after diagnosis, can become even more so.

Having a low mood can affect confidence and reduce sexual desire. If you feel very low and these feelings do not pass, it could be a sign that you are depressed.

Symptoms of depression include:

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

If you are experiencing these symptoms, you can ask your GP for guidance.



For more information about managing the emotional challenges of MND, see our guides: *Emotional and psychological support* and *Changes to thinking and behaviour with MND*

How might MND affect my relationship?

If you are in an existing relationship, any problems experienced before the MND diagnosis could continue. However, as you face the challenges of the disease together, you may find new understanding and be able to resolve previous difficulties.

When one person becomes ill or disabled, the balance of the relationship can change. This can result in different expectations and sometimes leads to tension between partners. It is helpful to discuss any worries you have with your partner, as they might have similar concerns. Open and honest communication can help both of you adjust to these changes and can reduce any sense of conflict.



"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 each other that you still care. I can't stress how important this is."

2: How can sex and intimacy be maintained?

How can we still be intimate when I have limited movement?

If your movement is affected by MND, your partner might need to take a more active role sexually. This could include trying different sexual positions or sexual activities such as massage, oral sex or mutual masturbation.

Sexual aids, for both men and women, can be obtained from the internet, as well as specialist shops. Although you might initially feel embarrassed if you have not used sexual aids before, they can be helpful if you have limited movement, or experience fatigue. Any changes can take time before you both feel at ease. It helps to keep an open mind, try to be patient with each other and don't be afraid to laugh together.

Websites vary greatly in terms of what they offer, how information is presented, and how much items cost. To help you start your search, see *Useful organisations* in section 6: *How do I find out more?*

Even if you have limited movement, your sense of touch is not affected by MND. Both you and your partner can still enjoy the comfort and pleasure of touch. If your hands or arms are affected, you could suggest that your partner takes your hands and uses them to stroke their body or face so that you can both share the warmth and intimacy of this touch.

If you enjoy the closeness and intimacy of kissing, hugging and cuddling, make sure your partner is aware of this. They might value this more than they used to. Telling your partner how you feel about them is important in maintaining intimacy.

Adjusting to my changing body

Having MND can make you more aware of your body. As changes take place, you may find you tend to focus on problems, difficulties and things that are no longer the same. This can affect your self-esteem, which can affect your sexual confidence.

You are likely to need time to adjust to these changes. It can be helpful to discuss your feelings with your partner, a close friend or someone from your health and social care team.

If you feel less attractive, it can be easy to assume that your partner is less attracted to you. This can result in you waiting for them to initiate sex. However, your partner might worry about putting pressure on you to have sex, and wait for you to show interest first. This can lead to a situation where you both misunderstand each other's needs and feelings. This is where open communication becomes very important.

To feel more confident sexually, it might help to adopt a different position, choose an item of clothing to wear, or adjust the lighting.

If you have any swallowing difficulties with MND, you might experience problems with controlling saliva. If you feel embarrassed by this, wearing dark, patterned tops or adopting a sexual position on your side can help.

If saliva is a problem, ask your doctor for guidance, as there might be medication that can help.



For more information about saliva control, see:
Information sheet 7A – *Swallowing difficulties*

How can I manage the effect of fatigue on my sexual relationship?

Fatigue is a common concern of people with MND. If your partner is supporting you and taking on more daily routines, they could also be experiencing tiredness. Both of you might need to be more flexible about the time you spend together. Some people find that they are less tired in the morning, and others are less tired in the evening. Listen to your body and pace yourself.

Although it might not feel as spontaneous, planning when and how you are going to have sex can help you both. It can help to experiment with less demanding sexual positions, perhaps with your partner taking on the more active role, or by having sex lying side by side. You could also agree with your partner that love-making need not always be a long session.


There are a variety of ways of being intimate and showing each other how you feel. You might find that oral sex, mutual masturbation or using sexual aids is less tiring than penetrative sex. You might both find that kissing, rubbing noses, cuddling or stroking is all you need to feel close.

SH&DA have produced a leaflet on sex and fatigue. See *Useful organisations* in section 6: *How do I find out more?*

Can I have sex if I have a feeding tube?

If you have a feeding tube, you might be worried that it could move or fall out during sex. If you have a tube secured by a button inside the stomach, this is rarely dislodged (this is usually known as a PEG tube). If your feeding tube is held in place by an inflated balloon of water (usually known as a RIG tube), a little more care might be needed.


You might feel more confident if you tape the tube to your skin during sex. Some people prefer to wear tighter clothing to hold the tube still, such as a tight t-shirt, vest or camisole.

 For further details about tube feeding see:
Information sheet 7B – *Tube feeding*

Can I have sex if I have breathing problems?

If you have any breathing problems with MND, you may worry about getting breathless during sex. If pressure on the chest or abdomen feels uncomfortable, it might be necessary to consider a more upright or semi-upright sexual position so that you don't feel as restricted. You might find intercourse easier if your partner supports their own body weight in a seated position.

If you use a ventilator, it is not harmful to have sex. You can wear your face mask during intercourse, if needed. If you feel able to manage without it, you might want to keep it nearby in case you feel the need to use it following sex.

 For further details about ventilation with MND see:
Information sheets 8A to 8E

Will any of my medication affect sex?

Some prescription medications can affect sexual function, sexual desire, or the ability to become aroused or achieve orgasm. Other drugs, such as those that reduce saliva, can cause vaginal dryness. If you have any questions or concerns about medication that you, or your partner, are taking, it is important to discuss these with your doctor.

Which sexual positions might be more comfortable?

This is very much a matter of individual preference, and you might need to experiment in order to find the most comfortable position for you. It might be necessary for your partner to take a more active role.

Whatever you try, a willingness to laugh together while you experiment can help to maintain intimacy.

If you find your breathing is restricted lying down, being in an upright or semi-upright position can help you to breathe more freely. You may find a sofa or chair more supportive than a bed. You can ask your occupational therapist for advice, as there are slings and other equipment available to help achieve more comfortable positions.

How can I use condoms?

If your hands are affected by MND and you want to use a condom, your partner may be willing to help you put it on as part of your love-making. Your GP, practice nurse or family planning clinic can advise on other forms of contraception if preferred.

What if sex has become routine?

In long-standing relationships, sex can sometimes follow a similar pattern, possibly in the same place, or at the same time of day. Now might be a good time to be more creative and revisit some of the things you used to do when your relationship was new. You may want to try different ways of pleasing each other.

Many people find it helpful to rediscover their sensual areas by gently exploring the whole body and identifying areas that are pleasurable. Try altering the pressure and rhythm of touch, not just for areas commonly associated with sexual pleasure, but for the whole body. The purpose is not to lead up to sexual intercourse or orgasm, but to learn about each other's preferences, likes and dislikes. This is not something that can be rushed. Health professionals might refer to this technique as 'body mapping' or 'sensate focus'.

Body mapping can be done either on your own or with your partner. If you do this together, it provides an opportunity to learn what each other finds stimulating and pleasurable. You might prefer to use your hands, or you might kiss, lick or nibble each other's bodies to discover what each other enjoys.

Be honest with each other and say how you feel, what you like and what you don't like. This process can help to improve communication and understanding between you both.

What if my partner is also my carer?

If your partner is also your main care-giver, this can strengthen your relationship, but you might find it causes strain as roles shift and change.

Accepting external support for some of your care can be helpful. This can help you both hold on to what was unique about your close relationship before you had MND. It also provides rest for your partner, as worry or tiredness will affect their wellbeing.



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

Can professionals help?

You can ask a health and social care professional about any concerns regarding your sexual relationships and sexual expression. They may not raise the subject themselves in case they cause offence or appear intrusive, so do ask for help if needed.

They can advise or refer you to a specialist. For example, occupational therapists and physiotherapists can provide guidance on all aspects of daily living, including any worries about sex. You can also raise concerns with one of the team at your MND care centre or network, or at your local neurological clinic.

If starting the conversation feels awkward, you could ask: *'Can I talk to you about something personal?' or 'Do other people find that...?'* You could even show them this information sheet. If you feel the member of staff is uncomfortable, do not be put off and ask if you can be referred to another professional for appropriate guidance.

3: Are there other ways we can be close?

You might find that sexual intimacy becomes less important, as your priorities change. For example, you might begin to value other aspects of life differently and find that shared activities become more significant for you both.

Telling your partner how you feel about them is important in maintaining intimacy. If you value the closeness and intimacy of kissing, hugging and cuddling, make sure your partner is aware of this. They might also value this more than they used to.

It is helpful to talk about how you can create times within your day when you can have quality time together as a couple. Something as simple as going to bed at the same time can provide opportunities to be together, to talk and touch.

If you sleep in separate beds, you might want to explore other ways you can be physically close during the day. A sofa or inflatable mattress might provide opportunities for shared intimacy.

What if we have different sex drives?

In any relationship, there can be times when one partner is keener to have sex than the other. This can be for a variety of reasons, including different sexual appetites, being busy or tired, and being pre-occupied with thoughts or worries. See earlier heading *Why has my sex drive changed since diagnosis?* in section 1: *How might MND affect sex and intimacy?*

If your partner's need for sex is less than yours, enjoying closeness for its own sake can help them feel less pressured. If your sexual needs have lessened, it is helpful to explain this to your partner so that they don't feel that your lack of interest in sex is a lack of interest in them. Feelings of self-doubt, fear or uncertainty, can be avoided if your partner knows your feelings for them are unchanged and only your appetite for sex has lessened.

Choose your moment carefully, when you have uninterrupted time together, and be prepared to listen to your partner's feelings and point of view. In order to prevent them feeling rejected, it is helpful to offer an alternative, such as: *'We don't need to have sex for me to feel... but I would love to...'*

It might be that your partner's sexual needs can be met through masturbation or by using sexual aids. This could be something you feel able to share with them or that they do alone.

If differences in sexual interest create tensions within your relationship, it can be helpful to talk to a counsellor who specialises in this area. See *Useful organisations* in section 6: *How do I find out more?*

What if my speech is affected?

If MND affects your ability to speak, you may feel that it limits intimacy. However, sex is often a time when people can express themselves without having to talk.

You might want to develop a sign language or a personal code that has special meaning for you as a couple. You could also write or record your feelings for your partner in advance. Although this is less spontaneous, it can still be a helpful way to let them know how you feel about them.

Communication aids can help, so ask your GP for a referral to a speech and language therapist. They can assess your needs and advise about appropriate aids and therapy.



For more information about difficulties with speech, see: *Living with MND* – our guide to MND and how to manage its impact

4: How can my sexual needs be met if I don't have a partner?

If you are single, this could be your personal choice and preference. However, if the lack of a sexual partner is a concern, these worries can increase when MND causes physical disability.

If you want to start a relationship, it can be difficult to know when and what to tell a new partner about your diagnosis. There is no simple answer to this, as it will depend on the relationship you have with the person and how your symptoms have progressed. You might fear rejection, but this can happen to anyone, regardless of their health or circumstances.

If you would like to meet other people with a disability, you might want to consider joining a social club for single people with disabilities, such as Outsiders. Their groups offer support, friendship and the possibility of romantic or sexual relationships.

For further information and suggestions about meeting your sexual needs as a single person with a disability, visit the website. See *Useful organisations* in section 6: *How do I find out more?* for contact details.

If you have carers, you might need to establish some rules with them so that you have the privacy you need. You might need time alone to masturbate or to watch sexual films. Some carers will be more understanding of this than others, but you can simply ask for time alone, rather than being specific about the purpose.

If masturbation becomes difficult, there are a number of sexual aids for both men and women that might be helpful. These are available from some high street shops, as well as on the internet. See *Useful organisations* in section 6: *How do I find out more?*

5: Where can I get support if I have experienced sexual violence or abuse?

An MND diagnosis often provides an opportunity for people to 'take stock' of their lives. This may uncover painful and distressing emotions.

If you or your partner have been affected by sexual violence or abuse and would like support in dealing with this, one of the following organisations could be of help. For general support regarding sex and relationships, see also *Useful organisations* in section 6: *How do I find out more?*

Please note: contact details are correct at time of going to print, but can be subject to 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).

National Association for People Abused in Childhood (NAPAC)

Provides support and information for people who have been abused in childhood, and those close to them. Support is available via email or telephone.

Address: PO Box 63632, London SW9 1BF

Telephone: 0808 801 0331

Email: support@napac.org.uk

Website: www.napac.org.uk

Rape Crisis

Provides support and information for men and women who have survived sexual abuse or rape, as well as partners, family and friends.

Address: BCM Box 4444, London, WC1N 3XX

Telephone: 0808 802 9999

Email: info@rapecrisis.org.uk

Website: www.rapecrisis.org.uk

Survivors UK

Provides support for men who have been raped or sexually abused.

Address: Ground Floor, 34 Great James St, London WC1N 3HB

Telephone: 0203 598 3898

Email: info@survivorsuk.org

Website: www.survivorsuk.org

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 can 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).

College of Sexual and Relationship Therapists (COSRT)

Provides information on sexual problems and a list of local therapists.

Address: PO Box 13686, London SW20 9ZH

Telephone: 020 8543 2707

Email: info@cosrt.org.uk

Website: www.cosrt.org.uk

LGBT Foundation

Provides information, support and advice to lesbian, gay and bisexual people. They offer online support and a forum specifically for carers.

Address: 5 Richmond Street, Manchester M1 3HF

Telephone: 0345 3 30 30 30

Email: info@lgbt.foundation

Website: <http://lgbt.foundation/>

Outsiders

Contact their helpline for guidance on sex and relationship problems or join their group to find others looking for a relationship.

Address: WestEnd, Redwood Farm, Barrow Gurney, Avon, BS48 3RE

Telephone: 07074 990 808 (sex and disability helpline)

Email: trust@outsiders.org.uk

sexdis@outsiders.org.uk (sexual information and advice)

Website: www.outsiders.org.uk

Relate

Provides information, counselling or psychosexual therapy to help with relationships.

Telephone: 0300 100 1234

Email: Via the website

Website: www.relate.org.uk

The Sexual Advice Association

Provides information and advice about a range of sexual issues.

Address: Suite 301, Emblem House, London Bridge Hospital,
27 Tooley Street, London SE1 2PR
Telephone: 020 7486 7262 (helpline)
Email: info@sexualadviceassociation.co.uk
Website: www.sexualadviceassociation.co.uk

SH&DA Sexual Health and Disability Alliance

Supports health and social care professionals supporting disabled people with sex and relationships. You might want to share these details with professionals working with you.

Address: BCM Box Lovely, London WC1N 3XX
Telephone: 07770 499 3527
Email: trust@Outsiders.org.uk
Website: www.shada.org.uk

Spokz

Website offering a range of disability equipment, including sexual aids.

Address: 2 Jordan Croft, Fradley, Lichfield WS13 8PN
Telephone: 01543 899 317
Email: info@spokz.co.uk
Website: www.spokz.co.uk

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And for additional guidance:

Dr Tuppy Owens at Outsiders

Lorna Couldrick, Senior Lecturer School of Health Professions (retired), University of Brighton and member of SH&DA

References

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

Email: infofeedback@mndassociation.org

Or write to:

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

Further information

We have related information sheets you might find helpful:

7B – *Tube feeding*

8A-8E our range of sheets about breathing and ventilation

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

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

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

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

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

MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

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

MND Association website and online forum

Website: www.mndassociation.org

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

We welcome your views

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

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

www.surveymonkey.com/s/infosheets_1-25

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

infofeedback@mndassociation.org

Or write to:

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

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