


Sex and relationships for people with or affected by MND or Kennedy's disease



A photograph of two women standing on a beach, looking out at the ocean. The woman on the left has bright pink hair and is wearing a blue denim jacket. The woman on the right has blonde, curly hair and is wearing a dark red sleeveless top. They are both looking towards the right side of the frame, where the ocean is visible. The lighting is warm, suggesting a sunset or sunrise.

“Both motor neurone disease (MND) and Kennedy’s disease can impact on relationships, sex and intimacy. This guide openly and sensitively addresses likely issues, with ways to maintain intimacy and find support. Whether single and living with either condition, in a couple or the partner of someone who has been diagnosed, this inclusive guide is well worth a read.”

Dee Holmes, Senior Practice Consultant at Relate

Contents

How can this booklet help me?	4
1: How can MND affect sex and intimacy?	5
2: How can sex and intimacy be maintained?	7
3: Are there other ways we can be close?	16
4: How can my sexual needs be met if I don't have a partner?	20
5: Is there support if I have experienced sexual violence or abuse?	26
6: What do I need to think about as a partner of someone with MND?	27
7: How do I find out more?	32



This booklet has been kindly endorsed by Relate.



Patient Information Forum

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

<https://piftick.org.uk>

How can this booklet help me?

An illness like motor neurone disease (MND) can affect all aspects of your daily life, including sex and relationships. The aim of this booklet is to explore ways to maintain physical connection with MND, whether in a relationship or not, and regardless of your sexuality. It can also help you maintain intimacy as the partner of a person diagnosed with MND.

This booklet can also help if you have Kennedy's disease, which shares similar symptoms to MND. However, Kennedy's disease also has a hormonal impact that can affect sex drive. Ask your specialists for further guidance with your individual needs.



See information sheet 2B – Kennedy's disease. Find *Further information* in section 7: *How do I find out more?* to order printed copies of resources.



All quotes are from people living with or affected by MND or Kennedy's disease.



1: How can MND affect sex and intimacy?

It can be reassuring to know that MND has no direct impact on fertility, libido, sexual arousal, or ability to have an erection or orgasm. Ask your GP about any changes to sexual function, as this may not be caused by MND. However, MND can affect sexual expression, movement and confidence.

Why has my sex drive changed since diagnosis?

An MND diagnosis can cause strong emotions and you may need time to adjust. It can change how you do things and how you feel about yourself. For some couples, sex becomes less important than shared activities and time together. For others, sex is very important, even more so after diagnosis.

Anxiety, fear, depression or fatigue can all reduce desire, arousal and interest in sex. For some people, age can also have an impact on how you feel about sex. Low mood can affect confidence and could be a sign of depression if you:

- feel sad or anxious all the time
- feel lacking in worth
- lose interest and pleasure in things.

Ask your GP for guidance on depression. Also if you experience emotional lability – this is where some people with MND laugh or cry when unexpected, but it doesn't match how they feel.



For more about low mood and emotional lability, see our booklet: *Emotional and psychological support*.

How could MND affect my relationship?

When one person becomes ill or disabled, the balance of a relationship can change and bring different expectations.



“You’re chasing everybody all the time and, with personal interaction, we’ve been niggled a bit more than we should – such as waiting for support and home adaptations, which affects quality of life... it really affects both of us emotionally.”

You may find this leads to tension and any existing relationship problems could get worse after an MND diagnosis. However, facing the challenges of the disease together can help some relationships grow stronger.

It can help to discuss worries with your partner, as they could have similar concerns. Open and honest communication can help bring understanding.

As MND progresses, things will continue to change, but being open about this can help you both adapt.



2: How can sex and intimacy be maintained?

“

“I have feelings... but cannot express them actively.”

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.

“

“A sexual relationship can be maintained through other means than penetrative sex. There are plenty of examples of other ways of being intimate, that can help people with MND still be close with their partners.”

Even if your movement is limited, sense of touch is not affected by MND. You and your partner can still enjoy the warmth and pleasure of touch. If your hands or arms are affected, your partner can take your hands and use them to stroke their body or face, so you can both share this sense of intimacy.



If you enjoy closeness, kissing, hugging and cuddling, make sure your partner knows this. They may even value this more than they used to, but don't know how to tell you. Telling your partner how you feel about them can help intimacy.



“The idea of sharing helps – it gives a feeling of togetherness.”

Sexual aids, for both men and women, can be ordered from the internet or specialist shops. If you haven't used sexual aids before, you might feel embarrassed at first, but they can help if you have limited movement or get tired easily. Websites vary greatly in terms of the products they offer, how information is presented, and how much items cost.



To help start your search, see *Useful organisations* in section 7: *How do I find out more?*

When you change how you do things, it can take time for both of you to feel comfortable. Keep an open mind and try to be patient with each other – it's okay to laugh together too.

Adjusting to my changing body

As your body changes with MND or Kennedy's disease, you may focus on things that are no longer the same. This can affect your self-esteem and sexual confidence.



“My thoughts were along the lines of, ‘Am I still lovable or even attractive, anymore?’”

Take time to adjust, but it can help to discuss how you feel about the changes with your partner, a close friend or someone from your health and social care team.

You may worry that your partner is less attracted to you and wait for them to initiate sex. However, your partner may worry about putting pressure on you and wait for you to show interest. Open communication can avoid misunderstanding.

To feel more confident sexually, wear clothing that helps you feel good, set the scene with lighting and music, or adopt a different sexual position.

If you have swallowing difficulties with MND, saliva can be difficult to control. If you feel embarrassed by this, wearing dark, patterned tops or adopting a sexual position on your side can help. Ask your doctor for guidance too, as medication may help.



See: Information sheet 7A – *Swallowing difficulties*.

How can I manage fatigue?

Fatigue can be a problem with MND. Your partner may also be more tired than usual if they are taking on more daily routines. Be flexible about the time you spend together. For example, you may be less tired in the morning than the evening.



“Fatigue is very hard to accept, especially when you have been active in the past.”



Although less spontaneous, planning when and how to have sex can help. Experiment with shorter sessions and less demanding sexual positions. Your partner could take a more active role or you could try having sex lying side by side.

There are a variety of ways of being intimate. Oral sex, mutual masturbation or using sexual aids may feel less tiring than penetrative sex. Kissing, rubbing noses, cuddling or stroking can help you feel close.

Can I have sex if I have a feeding tube?

If you have a feeding tube, you may worry it could move or fall out during sex. If the tube is secured by a button inside the stomach (usually known as a PEG) it cannot be easily moved. If your feeding tube is held in place by an inflated balloon of water (usually known as a RIG), a little more care is needed.

You may feel more confident if you tape the tube to your skin during sex or wear tight clothing to hold the tube still. This could be a close fitting t-shirt, vest or camisole.



For more about tube feeding, see information sheet:
7B – Tube feeding.

Can I have sex if I have breathing problems?

You may worry about getting breathless during sex, especially if pressure on your chest or abdomen feels uncomfortable. Try a more upright or semi-upright position to help you breathe more freely.

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 after sex.



See information sheets 8A to 8D on breathing support.

Which sexual positions might be more comfortable?

This is up to individual choice, and you might need to experiment in order to find the most comfortable position.

It might be necessary for your partner to take a more active role or support their own weight in a seated position. Whatever you try, a willingness to laugh together while you experiment can help a feeling of shared intimacy.

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.

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, but you can buy lubricants from chemists. If using condoms, apply a water-based lubricant, not oil-based.

Ask your doctor if you have any concerns about medication, lubricants, hormone treatments, (or hormone problems with Kennedy's disease), periods, menopause or sexual worries.



For more about intimate care, periods and menopause, see our booklet, *Personal care*.

How can I use contraceptives?

Your GP, practice nurse or family planning clinic can advise on all forms of contraception. If your symptoms affect your hands and you want to use a condom, your partner may be willing to help you put it on.

If you are planning a pregnancy, ask your health and social care team for guidance about any support you may need.

What if sex has become routine?

In long-standing relationships, sex can sometimes follow a similar pattern, in the same place, or at a similar time. It can help to be creative and revisit 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 gently explore the whole body, not just areas most often linked with sexual desire. Rediscover or find new areas that feel pleasurable and try altering pressure and rhythm of touch. Health professionals often call this technique 'body mapping' or 'sensate focus'. The purpose is not to lead up to sexual intercourse or orgasm, but to learn more about each other's likes and dislikes. This is not something that can be rushed.

Body mapping can be done on your own, but with your partner, it provides an opportunity to learn what you both find stimulating. Depending on your symptoms, you may wish to use your hands, or kiss, lick or nibble each other's bodies to discover what each other enjoys. Be honest about what you like or don't like. This process can improve communication and understanding between you both.



“Thanks so much for providing help and information on what may be seen as a difficult topic to discuss... A quality of life grant from the MND Association also helped us towards buying a hot tub, to ease muscle pain for my husband with MND. He sees it as financial help, but I see it as another arm around us in support. It’s like a virtual hug. I can relax and forget everything for an hour or two. It’s like being on holiday.”

Person affected by MND

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 your diagnosis. It also provides rest for your partner, as worry or tiredness will affect their wellbeing.



See section 6, *What do I need to think about if I'm a partner of someone with MND?* Find more for carers in our guide: *Caring and MND: support for you.*

Can health and social care professionals help?

You can ask a health and social care professional about any concerns regarding your sexual relationships or sexual expression. If they don't raise the subject themselves, 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 worries about sex. This helps make sure that any aids or solutions, or equipment such as a seated sling to help with physical disability during sex, are suitable and safe for your individual needs and for your partner.

If you sense that a health and social care professional is uncomfortable about discussing sex, do not be put off. Ask to be referred to a professional who can provide appropriate guidance. You can also raise concerns with a member 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?'

'Do other people find that...?'

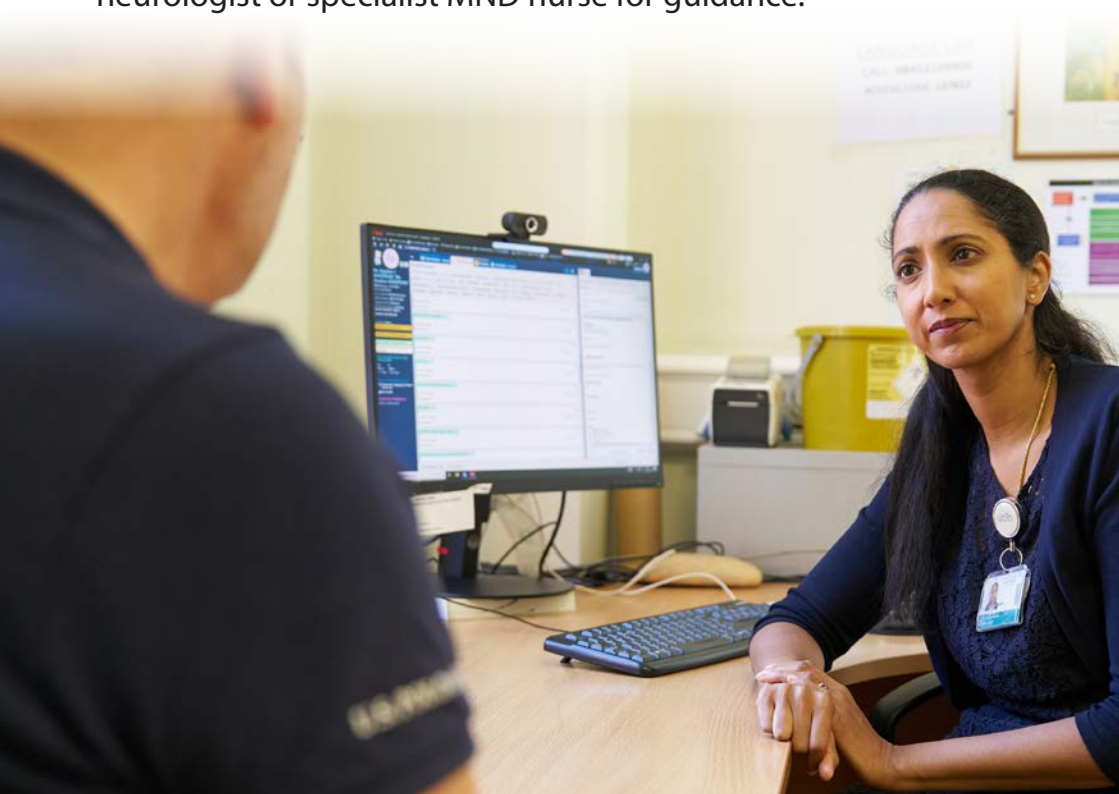
'Could we chat about how MND affects... ?'

Taking written information like this to an appointment can help guide discussion. It also lets the professional know you would like to ask sensitive questions.



“These topics are not always easy to discuss, but taking this booklet to an appointment can initiate a conversation, so that you can ask for help.”

If you have any concerns about MND and pregnancy, ask your neurologist or specialist MND nurse for guidance.



3: Are there other ways we can be close?

As priorities change, sex may become less important to you. For example, other shared activities and intimacy can become more significant.

Telling your partner how you feel about them can help a sense of sharing and intimacy. If you value closeness from touch, kissing, hugging and cuddling, let your partner know. They may feel the same way.

Think about times of day when you can have quality time as a couple. Something as simple as going to bed at the same time can provide opportunities to be together, share your feelings and connect.

If you sleep in separate beds, a sofa or inflatable mattress may help you both explore ways to be physically close to each other during the day.



Twin profiling beds can help you find a comfortable position for time together, then adjust each side for sleep. Or use a single bed next to a profiling bed.



“We had to have single beds, having shared a bed for twenty years... Every night he adjusted his bed so it was exactly the same height as mine. It was so important to me that we had that time together – to be able to reach across and touch him.”

What if we have different sex drives?

In any relationship, there can be times when one partner is more interested in sex than the other. This may be due to different sexual appetites, being busy or tired, or being preoccupied with thoughts or worries.

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 don’t feel as high as before, let your partner know the change is not a lack of interest in them. This can help them avoid feelings of self-doubt, fear or uncertainty.

Choose your moment carefully, when you have quiet time together, and be prepared to listen to your partner’s feelings and point of view. It can help to offer an alternative, such as:

‘We don’t need to have sex for me to feel... but I would love to...’

Your partner’s sexual needs could be met in other ways too, through masturbation or sexual aids. This could be something you share with them or they do alone.

If differences in sexual interest create tension within your relationship, it can be helpful to talk to a professional or counsellor who specialises in this area.



See *Useful organisations* in section 7: *How do I find out more?*

What if my speech is affected?

MND may affect your speech, but sex is often a time when people can express themselves without having to talk. You may already use sign language that has special meaning for you as a couple. Some people blow a kiss, or glance in a particular way to tell their partner that they love them. You can also work out signals to explain how you feel about something.



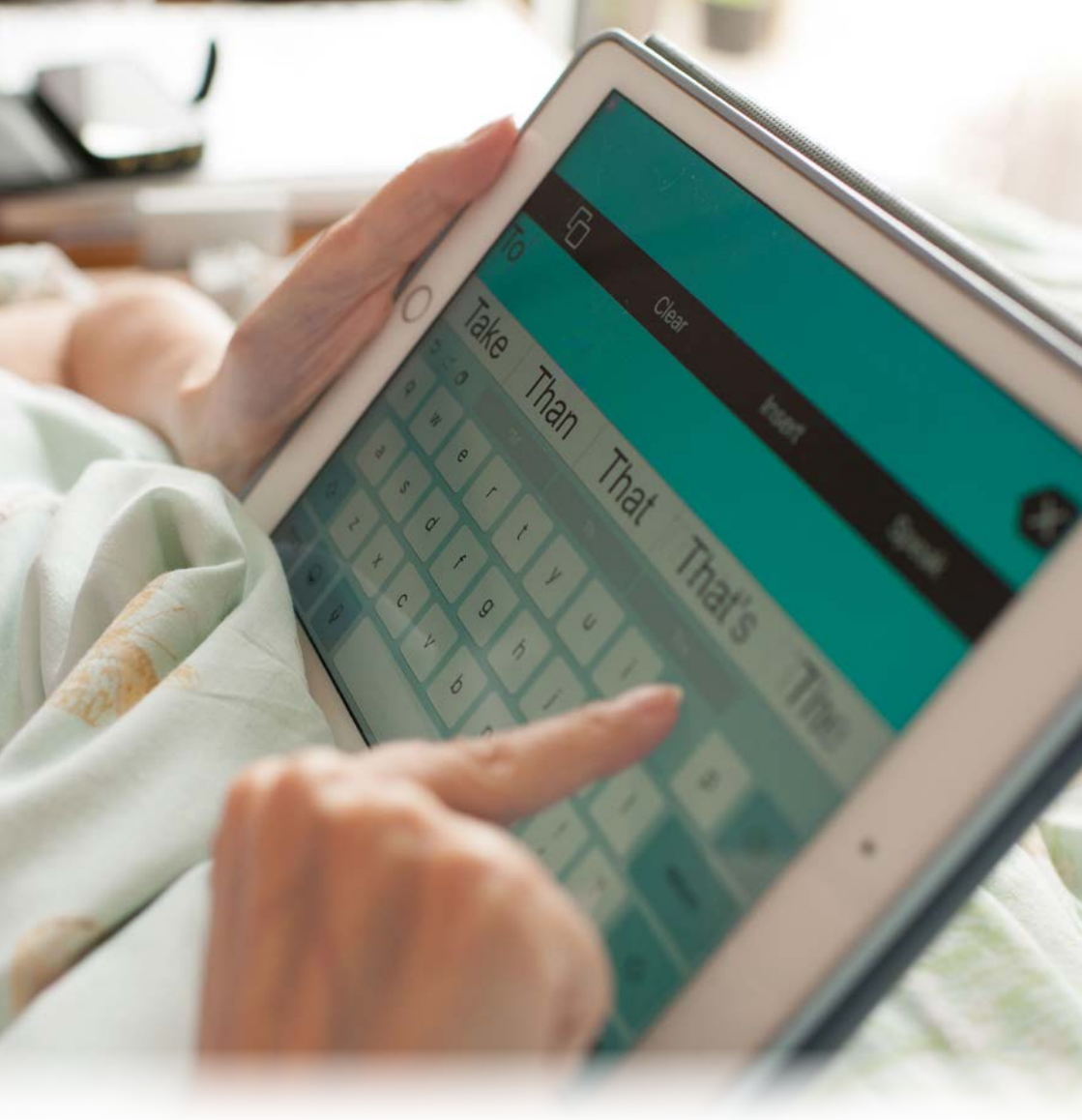
“Try new ways to communicate as physical ability changes. For example, turning your head right can mean ‘yes’, to the left ‘no’ and looking straight ahead ‘don’t mind’ or ‘don’t know’.”

You could also write or record messages for your partner. Although done in advance, messages can still let them know how you feel about them. Using communication aids can also help, so ask your GP for a referral to a speech and language therapist for assessment. They can advise about appropriate aids and therapy.



For more about difficulties with speech, see:

- 7C – *Speech and communication support*
- 7D – *Voicebanking and message banking*
- *Living with motor neurone disease (MND)*



“My voice is now very slurred and at times not understandable to other people. I had my voice banked a few months ago and I have been offered support in getting an app for my computer tablet.”

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

You may be single by choice, but if you're seeking a sexual partner, you may worry about how to explain your diagnosis, and when. There is no simple answer, as it will depend on your relationship and symptoms. You may fear rejection, but this can happen to anyone, whatever their situation.



"I am single... I never go out in the evening as I am too vulnerable on my own."

If it becomes difficult with MND to go out and meet people, online dating sites and apps can help. Always consider safety before meeting someone. If you specifically want to meet people who share understanding of your physical needs, try joining a social club or a dating site for disabled people.



Find *Useful organisations* in section 7: *How do I find out more?* See our booklet, *Telling people about MND*.





**Please
Do
Not
Disturb**

What if I need sexual privacy?

If you have carers, work out how to ensure privacy, in case you want to masturbate or watch sexual films. You can just ask for time alone, without explaining why. Sexual aids for both men and women are available from some high street shops and the internet, but physical impairment can make these more difficult to use as time goes on.

Is it legal to pay for sex?

Some people with MND ask us for information about employing a sex worker, to assist with sex when disabled. There can still be a sense of taboo or shame around this subject, but you have the right to the same privileges as other people if you are disabled. This is governed by the *Human Rights Act 1998* and the *Equality Act 2010*. Search for legal Acts at: www.legislation.gov.uk

If you have the mental capacity to consent to sexual activity, your right to sexual expression and consensual sex in private should not be restricted. However, the law governing payment for sex can vary depending on where you live:

In England, Wales and Scotland

It is legal to pay for sexual services if you are over 18 and ALL of the following apply:

- it takes place in a private space
- the person is not involved in your professional care
- the sex worker is over the age of 18 and providing a sexual service by their own choice.

In Northern Ireland

It is illegal to pay someone for sexual services.

Other regions

If you live in a region or Isle of the UK where local laws may apply, ask your health professionals or a legal professional for further advice.

Where to get further help or support

It may feel difficult to open conversations about problems with sex and intimacy, but health or social care professionals may have guidance. Try to ask a trusted professional what can be done if you have sexual needs that cannot be met. If you are thinking of arranging a visit with a sex worker (where it is legal to pay for sex) the professional may have advice on this.

Some care professionals may have beliefs or views that make these conversations difficult for them. If this is the case, seek out a care professional who:

- you trust and have a good relationship with
- is open and approachable
- has solved a problem creatively in the past.

The National Institute for Health and Care Excellence (NICE) has a NICE guideline for motor neurone disease. The guideline recommends professionals discuss sexuality and intimacy with people with MND, to ensure their psychological and emotional needs are being met. We have resources about the NICE guideline to help you during appointments.



See *Further information* in section 7: *How do I find out more?*

What to consider

Where it is legal to pay for sex and you want a visit, take time to plan. You need to be clear what you do and don't want to happen. How you provide consent and communicate your needs will be important, as is safety for you and the sex worker.

Ask a trusted care professional for further guidance.

Think about:

- finding a sex worker who has experience of working with physical impairment
- how to access sex workers registered with a trustworthy organisation - this helps avoid contacting street sex workers who may not be working by their own choice



See *Useful organisations* in section 7: *How do I find out more?* for contacts with registered sex workers.

- how to ensure physical and hygiene safety for yourself and for the sex worker
- using condoms if needed to protect against infection, and arranging a health check if you have any signs of a sexual infection before or after the visit
- practical things, such as someone to help with personal hygiene before and after the visit
- putting in place any emotional support you may need
- where you want to be during the visit
- how to ensure privacy if you have regular support from carers or care workers
- informing the sex worker about MND symptoms that may impact on a visit, including problems with speech and communication – or changes to thinking and behaviour that can happen for some people with MND (which may affect emotions or how you behave with other people)
- communication signals to use with the sex worker, so you can express your wishes if speech is difficult.

If you live in a nursing or residential care home, or receive help from a paid care worker

Staff and paid carers cannot provide sexual services, but do discuss your needs with a senior staff member who you find approachable. If living in a nursing or residential home, find out if a sex worker can make a private visit, but the law is not clear in these circumstances. Each home has to consider each request and it is important to follow the agreed policies.

If sex worker support is agreed, with your consent, think about where you want this to happen. You may not want the visit in the care home itself or it may be difficult for the care home to do this. Although staff and care workers may not be able to make arrangements for a sex worker, it's still worth asking if a staff member could help you travel to a selected and safe address for a visit.

You will need to pay costs for the sex worker, and possibly for any paid travel or premises being visited.



5: Is there 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.

This could relate to sexual violence or abuse where you have not given your consent for a sexual act. This may have happened in the past or it might be something happening in your life now.

Giving consent means giving permission for something to happen. By law, everybody involved in sexual activity must give consent, and this consent can change at any time.

Consent is where you agree by choice **and** have the freedom and mental capacity to make that choice.

If you or your partner have been affected by sexual violence or abuse at any time, there are organisations that provide specialist support. They may be able to offer emotional support, counselling, information or guidance on what to do if you wish to take action.

If you need immediate support, or help to find the right type of organisation, contact our MND Connect helpline.



Find our contact details and wider organisations in section 7: *How do I find out more?*

6: What do I need to think about as a partner of someone with MND?

Sections 1 to 5 of this booklet explore the likely impact of MND on intimacy, with suggested approaches to sex that may help. You may find it reassuring to know that MND does not usually affect sexual function, but physical impairment can impact on sexual expression. Sex drive can also be affected if either of you feel anxious, depressed or tired.

If you are both the partner and main carer of someone with MND, your roles within the relationship are likely to change. You may take on more household tasks and responsibility, and feel under pressure, emotional and tired.





“Being a carer especially for a partner can be extremely isolating, as it becomes increasingly difficult with MND. It can be a very fine emotional balance between wanting to do what you can, to being expected to do what you can.”

Looking after yourself can often take second place when facing the challenges of the caring role, but you matter too.



See our comprehensive guide on carer wellbeing: *Caring and MND – support for you* and our booklet: *Emotional and psychological support*.

Accepting some support can give you time just to be a couple and enjoy social time together.





“Sometimes taking a step back, and accepting or asking for help, can help you not to lose your relationship within it all.”

Having a needs assessment for the person with MND and yourself as a carer can help you find support. Contact adult social care services, through your local authority in England and Wales, or health and social care trust in Northern Ireland.



See information sheet 10B – *What is social care?*

If the person with MND loses confidence or finds it difficult to be sexually active, you can help by:

- explaining that your feelings for them haven't changed
- taking a more active sexual role
- having open conversations about needs and emotions
- sharing communication signals if their speech is affected
- finding new ways to be intimate and share touch, as well as sex
- trying sexual positions that feel more comfortable for the person with MND, especially if their breathing is affected.



“His physicality and needs are changing... and the day to day coping and stresses of MND can get very challenging and in the way of the affection and physical love I have for him. At times I feel I really have to focus on not slipping into just being his carer but continuing the relationship people who love each other very much, should have.”



“People living with MND still seek intimacy despite body and relationship changes... I live with James, my husband, Little Man, our son, and Ralph, our sausage dog who keeps us busy... James works in theatre, and I’ve always been into theatre, which is probably what attracted us to each other. We’ve travelled a lot and have seen a lot and it’s still my intention to do that.”

You may find your relationship strengthens after diagnosis, but the challenges of MND can also create tension, anticipated grief and fear. These can impact on intimacy, but sharing your feelings can help you support each other.



“It’s affected our relationship. He doesn’t cope well with loss of independence.”

MND can cause changes to thinking and behaviour for some people with the disease. You may notice a clear difference in the way the person with MND behaves.

For example, your partner may show a lack of care for others that is very different to the way they responded before MND. Or they may behave in an inappropriate way. If this happens, they may not be aware that anything has changed.

Finding out about this may help. Try to get this symptom checked, as this can help both of you find ways to manage these effects. Over time, you may both need extra support.



“Once you get your head around this, you find ways to cope and place structure into each day.”



See our booklet, *Changes to thinking and behaviour with MND*.

Discuss any worries with a trusted health and social care professional. You can do this as a couple or separately if needed. Try to do this with a professional who is comfortable exploring questions about intimacy.



“Grab the precious moments you can have together with open arms, no matter how hard it seems.”

7: How do I find out more?

Useful organisations

We do not endorse organisations, but these may help you begin your search. Contact our MND Connect helpline for support with finding services (see *Further information*).

Choice Support

For people with learning difficulties, with a *Supported Loving Toolkit* and guidance on sex workers.

Website: www.choicesupport.org.uk

College of Sexual and Relationship Therapists (COSRT)

Information on sexual problems and a list of local therapists.

Telephone: 0208 106 9635

Email: info@cosrt.org.uk

Website: www.cosrt.org.uk

Enhance the UK

Changing views on disability, including sex and disability.

Telephone: 0208 226 5055

Email: hello@enhancetheuk.org

Website: <https://enhancetheuk.org/sex-and-disability>

LGBT Foundation

Support if you are lesbian, gay, bisexual or transgender.

Telephone: 0345 3 30 30 30

Email: through the website

Website: <https://lgbt.foundation>

National Association for People Abused in Childhood

NAPAC supports people who have been abused in childhood.

Telephone: 0808 801 0331

Email: through the website

Website: **<https://napac.org.uk>**

Outsiders

A social and dating club, run by and for disabled people.

Telephone: 07900 957 393

Email: members@outsiders.org.uk

Website: **<https://outsiders.org.uk>**

Rape Crisis

Supporting women and girls subject to sexual abuse or rape.

Telephone: 0808 802 9999

Email: Website chat

Website: **<https://rapecrisis.org.uk>**

Relate

Information, relationship counselling or psychosexual therapy.

Email: through the website for local contact details

Website: **www.relate.org.uk**

The Sexual Advice Association

Online information only for a range of sexual issues.

Website: **www.sexualadviceassociation.co.uk**

The Sexual Respect Tool Kit

Guidance and discussions on sex.

Website: **<https://sexualrespect.com>**

SHADA Sexual Health and Disability Alliance

Founded by The Outsiders Trust to support health and social care professionals who help disabled people on sex and relationship needs.

Email: through the website
Website: **<https://shada.org.uk>**

Spokz

A range of disability equipment, including adapted sex aids.

Telephone: 01543 399760
Email: info@spokz.co.uk
Website: **www.spokz.co.uk**

Stonewall

Guidance if you are lesbian, gay, bisexual or transgender.

Email: through the website
Website: **www.stonewall.org.uk**

Survivors UK

Support for anyone identifying as male, trans, non-binary, or as male in the past, who has survived sexual abuse or rape.

Telephone: 0203 598 3898
Email: help@survivorsuk.org
Website: **www.survivorsuk.org**

TLC Trust

Part of The Outsiders Trust, focusing on sexual and intimate services for disabled people, with registered sex workers.

Website: **<https://tlc-trust.org.uk>**

Additional providers: online and high street retailers also offer products that may help. Search for *sex toys* and *sex aids*.

Acknowledgements

Many thanks to the original authors of this content and for their help with revisions and the devising of this booklet:

Rachael Marsden, Consultant Nurse MND, Oxford

Bridget Taylor, Senior Specialist Nurse in Palliative Care,
Sobell House, Oxford

Thanks to the following for additional guidance with this booklet:

Dr Tuppy Owens, founder member of Outsiders and
the TLC Trust

Barbara Strevens, Occupational Therapist, Leicestershire

References

References used to support this information are available on request from: email: **infofeedback@mndassociation.org**

Or write to: Information Feedback, MND Association
Francis Crick House (2nd Floor), 6 Summerhouse Road
Moulton Park, Northampton NN3 6BJ

Further information

We have other resources related to the content in this booklet:

What you should expect from your care: using the NICE guideline on motor neurone disease (MND)

Telling people about MND

Personal care

Emotional and psychological support

Changes to thinking and behaviour

Making the most of life with MND

Living with motor neurone disease (MND)

Caring and MND: support for you

Kennedy's disease

7B - Tube feeding

8A-8D our sheets about breathing and ventilation

Download at: **www.mndassociation.org/publications**
or order printed copies from our MND Connect helpline:

MND Connect

Our helpline team can provide emotional support, guidance and help you find our local branches, groups, volunteers, services and financial support for people with and affected by MND, or Kennedy's disease.

Telephone: **0808 802 6262**

Email:

MND Association website and online forum

Website: **www.mndassociation.org**

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

We welcome your views

Let us know what you think of this booklet. We'd love to hear what you think we did well and how we can improve the content for people with or affected by MND. Your anonymous comments may also be used to support and influence, as they help us share real MND experience and raise awareness in our resources, campaigns and applications for funding.

Please use our online feedback form at:

www.smartsurvey.co.uk/s/sexandrelationships

or contact by email:

infofeedback@mndassociation.org

or write to:

Information Feedback
MND Association
Francis Crick House (2nd Floor)
6 Summerhouse Road
Moulton Park
Northampton NN3 6BJ

“It helps to be open about a difficult subject, where normally nothing would be said. This stops people with MND from being isolated, as somebody cares and that is important. Information to support sex and intimacy also helps you feel less alone.”

Person affected by MND



Last revised: December 2024
Next Review: December 2027
Version: 1



Patient Information Forum

Registered Charity No. 294354
Company Limited by Guarantee No. 2007023
© MND Association 2021

