

# INTIMATE RELATIONSHIPS AND PARKINSON'S

**PARKINSON'S<sup>UK</sup>** CHANGE ATTITUDES. FIND A CURE. JOIN US.

## **Whether you have Parkinson's or care for someone who does, the condition may affect your relationships and your sexual identity.**

This booklet is for you whether or not you are sexually active, and whether you're single or in a relationship.

It looks at relationships in general, the challenges couples may face, starting new relationships and how Parkinson's may affect your sexual functioning, both physically and emotionally.

In each section there is information and suggestions for ways to overcome problems.

Details of where you can get more information and support can be found at the back of this booklet.

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# HOW CAN PARKINSON'S AFFECT RELATIONSHIPS?

While not everyone with Parkinson's finds it affects their relationship, the condition may affect your mood, self-image and how you communicate with others. But it's important to remember that many people have sexual and relationship issues at some stage in their life, so any problems you experience may have nothing to do with Parkinson's at all.

Each person with Parkinson's has an individual experience of the condition and the symptoms you have may be different from other people's. Some people have relationship issues in the early days, when they're adjusting to diagnosis, while others may run into problems after many years.

## First reactions

How you handle the issues Parkinson's presents can have a big effect on your relationships. Whether you have the condition or are in a relationship with someone who does, how you both react to the diagnosis can affect your wellbeing and your relationship.

Your reaction will be personal to you and there is a range of emotions many people experience, such as anger, frustration, denial or guilt. You may even experience relief in finally knowing what has been causing your symptoms.

It is not unusual to go through a number of stages when you're coming to terms with your diagnosis. People affected by Parkinson's have told us how important it was to their relationship to allow for a period of adjustment.

## Expectations

Your expectations of Parkinson's may be very different from someone else's. Some people are fearful and assume they will become disabled very quickly. Others may barely expect Parkinson's to affect their lives.

If you're in a relationship, you and your partner may have different expectations. Perhaps one of you is more optimistic than the other.

One of you may like to talk about problems, while the other prefers to reflect on them alone.

There is no right or wrong way to come to terms with a diagnosis. But trying to understand each other's view can help to minimise conflict. Talking frankly to each other can be a great help.

Wherever possible:

- share your opinions without judging each other
- make sure you get as much accurate information about Parkinson's as you can, so your expectations are as realistic as they can be



- share this information with the people in your life who you think will be affected

**Find out more:** we have a range of information sheets and booklets about Parkinson's that are available to download from [parkinsons.org.uk/publications](http://parkinsons.org.uk/publications) or to order for free (see inside back cover for details).

## Emotional changes

After a diagnosis of Parkinson's, some couples find themselves in a period of mourning for the life they previously had. You may be coming to terms with changes in your lifestyle, personal identity and your working life.

If you have Parkinson's, your self-image may be affected. You may have symptoms, such as involuntary body movements, poor posture or excess saliva, that make you feel self-conscious or embarrassed. Low self-esteem can cause you to become withdrawn, which may affect your relationship.

When relationships are going well and we feel positive about ourselves, it's easier to manage life's ups and downs. When they're not, even simple things can feel like a struggle. You may find your

relationship changes in ways you hadn't expected.

Talking openly to each other can bring you closer as a couple. Some people may find they're dealing with these emotions on their own and they may feel isolated and resentful. If this sounds familiar, you may want to try relationship counselling. See page 33 for more details.

## Changing roles

When someone has Parkinson's, it's common for relationship roles and the dynamics of a relationship to change. This can happen at any stage of the condition. Any long-term illness or disability is likely to have a big impact on even the healthiest of relationships.

As Parkinson's progresses, you may find you and your partner take the roles of carer and cared for. This can be difficult if your relationship was very different before – for example, if the cared for person was used to being the breadwinner and decision maker in the household or if the carer had an independent lifestyle.

Some couples find it hard to see each other as equal partners in these new roles. It may take time to adapt to a new type of

relationship that continues to be fulfilling. You could both try to:

- maintain a sense of independence. You should have time to be alone and do your own thing, as well as doing things together
- take any opportunity to reverse the caring role. This may be where the person with Parkinson's continues to be an emotional or intellectual support
- find mutual activities, such as playing board games, spending time watching a film or socialising with friends, where you can be equals
- come up with a list of things you can continue to do together, or new things you'd like to try
- keep communicating with each other. Parkinson's can affect all types of communication – verbal, written, and facial expression, but it's important to keep these channels open as much as possible

**Find out more:** see our [information sheet \*Communication and Parkinson's\*](#).

# HOW CAN STRESS, ANXIETY AND DEPRESSION AFFECT MY RELATIONSHIPS?

Adjusting to life with Parkinson's may be stressful, whether you're a person with Parkinson's or you care for someone who has the condition. Some people may experience feelings of depression. This may be due to Parkinson's itself or felt as a reaction to living with the condition.

You may find the following tips useful.

## Ask for support

The support of friends, family and professionals can help. You may want to talk about your feelings with your GP or Parkinson's nurse (if you have one). You can also call our helpline on **0808 800 0303** to speak to a trained adviser, or ask them for the details of your local Parkinson's UK information and support worker, who can offer one-to-one information and emotional support.

## Relax

It's easier to say than do, but it's important to try and relax.

“Relationship issues, depression and anxiety can be more of a problem than movement symptoms to many, yet they often come low on the list of priorities to tackle.”

## Sue, whose husband has Parkinson's

You could try having a bath, going for a stroll, reading a book or just chatting with friends, which may help lift your mood.

## Treat yourself

Take every opportunity to give yourself a treat. It might be something as simple as enjoying a cup of tea, listening to a new album, having a foot soak, or something bigger like having a weekend away.

## Start a journal

Many people find it helpful to write down their thoughts and feelings. Try to do this at a quiet point of the day when you won't be interrupted. It can be encouraging to look back over time and see how much you have moved forward.

## Look after your physical health

Sometimes, it can be tempting to eat comfort food and spend a lot of time sitting on the sofa, but this will only add to your negative feelings. Taking regular exercise and maintaining a healthy diet will benefit your mind and body.

## Talk

Not everyone will feel comfortable with this, but talking stops us feeling alone and allows us to connect with people. It doesn't matter who you talk to – it could be a trusted friend or a family member. If you're in a relationship, it's important to talk to each other.

## Let yourself cry

There will be some days when you may just want to cry. It's important to allow yourself to do this – recognise how you feel and let yourself express your emotions.

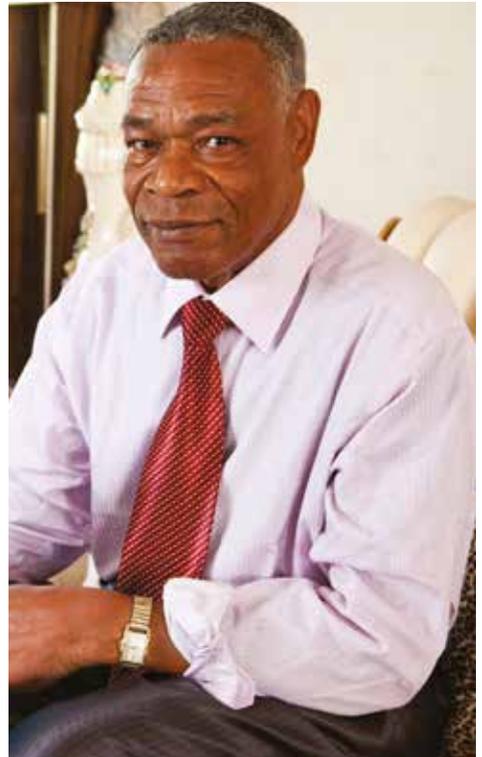
When you're angry, let those feelings out too, where you can

do so safely and appropriately. Keeping powerful feelings bottled up tends to make things feel worse.

## Laugh

It may be difficult to find things to laugh about sometimes, but when you laugh, your body releases feel-good chemicals. If you like TV comedies, keep watching them, and ask your friends to tell you their latest corny joke.

**Find out more:** see our [information sheets \*Depression and Parkinson's\* and \*Anxiety and Parkinson's\*](#).





# HOW CAN I IMPROVE MY RELATIONSHIP WITH MY PARTNER?

These tips are often suggested by Relate counsellors:

## Love yourself

A strong relationship starts with positive self-esteem. If you don't love yourself, it's hard to believe anyone else will.

## Accept difference

We're all unique, so differences of opinion are a part of life. Accept arguments as a healthy part of life as a couple.

## Argue well

When you argue, make sure you confront the issue, not each other. Listen, be respectful and try to find a common solution.

## Say sorry

Love does not mean never having to say you're sorry. We all make mistakes and can be wrong, so be ready to apologise.

## Listen and learn

People change and grow over the years. Don't ever think you know

your partner so well that you can predict what they're going to say.

## Make good quality time

It's a cliché but it's true: quality is more important than quantity. Make sure you make time to talk, laugh, chat, or just to be quiet together.

## Share goals

Another way to connect is to talk about and work towards common goals. It doesn't matter if that's planning a party, decorating a room or saving for a holiday. The important thing is that you share the goal.

## Spend time with other couples

It's easy to think that only you have problems, but when you spend time with other couples, you'll see you're not alone. All relationships have their ups and downs.

## Give each other the benefit of the doubt

Don't jump to conclusions about each other's behaviour or motivation. If you feel irritated about something, first check that what you think they're saying is what they meant.

If it wasn't then let it go. If it was, sit down and discuss the problem.

### Explore your senses

Exploring your senses is something you can share and enjoy. You can try:

- laughing together – this is one of the most bonding activities of all
- holding hands and looking into each other's eyes
- lighting scented candles or experimenting with different smelling oils in an oil burner
- enjoying taste together by trying a range of foods
- listening to music

### Physical affection

Physical intimacy is a crucial part of many relationships. Some movement symptoms may make it more difficult to be spontaneous, but touch is an essential part of being human and you can experience this, whatever your physical condition.

Touch has the power to soothe, support and encourage, whether it's a peck on the cheek, a hug or making love.

### When a relationship ends

We've heard from many people with Parkinson's whose relationships have broken down.

Sometimes the affects of living with the condition and the demands it makes on a relationship can be a contributing factor. But there are lots of other reasons why a relationship may end and often it isn't due to one reason alone.

It's important to come to terms with what happened if your relationship has ended. This may take time.

It often helps to talk to friends or family about things as this can make you feel less isolated. It can also help to give perspective.

You may also consider talking to a counsellor. Setting yourself goals or making plans is very useful – achieving something can be a great confidence booster and a helpful reminder that you are moving on, even if on some days, you may not feel like you are.

For some people we've spoken to, a separation or divorce has been a very difficult experience. Others have told us that they saw the end

of their relationship as a change for the better. Whatever the circumstances, if your relationship does end, it can feel overwhelming and you may worry about what the future will hold. But there will be others going through a similar experience and it's important to remember there is support available to help you.

Organisations such as Relate offer counselling for people coming out of a relationship. Their contact details can be found on page 37.

Your local Parkinson's UK information and support worker can offer emotional support to you and your family.

To find details of your nearest information and support worker, visit [parkinsons.org.uk/localtoyou](https://parkinsons.org.uk/localtoyou) or call our helpline (0808 800 0303). You can also visit [parkinsons.org.uk/forum](https://parkinsons.org.uk/forum) to speak with other people in a similar situation on our online discussion forum.



# HOW CAN PARKINSON'S AFFECT DATING AND NEW RELATIONSHIPS?

If you are single, Parkinson's shouldn't stop you dating or beginning a new relationship. At some point, you will need to decide whether or not to tell a new partner about your condition, and how and when you will have the conversation. This will often depend on different things, such as the severity of your symptoms and how serious you may be about the person and your relationship with them.

You may be happy to tell someone you are dating about your Parkinson's very early on. Other people are more comfortable getting to know someone better before they choose to share details of their condition.

Opening up to someone else about Parkinson's is a very personal decision. Some people may not see it as an issue, but others may be anxious about it. It may lead to some people avoiding romantic situations completely, which can be very isolating. Remember, not everyone needs to know, and not everyone needs to know straight away, so wait until you are

comfortable – there is no 'right' time to share your diagnosis.

When you do tell someone you have Parkinson's, they may have lots of questions for you. They may also have ideas or assumptions about the condition that might not be true. You are the expert on Parkinson's, so talk to the person about how it affects you. If someone doesn't ask lots of questions, don't assume it's because they aren't interested – perhaps they want to get to know you more, not the condition.

You can't decide for someone else if they want a relationship with you, so be yourself and see what happens. Some people may be put off by knowing you have Parkinson's, but lots of people won't – you may be surprised by their reaction.

“ I left it six months to tell the first man I had a relationship with since being diagnosed with Parkinson’s that I had the condition.

We saw each other once after that conversation and he phoned the next day and said it wasn’t working.

My friends rallied round and told me, ‘Don’t waste your energy being upset, he obviously wasn’t the one’.

Looking back he wasn’t, but it was hard seeing the difference at the time between rejection due to an illness and good, old-fashioned missing chemistry!”

**Alison, diagnosed in 2006**

# HOW CAN PARKINSON'S AFFECT SEX FOR MEN AND WOMEN?

Sexual problems can affect many people with Parkinson's. This can be due to the physical effects of the condition on things such as co-ordination and speed of movement, or emotional issues such as low mood or depression.

Parkinson's does not affect everybody's sexual functioning though. While some couples experience problems, a significant number don't.

Both men and women can experience difficulties with sex and the likelihood of experiencing problems increases with age.

Sex is an important part of life for many people, so any problems you experience may have a big effect on your life. Sexual problems can be overcome or another form of intimacy can be found.

Sexual problems can affect either the person with Parkinson's or their partner. Finding out one of you has a life-changing condition can

“ Sometimes it can be difficult to have the agility I used to have with intercourse. My wife and I find different positions make this easier. To be frank, the loss of ability is somewhat upsetting. ”

**Michael, diagnosed in 2007**

change your view of your physical relationship. It may be less or even more important than before, as you feel you need to make the most of your time together for fear of less ability, or simply want to express your love for one another.

If you have Parkinson's, this can affect your sexual self-esteem. You may feel less attractive or desirable. If you're a carer, you may worry

you're being demanding by wanting to have sex with your partner. Having new roles as carer and cared for may sometimes make it hard to feel like equal sexual partners.

These factors, as well as the impact of the condition and medication on the body, can affect sexual function.

Our sexual relationships change over our lifetime and problems happen in every relationship at some time or another. They may resolve themselves, or a couple may have to:

- adjust what they do together to take account of changing physical abilities

- redefine their expectations to fit with reality – some couples may think it's a problem not to be enjoying regular sex, while others may be perfectly satisfied with a sensual caress once a month

If you've been in a relationship where sex has been good and you've both felt comfortable and confident talking about your desires and limitations, then it may be easier to face the challenges Parkinson's can bring.

You may have to work harder to get over the hurdles if this has been an awkward topic in the past. It's worth trying – the increased openness and creativity required in your sex life may make it better than before.





# WHAT FACTORS MAY CONTRIBUTE TO SEXUAL PROBLEMS?

Difficulties with sex can often happen when something disrupts your sexual responses. Causes of sexual problems include movement problems, fatigue or depression.

These difficulties are common in people with and without Parkinson's, so it may not be easy to tell whether a problem you experience is a result of your condition or not.

The physical ability to have sex is affected by the nervous system, so it is more common for people with neurological conditions, such as Parkinson's, to experience problems with sexual function.

Some Parkinson's symptoms may affect sexual activity. Here we look at these and what can be done to help treat and improve these issues.

## Movement problems

The physical symptoms of Parkinson's, such as stiffness, rigid muscles and slowness of movement, may affect sexual activity. Making sure your

Parkinson's medication is working effectively may help improve these symptoms – speak to your specialist or Parkinson's nurse. They may also be able to give you advice on sexual positions that may help you.

## Fatigue

Fatigue can be a symptom of Parkinson's. Some medications for this, such as amantadine, have been shown to improve sexual function. If tiredness is an issue, try being intimate or having sex at a different time of the day when you are more alert.

## Bowel and bladder problems

Fear of incontinence during sexual activity may have a negative impact not only on self-esteem, but also on personal relationships. If you experience urinary incontinence, certain drug treatments may be helpful.

Emptying your bladder before intercourse may help with continence. For some individuals,

using a catheter to help empty your bladder may be appropriate.

If you experience bowel incontinence, an enema before intercourse or using an anal plug may be helpful.

The Bladder and Bowel Foundation can offer more information at



[www.bladderandbowelfoundation.org](http://www.bladderandbowelfoundation.org) or by calling 0845 345 0165.

**Find out more:** see our booklet *Looking after your bladder and bowels when you have Parkinson's*.

## Medications

Any medications you're taking should be reviewed for any side effects they may have on sexual function. Some drugs for depression may cause a reduction in sexual desire, problems with arousal and delayed, or lack of, orgasms.

These problems cause many people to stop taking their medication. It is best to speak to your specialist or Parkinson's nurse about the options available for you.

Do not stop taking your Parkinson's medication unless your specialist or Parkinson's nurse tells you to, as this can be dangerous.

## Hypersexuality

Some people who take dopamine agonists experience impulsive and compulsive behaviour. For a small number of people, other types of Parkinson's medications, in particular levodopa, have been shown to have similar side effects.

Hypersexuality is a type of impulsive and compulsive behaviour, where someone is focused on sexual feelings and thoughts.

If a person is experiencing this, their sexual impulses become more intense. They might be felt at inappropriate times or towards people other than a partner. This can be distressing for the person and those around them.

With hypersexuality, there is also a risk that someone will behave in a way that is socially unacceptable, or may even break the law.

This type of behaviour can have a big impact on the person affected and the people around them. It may be accompanied by sexual delusions and hallucinations, such as imagining that a partner is having an affair or thinking others are having sex when they're not.

While some couples may enjoy the extra sex, for some it may become a difficult and distressing problem, particularly if the sexual desires feel out of control and are out of character.

If you think you are experiencing this behaviour, the first step is to talk to your specialist or Parkinson's nurse. You may find it uncomfortable

to talk to a healthcare professional about the difficulties you are having. But remember they will have spoken to others with similar problems before and everything you tell them will be treated confidentially.

Sometimes people who experience impulsive and compulsive behaviour may not realise they have a problem. If you notice your partner's sex drive has increased or their sexual behaviour has changed towards you or anyone else, it is important to discuss it with a healthcare professional as quickly as possible.

Impulsive and compulsive behaviour can usually be controlled and steps taken to address changes in behaviour. Sometimes a change in medication can ease or remove the problem. Some people may need to seek more professional support, for example from a psychosexual therapist.

Details of organisations where you can find psychosexual therapists can be found on page 36.

**Find out more:** see our [information sheet \*Impulsive and compulsive behaviour in Parkinson's\*](#).

“ The first difficulties I encountered, though at the time we did not see it as a problem, was hypersexuality. At the time we took advantage of this new lease of life and had great fun as in our late forties/early fifties, we saw it as an unexpected bonus.

As time went by though, the ‘HS’ as I called it became the most dominant aspect of my life, and instead of being fun, it became dangerous.

My wife was quite happy to try different things up to a point, but I became more and more demanding and if I could not have my own way, I effectively changed personality and became unpleasant to live with.

I realised this pattern of behaviour could not go on, so I spoke to my Parkinson’s nurse about it. My medication was changed and finally normality returned.”

**Des, diagnosed in 1999**

## Lowered sex drive

Many people with Parkinson's and their partners experience lowered sex drive. This is often more to do with the psychological and emotional impact of diagnosis than as a direct result of the condition.

General tiredness and depression, which are common for someone with Parkinson's, can also lower desire.

Your GP or specialist will look to treat any depression or mood disorders you may experience.

There are many different things you can try to get in the mood for intimacy or sex. You should do whatever suits you as a couple, but you could try the following:

- Take time to relax in the bath.
- Have a sensual massage by candlelight.
- Do something more energetic or playful together to get you in the mood.
- Revive the spark by investing in new lingerie or sex toys, watch an arousing DVD or read erotic stories to each other.

Whatever you do, agree beforehand that your goal is to get close and

enjoy time together. The result may be sex, but it may not.

Take the pressure off by investing your energy into creating the right environment. The outcome will happen more naturally.

## Problems with sexual arousal

Both men and women can struggle with sexual dysfunction. You may experience this as a side effect of Parkinson's medication or of the condition itself, or because of tiredness, stress, depression or low self-esteem.

The most important way to overcome this is to try and relax. Before seeking treatment, try to rule out any emotional causes, such as stress, or tensions in your relationship.

You may benefit from:

- changes in routine, such as having sex in the morning when you've got more energy, instead of the evening
- an increase in stimulation, such as using a vibrator
- taking plenty of time to set the scene and get the mood right

The more you can do to be sensual together, the better the chances of arousal happening naturally.

Relationship counselling or psychotherapy may be useful if you are experiencing a lack of sexual interest or desire. See page 36–37 for contact details.

## Orgasm problems

Both men and women may experience reduced or absent orgasms. Some men may experience problems with premature or delayed ejaculation, or not ejaculating at all. Treatments for problems in orgasming may include therapies such as psychosexual therapy or cognitive behavioural therapy. This can help individuals or couples find more helpful ways of sexual communication.

If you have problems reaching orgasm:

### Try not to worry

As with all sexual problems, the first thing to do is to try and minimise anxiety. If you worry about orgasm, it's more likely to happen too quickly or not happen at all. Spend more time on general arousal and excitement. Agree that it won't matter if one of you doesn't experience orgasm – you'll enjoy the time spent together.

## Understand what you enjoy

Masturbation can help you understand what you find enjoyable. Give yourself enough time to explore what you find pleasurable without being disturbed. Feeling ashamed or embarrassed about what you are doing will not help you achieve orgasm, so try and relax into the sensations you experience.

## Get to know each other

Take time to really get to know each other's bodies. Ask about the kind of stimulation your partner likes. Try to fine-tune your technique so you're always giving the best experience. When sex is approached in a more relaxed and exploratory manner, orgasm may follow more naturally.

## Sex aids

Sex aids including vibrators and vacuum devices may be of some use to aid stimulation and orgasm.

The Family Planning Association has its own e-commerce website, Desire and Pleasure (**www.desireandpleasure.co.uk**), that offers a selection of products and useful guidance for people with reduced mobility and limited manual dexterity.

### Pelvic floor exercises

For some women, pelvic floor exercises may help increase awareness of pelvic floor contractions and improve pelvic tone. These exercises can be tricky, but a physiotherapist, nurse or GP will be able to explain how to do them properly.

### Seek help

If problems persist, then speak to your GP, specialist or Parkinson's nurse. A change in medication may put you back on track again.



# WHAT SEXUAL PROBLEMS MAY AFFECT MEN WITH PARKINSON'S?

It's important to remember that many sexual problems can be common in men of all ages, whether they have Parkinson's or not. So, it doesn't mean that any problems you might have are necessarily as a result of your condition. There may be other causes such as the prostate gland.

The prostate is a small gland found only in men. It is the size of a walnut and surrounds the first part of the tube (urethra) that carries urine from the bladder to the penis.

As men get older, the prostate around the neck of the bladder gradually gets bigger. This is normal in older men, but for some, it causes problems by blocking the outflow of urine, which makes it difficult to empty the bladder.

It can cause some men to experience the need to urinate more often, a difficulty in starting to urinate, a need to strain or an urgent need to go to the toilet.

Some men with an enlarged prostate gland may experience sexual problems, such as erectile dysfunction.

Medication may help reduce the size of your prostate, alongside making changes to your lifestyle. Surgery may be recommended for moderate to severe symptoms of prostate enlargement, if medication hasn't worked.

Be aware that a side effect of this surgery may include sexual dysfunction, so it's important to talk to your healthcare professional about all possible advantages and disadvantages of the procedure.

You should talk to your GP if you begin to experience symptoms. They can assess you and refer you to a urologist if necessary.

## Erectile dysfunction

Research has shown that one of the sexual problems which affects men is not being able to get aroused.

When a man is struggling to get aroused, he will find it difficult to get an erection. This is a common problem even in men who don't have Parkinson's, especially as they get older, or if they have medical conditions such as diabetes or high blood pressure.

Some may have difficulties getting an erection at all, while others get an erection, but then lose it too soon.

If you are experiencing erectile problems, speak to your GP or specialist. They will ask you about how much response you have to stimulation, or in specific situations, such as when you wake up in the

morning, or when you are with a partner. This is because erectile problems may affect you in different ways at different times.

When someone has a neurological condition, erectile problems are not always assumed to be related to emotional issues.

There is a range of options your GP or specialist may explore with you. These include:

### Viagra/Cialis/Levitra

Medication is one option for treating erectile problems. Research has shown that Viagra is safe for most men with Parkinson's to use, but talk to your GP, specialist or Parkinson's nurse if you have any concerns. There is a range of alternative drugs now available that work in different ways, but are still effective at producing an erection.

If you have Parkinson's, you can get these drugs on the NHS.

### Self injection

A drug is available that can be injected into the penis to produce an erection. A man can be taught the self-injection technique. This treatment needs supervision at first. Specialists such as urologists and, occasionally, GPs, run clinics that provide this treatment.

### Pessary

A pessary is less intrusive than an injection. Some men choose a product called 'MUSE', which is a pessary that can be inserted into the end of the penis. Speak to your GP to find out more.

## A vacuum pump

Vacuum constriction devices are an option for men who do not want to or are unable to take medication.

These can be put around the penis to produce an erection. This option is often more successful for men in stable relationships. Speak

to your GP, specialist, Parkinson's nurse or pharmacist for advice before you buy one.

## Surgery

Surgery to implant a penile prosthesis may be an option for men with erectile problems. It is normally a last resort, however.



“ In the couple of years leading up to my wife’s diagnosis, she gradually lost interest in everything, especially sex.

When she started her medication, she gradually regained her interest and she made an appointment with our doctor for us to discuss this matter.

The doctor was very understanding. We discovered we had to learn all over again, as we did nearly 50 years ago when we were first married. Being much older and not quite so fit, everything seemed much more difficult. But we talked it over together and did as advised, such as finding times when things worked better.

We both treated the whole exercise as a bit of fun and had quite a few laughs.

Nearly two years on from that appointment with the doctor, we are still learning.”

**Jim, whose wife has Parkinson’s**

# WHAT SEXUAL PROBLEMS MAY AFFECT WOMEN WITH PARKINSON'S?

Women are most likely to experience problems with vaginal lubrication, low desire or orgasm.

A woman may continue to enjoy sex, even if her body isn't really in the mood (though it's important not to try penetration unless you're aroused, as it can be painful).

There are not so many evidence-based treatment options for female sexual problems, but therapies relate to the treatment of sexual desire, arousal or orgasm problems and/or sexual pain.

Some women feel pain during sex. You may also experience fewer feelings or a lack of sexual excitement, or lack of lubrication when you have sex. Your GP or specialist may recommend trying anaesthetic gels, vaginal lubricants or different methods to reduce any pain.

It's important to remember that many sexual problems can be common in women of all ages, whether they have Parkinson's or not. So, it doesn't mean that any problems you might have are necessarily as a result of your condition. There may be other causes, such as:

## Menopause

The menopause can affect vaginal lubrication and sexual sensations. If you are experiencing these symptoms and are of menopausal age, you should talk to your GP.

## Pelvic floor prolapse

Women may experience prolapse of pelvic organs such as the bladder or womb. This happens when organs have dropped out of their usual position, perhaps in relation to ageing and previous childbirth.

Lack of tone in pelvic floor muscles can increase this risk.

Pelvic organ prolapse and urinary incontinence have a negative effect on sexual function.

Pelvic floor prolapse may be corrected using either a ring pessary or surgery, which may improve sexual function. Talk to your healthcare professional about what options are available to you.



# WHERE CAN I GO FOR MORE INFORMATION AND SUPPORT?

Sexual relationships are an important part of life for many people. People of every age and physical ability can, and do, enjoy their sexuality, but it isn't always easy to talk about, as it's often a private part of life.

If you're worried someone may laugh or disapprove, it can make it hard to talk about sex, but there are professionals you can turn to for advice and support.

## Speaking to healthcare professionals

You may feel uncomfortable talking to a healthcare professional about the issues you are having, but remember they will have spoken to others with similar problems before.

They will need to take your particular needs into account when talking to you, including your attitude towards sex and cultural influence.

Remember, the medical profession is governed by strict privacy laws, so anything you do share with

a healthcare professional will remain totally confidential.

Although you are not alone in experiencing problems with sex, you may be more affected by particular aspects than others. If you find it difficult to talk about, try writing your questions down and giving them to the person you're seeing.

You may want to attend appointments with your partner if you have one, so you can discuss the issues together. Ask your healthcare professional if they have any literature you can take away, so you can read it in your own time at home.

## Support for your partner

Ideally, you should talk things through with your partner. This can sometimes be difficult, but it is essential for your partner to also get the support they need.

Parkinson's nurses and information and support workers (see page 34) can see people with Parkinson's

and their partners independently to discuss any issues if you don't feel you can talk to each other about things.

### Relationship counselling

If you've tried talking to each other about your relationship problems and you feel that you're not getting anywhere, couple counselling may help.

A trained couples counsellor can help you look at your problems differently and improve your communication, to help you overcome any issues you're facing. Counsellors can also work with individuals, so you can go alone if you're single or if your partner

doesn't want to attend. Some people prefer to talk through their feelings on their own, and find this very helpful.

If you think counselling may help, ask your GP if there are services available in your area, or contact your local Relate centre. They will advise you what they charge and how they may be able to help if payment is an issue.

If you'd prefer private counselling, you can get a list of local counsellors from the British Association for Counselling and Psychotherapy (see page 36 for contact details). If you see a private counsellor, make sure they're trained in the



appropriate area – relationships, couples or individuals.

### Counselling and psychotherapy for sexual problems

For some people, counselling or psychotherapy can help them talk openly about relationship and sexual problems, so they can find ways of making changes.

There are several ways of helping people and your counsellor or psychotherapist should explain how they work and decide with you what you would like to focus on.

Cognitive behavioural therapy is useful when beliefs held by a person or couple about what is 'normal' are contributing to the sexual problem.

Also, treatments looking at interpersonal problems result in a better outcome than approaches that focus on problems with sexual function alone.

### Psychosexual therapy

A psychosexual therapist is trained in all aspects of sexual functioning and can help you understand the effects of medication and illness on sexual functioning. They often use a step-by-step approach to make realistic changes.

Many psychosexual therapists are also relationship therapists and can address both the practical problems you may be experiencing and help with any emotional or relationship difficulties.

You can choose to see someone on your own or as a couple. Your GP may be able to refer you to an NHS therapist, or you can see a specialist at your local Relate centre.

A list of private therapists is available from the College of Sexual and Relationship Therapists (see page 36 for contact details).

### GP or Parkinson's specialist

Your GP or specialist may be your first port of call. We continue to encourage professionals to discuss these issues with people with Parkinson's and their partners, rather than putting the responsibility on you to raise the matter.

### Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. They are used to dealing with anxieties about sex and relationships.

They can also act as a liaison between other health and social care professionals to make sure your needs are met.



Parkinson's nurses may not be available in every area, but your GP or specialist can give you more details on local services. Where there is no Parkinson's nurse, your local district nurse may be able to help.

### At your appointment

When you speak to a specialist in sexual problems, they should talk to you about the difficulties you are facing and do a clinical examination.

If you've been experiencing sexual problems since the onset of your Parkinson's symptoms, this suggests they are related. The professional examining you will also look for other underlying causes, which

could include heart disease or medication history.

Many of the treatments for sexual problems are the same as for those without a neurological condition. Difficulties surrounding sex for people with neurological conditions is common, but complex.

Your treatment should be tailored to you as an individual, with the opportunity for education and counselling for you and your partner, if you have one.

### Information and support from Parkinson's UK

You can call our free confidential helpline for general support and information. Call **0808 800 0303** (calls are free from UK landlines and most mobile networks) or email **hello@parkinsons.org.uk**

Our helpline can also put you in touch with one of our local advisers, who provide one-to-one information and support to anyone affected by Parkinson's. They can also provide links to local groups and services.

Our website has information about your local support team and how to contact them at **parkinsons.org.uk/localtoyou**

You can find details of our local groups and your nearest meeting at [parkinsons.org.uk/localgroups](http://parkinsons.org.uk/localgroups)

You can also visit [parkinsons.org.uk/forum](http://parkinsons.org.uk/forum) to chat to other people with similar experiences on our online discussion forum.

## Useful contacts

### British Association for Counselling and Psychotherapy (BACP)

The BACP can help you find a private counsellor in your area.

**01455 883 300**  
**bacp@bacp.co.uk**  
**www.bacp.co.uk**

### College of Sexual and Relationship Therapists (COSRT)

They can provide information on therapists and clinics that can help with sexual and relationship problems.

**020 8543 2707**  
**info@cosrt.org.uk**  
**www.cosrt.org.uk**

### Family Planning Association (FPA)

They offer information, advice and support on sexual health, sex and relationships.

**0845 122 8687**  
**www.fpa.org.uk**

### Institute of Psychosexual Medicine (IPM)

The IPM includes medical practitioners who have additional training in the treatment of psychosexual difficulties.

**020 7580 0631**  
**admin@ipm.org.uk**  
**www.ipm.org.uk**

### Outsiders

This is a voluntary organisation that provides information and support to disabled people on personal and sexual relationships.

**07074 993 527**  
**sexdis@outsiders.org.uk**  
**www.outsiders.org.uk**

## Relate

Relate provides counselling for people with sexual or relationship difficulties.

**0300 100 1234**

**enquiries@relate.org.uk**

**www.relate.org.uk**

## The Sexual Advice Association

A charitable organisation that aims to help improve the sexual health and wellbeing of men and women.

It also aims to raise awareness of how common sexual conditions are among the general population.

**020 7486 7262**

**info@sexualadviceassociation.co.uk**

**www.sda.uk.net**

## United Kingdom Council for Psychotherapy (UKCP)

This organisation holds the national register of psychotherapists and psychotherapeutic counsellors.

**020 7014 9955**

**info@ukcp.org.uk**

**www.ukcp.org.uk**

## Further reading

*Young Parkinson's Handbook,*

by the American Parkinson's Disease Association

This guide has a useful section called 'Changing roles and relationships', which includes information on sex and sexuality.

You can download a copy from

**www.apdaparkinson.org**

or order it from:

**American Parkinson's Disease Association, 135 Parkinson Avenue, Staten Island, New York, NY 10305**

**(USA) 001 800 223 2732**

**apda@apdaparkinson.org**







## Intimate relationships (B034/2014)

Do you have any feedback about this information? Your comments will help us ensure our resources are as useful and easy to understand as possible. Please return to [Information Content team, Parkinson's UK, 215 Vauxhall Bridge Road, London SW1V 1EJ](#), or email [publications@parkinsons.org.uk](mailto:publications@parkinsons.org.uk). Thank you!

### 1. Please choose the option that best fits you.

- I have Parkinson's and was diagnosed in
  - I care for someone with Parkinson's
  - I have a friend or family member with Parkinson's
  - I'm a professional working with people with Parkinson's
  - Other (please specify)
- 
- 

### 2. Where did you get this information from?

- GP
  - Specialist
  - Parkinson's nurse
  - Parkinson's UK local group
  - Parkinson's UK local adviser
  - Ordered directly from us
  - Call to the helpline
  - Other (please specify)
- 
- 

### 3. Has it answered all your questions?

- Yes, completely
- Not sure
- Yes, mostly
- Not at all
- Partly

### 4. How easy was it to understand?

- Very easy
- Quite difficult
- Easy
- Very difficult
- Not sure

Continued over the page



## 5. Has it helped you manage your condition better, or make choices that have improved your life in some way?

- |   |   |
|---|---|
| <input type="checkbox"/> It helped a lot    | <input type="checkbox"/> It didn't help       |
| <input type="checkbox"/> It helped a little | <input type="checkbox"/> It made things worse |
| <input type="checkbox"/> No change          |   |

## 6. What is your ethnic background?\*

- |   |  |
|---|--|
| <input type="checkbox"/> Asian or Asian British | <input type="checkbox"/> Mixed         |
| <input type="checkbox"/> Black or Black British | <input type="checkbox"/> White British |
| <input type="checkbox"/> Chinese                | <input type="checkbox"/> White other   |
| <input type="checkbox"/> Other (please specify) |  |
- 

\*We ask about your ethnicity to ensure our information is reaching a broad range of people. However, this question is optional.

## Want to hear more from us?

- I would like a response to my feedback
- I would like to be a member of Parkinson's UK
- I'm interested in joining the Information review group, to offer feedback on Parkinson's UK information

## If you've answered yes to any of these options, please complete your details below.

Name

---

Address

---

Email

---

Telephone

---

## How would you prefer us to contact you?

- Email    Post    Phone

We will not pass on your details to any other organisation or third party.  
To find out more, read our privacy policy at [parkinsons.org.uk/termsandconditions](https://parkinsons.org.uk/termsandconditions)



**Thank you to everyone who contributed to or reviewed this booklet:**

**Dr Jalesh Panicker, Consultant and Honorary Senior Lecturer, The National Hospital for Neurology and Neurosurgery, London**

**Collette Haslam, Clinical Nurse Specialist, The National Hospital for Neurology and Neurosurgery, London**

**Ammanda Major, Senior Practice Consultant for Psychosexual Therapy, Relate**

Thanks also to our information review group and other people affected by Parkinson's who provided feedback.

### **Our information**

All of our most up-to-date information is available at

**[parkinsons.org.uk/information-support](https://parkinsons.org.uk/information-support)**

If you'd prefer to read one of our printed leaflets or booklets, find out how to place an order at **[parkinsons.org.uk/ordering-resources](https://parkinsons.org.uk/ordering-resources)** or by calling **0300 123 3689**.

We make every effort to ensure that our services provide current, unbiased and accurate information. We hope that this will add to any professional advice you receive and help you to make any decisions you may face. Please do continue to talk to your health and social care team if you are worried about any aspect of living with Parkinson's.

If you'd like to find out more about how we put our information together, including references and the sources of evidence we use, please contact us at **[publications@parkinsons.org.uk](mailto:publications@parkinsons.org.uk)**

### **Can you help?**

At Parkinson's UK, we are totally dependent on donations from individuals and organisations to fund the work that we do. There are many ways that you can help us to support people with Parkinson's. If you would like to get involved, please contact our Supporter Services team on **0800 138 6593** or visit our website at **[parkinsons.org.uk/donate](https://parkinsons.org.uk/donate)**. Thank you.

Every hour, two people in the UK are told they have Parkinson's – a brain condition that turns lives upside down, leaving a future full of uncertainty.

Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.

We want everyone to get the best health and social care. So we bring professionals together to drive improvements that enable people to live life to the full.

Ultimately, we want to end Parkinson's. That's why we inspire and support the international research community to develop life-changing treatments, faster. And we won't stop until we find a cure.

**Together we can bring forward the day  
when no one fears Parkinson's.**

Parkinson's UK  
215 Vauxhall Bridge Road  
London SW1V 1EJ

Free confidential helpline **0808 800 0303**  
(Monday to Friday 9am–7pm, Saturday 10am–2pm).

Interpreting available.

NGT Relay **18001 0808 800 0303** (for use with smart phones, tablets, PCs and other devices). For more information see **[www.ngts.org.uk](http://www.ngts.org.uk)**

**[hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)**  
**[parkinsons.org.uk](http://parkinsons.org.uk)**

Order code: PKB034

Last updated September 2014. We review our information within three years. Please check our website for the most up-to-date versions of all our information.

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