

INTIMATE RELATIONSHIPS AND PARKINSON'S

Symptoms and lifestyle

PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

Whether you have Parkinson's or care for someone with the condition, Parkinson's 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, at the challenges couples may face, and how Parkinson's may affect your sexual functioning, both physically and emotionally. In each section there are tips and suggestions for ways to overcome problems.

At the end of the booklet we've included places to go for more information and support.

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HOW CAN PARKINSON'S AFFECT RELATIONSHIPS?

Whether or not you have an active sex life, your sexuality is a core part of who you are. How you feel about being single or in a casual or committed relationship can affect your wellbeing.

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 essential to remember that everyone experiences sexual and relationship problems 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. The symptoms you have may be different from those experienced by other people. 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 Parkinson's or are in a relationship with someone who does, how you both react to the diagnosis will affect your wellbeing and your relationship.

Your reaction will be personal to you. But there is a range of emotions many people experience, such as anger, frustration, denial or guilt. You may experience relief, to finally know what has been causing various symptoms. You may go through a number of stages when you're coming to terms with your diagnosis – this is not unusual. People affected by Parkinson's have told us how important it was to their relationship to allow this period of adjustment to take place.

Expectations

Your expectations of Parkinson's may be very different from someone else's. Some people are very fearful and assume they will

become very 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 a 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 those who will be affected

Find out more: we have a range of information sheets and booklets available to download from parkinsons.org.uk/publications or to order for free (see inside back cover for details).

Communication problems

Parkinson's can affect all types of communication – verbal and written, facial expression and body language.

If you're in a relationship, you may have problems expressing yourself to your partner. If you're single, you may find it hard to start relationships, perhaps because you think people will react negatively to you having Parkinson's. Problems with communication can also impact on this.

Starting or maintaining a conversation may be difficult if your speech is affected, or misunderstandings may come up if you have problems with facial expression.

It takes a lot of courage and determination to face the potentially insensitive responses of others. But if you don't, you may feel isolated and lonely, which may contribute to anxiety and depression. Fortunately, awareness of Parkinson's is growing and attitudes are changing.

HOW MIGHT PARKINSON'S AFFECT MY RELATIONSHIP WITH MY PARTNER?

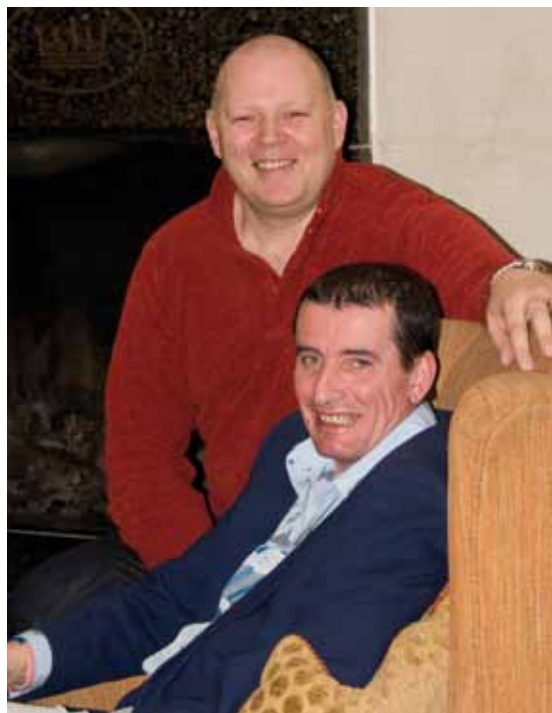
When relationships are going well and we feel positive about ourselves, it's easier to manage life's ups and downs. But when they're not, even simple things can feel like a struggle. You may find your relationship changes in ways you hadn't expected.

Emotional changes

After a diagnosis of Parkinson's, once initial feelings of shock have passed, many 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 relationship.

If you have Parkinson's, your self-image may have been affected by having to make changes in your working life. Or you may have symptoms, such as involuntary body movements, poor posture or excess saliva, that make you feel self-conscious or embarrassed. If you have low self-esteem, you may become withdrawn, which may affect your relationship.

If you can talk openly as a couple, it can bring you closer. But some people may find they're dealing with these emotions on their own. They may feel isolated and resentful. If this sounds familiar, you may want to try relationship counselling. A Relate counsellor can help you both talk about the problems you're facing together (see page 30 for contact details).





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 experience anxiety or depression as a feature of Parkinson's, but these can also be felt as a response 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, or you can call our helpline on **0808 800 0303** to speak to a trained adviser, or ask them for the details of your local information and support worker.

Relax

It's easier to say than do, but taking time out to relax in the bath, go for a stroll, read a book or just chat with friends can really help.

“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

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 CD or having a foot soak, or it could be having a professional massage or a weekend away.

Start a journal

Many people find it helpful to write down their thoughts and feelings. It can be encouraging to look back over the weeks and see how much you have moved forward.

Look after your health

Tempting as it is, eating comfort food and slumping on the sofa will only add to your negative feelings. Taking regular exercise and maintaining a healthy diet will benefit your mind and body.

Talk

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

Let yourself cry

There will be some days when you just want to cry – and that's OK. 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 right now, but when you laugh, your body releases its feel-good chemicals. If you like TV comedies, keep watching them, and allow your friends to tell you their latest corny joke.

Find out more: read our information sheets *Depression and Parkinson's* and *Anxiety and Parkinson's*.

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. If your relationship was a bit rocky in the first place, there may be even more issues to work through.

As Parkinson's progresses, you may find you and your partner taking 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.

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





TOP TIPS FOR IMPROVING YOUR RELATIONSHIP WITH YOUR PARTNER

These tips are often given 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 get it wrong sometimes, 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.

Touch regularly

Touch has the power to soothe, support and encourage, whether it's a peck on the cheek, a hug or making love. Show you love each other with physical affection.

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 decorating a room, saving for a holiday, or saving the planet. The important thing is that you share the dream.

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.

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.

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.

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

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



HOW CAN PARKINSON'S AFFECT SEX?

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. While many couples experience problems, a significant number don't.

Certain illnesses, medication and the symptoms of later stages of Parkinson's contribute to problems with sex. But issues can also be related to the impact Parkinson's has on the relationship and someone's sense of sexuality.

If you experienced sexual problems before Parkinson's was diagnosed, this may make you more likely to experience problems or give up on your sex life altogether.

Our sexual relationships change over our lifetime and problems happen in every relationship at

“ 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

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 a weekly athletic sexual marathon, while others may be perfectly satisfied with a sensual caress once a month

Our story

By Jim, whose wife has Parkinson's

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 the matter.

The doctor was very understanding. We discovered we had to learn all over again, as we had 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.

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 will be easier to face the challenges Parkinson's may bring.

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

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

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 sex. Having new roles as carer and cared for may 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.

Sexual problems

Difficulties with sex happen when something disrupts your sexual responses. This can affect many people, not just those with Parkinson's. But the physical ability to have sex is affected by the nervous system, so it is common for people with neurological conditions, such as Parkinson's, to experience problems with sexual function.

The four most common sexual problems are:

- loss of sexual interest or desire (reduced libido)
- sexual pain (in women)
- problems with arousal (poor or absent erections in men, or in women, lack of sexual excitement or problems with genital arousal, such as vaginal swelling or lack of lubrication)
- problems reaching orgasm or ejaculation

The likelihood of experiencing problems does increase with age. Both men and women can experience difficulties with sex. Research has shown that women are most likely to report problems with low desire, vaginal lubrication or with orgasm. The problem most

likely to affect men is problems getting or maintaining an erection.

Sex is an important part of life for many people, so any problems you have may have a big effect on your life. Sexual problems can be overcome altogether or an alternative form of intimacy can be found. Finding the right solution for your individual circumstances may involve a number of healthcare professionals.

What causes sexual problems?

Because difficulties with sex are common in people with and without Parkinson's, it may not be easy to tell whether a problem you experience is a result of your condition or not. Rather than being a direct result of the condition, sexual problems can also be a result of the impact the condition has on your emotions or your life more generally. There may also be other underlying causes.

Causes of sexual problems include:

- movement problems: physical immobility, muscle weakness, leg spasms, abnormal sensations, lack of co-ordination, tremor or pain
- depression, anxiety, anger, guilt and fear

- fatigue
- bladder or bowel incontinence, or presence of a catheter
- some medications
- altered self-image or low self-esteem
- difficulties in attention and concentration
- relationship with the partner, change in family role

Parkinson's symptoms and sex

For people with Parkinson's, the physical symptoms of the condition, such as stiff, rigid muscles and slowness of movement, can mean you have to make changes to the way you have sex.

Because symptoms can vary and be affected by so many factors, treatment of sexual problems for people with Parkinson's has to consider all factors that may contribute to the problem and involve a combination of therapies.

Your GP or specialist will look to treat any depression or mood disorders you may experience. They will also look at treating other symptoms, such as:

Movement problems

Any movement problems you have that are related to Parkinson's may affect sexual activity. If your Parkinson's medication is working effectively, this may improve these – speak to your specialist or Parkinson's nurse. Advice on sexual positioning may also help.

Fatigue

Fatigue can be a symptom of Parkinson's. Some medications for this (such as amantadine) have been shown to improve sexual function.

Bowel and bladder problems

Getting treatment for bowel or bladder problems may have an effect on any difficulties with sex you are experiencing. 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, then emptying your bladder before intercourse, or certain drug treatments, may help to promote continence. For those with severe problems, a catheter may be appropriate.

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

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

Other medications

Any other medications you take should be reviewed for the side effects they may have on sexual function. Some drugs for depression are associated with 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.

What can be done about sexual problems?

Lowered sex drive

Many people with Parkinson's and their partners experience lowered sex drive. But this is often more to do with the psychological and emotional impact of diagnosis than as a direct result of the condition. General tiredness, stress and depression, which are common for both someone with Parkinson's and their partner, can also lower desire.

There are many different things you can try to get in the mood for sex – do whatever suits you as a couple:



- 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.
- If tiredness is a problem, try making love at a different time of day.
- 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.

Sexual arousal problems

Both men and women can struggle with sexual arousal. 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 relax.

Female sexual arousal problems

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 experience pain during sex. If you're experiencing a lack of or fewer feelings of sexual excitement, or problems with vaginal swelling 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.

Erectile problems

When a man is struggling to get aroused, the consequence is more obvious. Erection problems are common, especially as men age. Some may have difficulties getting an erection at all, while others get an erection but then lose it.

Relationship counselling or psychotherapy may be useful if you are experiencing a lack of sexual interest or desire. There is a range of medical options your GP or

specialist may explore with you. These include:

- **Viagra/Cialis/Levitra**
Medication is the first option for treating erectile problems. Research has shown that Viagra is safe for men with Parkinson's to use. There is a range of alternative drugs now available that work in different ways, but are still effective at producing an erection. People with Parkinson's can obtain this group of 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 careful supervision at first, but many urologists (specialists who treat problems with the urinary tract in both sexes and with the reproductive system in males) have clinics that provide this treatment.

- **Pessary**
Less intrusive than an injection, some men choose a product called 'muse'. This is a pessary that can be inserted into the end of the penis. Speak to your GP to find out more.

- **A vacuum pump device**
Vacuum constriction devices (VCD) 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 erect-like state. Speak to your GP, specialist, Parkinson's nurse or pharmacist for advice before you buy one.

Surgery to implant a penile prosthesis may be considered for men with erectile problems, but it is only considered as a last resort, and is generally not considered for people with progressive conditions.

Before trying any of these, discuss the options with your partner and 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.

Orgasm problems

Both men and women may experience reduced or lack of orgasms. Treatments for this may

include therapies such as psychosexual therapy or cognitive behavioural therapy. Another option is 'sensate focusing' exercises, where a couple or an individual concentrates on a set of exercises that encourage a sensual experience rather than seeing orgasm as the only goal of sex.

Some men may experience problems with premature or delayed ejaculation, or not ejaculating at all. Women with Parkinson's may take longer to reach orgasm or may not experience it at all. This is because orgasm is a neurological response and those pathways can be affected by Parkinson's.

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 journey just the same.
- 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.

- 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.
- Sex aids
Sex aids including vibrators and vacuum devices (for women applied to the clitoris, which increases vaginal lubrication and enhances orgasm ability) may be of some use to aid stimulation and orgasm.
- Pelvic floor exercises
For some women, pelvic floor exercise may help increase awareness of pelvic floor contractions and improve pelvic tone.

Women may also have genital prolapse (where 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.

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. Sexual impulses become more intense and might be felt at inappropriate times. This can be really 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

“ I became preoccupied with sex and wanted to make love at least twice a day. I'm still unclear whether it was the effect of the dopamine agonist I was taking or me thinking, 'I have a progressive condition, so I may as well indulge in the enjoyable aspects of life'. ”

Michael, diagnosed in 2007

a difficult and distressing problem, particularly if the sexual desires feel out of control and are out of character.

Sometimes people who experience impulsive and compulsive behaviour may not realise they have a problem. If this is an issue in your relationship, then the first thing to do is to talk to your GP, specialist or Parkinson's nurse. Sometimes a change in medication can ease or remove the problem. Some people may need to seek additional professional support, for example from a psychosexual therapist.

Find out more: see our information sheet *Impulsive and compulsive behaviour in Parkinson's*.

My story

By Tony, diagnosed in 2004

For many men, Parkinson's can result in not being able to maintain an erection. I have also had treatment for prostate cancer, which can also cause erectile problems.

I tried medication and a capsule inserted into my urethra, but these did not work. I didn't want to try an injection into the penis so I used a vacuum pump for some months, but it was fiddly to use.

A consultant surgeon suggested inflatable penile implants, which replace the vessels that fill with blood in a normal erection.

They are made hard by pumping fluid into them from a reservoir in the body. The pump is a little squeezable bulb in the scrotum. The system produces a natural feeling erection that is hard for as long as it is needed, until the action can be reversed.

The operation to have this inserted depended on funding from my local NHS trust, which at first was turned down.

But after a successful appeal, I had the operation and my wife and I are once again able to enjoy good sexual health. The effect on my self-esteem and happiness is profound and of course this benefits my wife, too.

Men's sexual health problems are often swept under the carpet, because most men are too ashamed to admit they have a difficulty.



MORE INFORMATION AND SUPPORT

Sexual relationships are an important part of life for many people, and 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 will 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, sexual orientation and cultural influence. 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. If you feel comfortable, you may want to attend appointments with your partner, if you have one, so you can discuss the issues together.

Support for your partner

Although, ideally, you should talk things through with your partner, this can sometimes be difficult. But this can leave your partner having to cope alone. It is essential for your partner to also get the support they need. Parkinson's nurses and information and support workers (see page 30) can see people with Parkinson's and their partners independently to discuss any issues.

Relationship counselling

If you've tried talking to each other about your relationship problems and you're not getting anywhere, couple counselling may help. A trained couple counsellor, such as one at Relate, can help you to look at your problems differently and improve your communication, to help you overcome the problems 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 any changes in an individual can have a big effect on a relationship.

If you think counselling may help, ask your GP if there are services available in your area, or contact your local Relate centre who will make a charge based on your ability to pay (see page 30).

If you'd prefer the flexibility of private counselling, you can get a list of local counsellors from the British Association for Counselling and Psychotherapy (see page 30 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, treatment for sexual problems will also include specialised services such as psychotherapy, sensate focusing (where couples are guided through a set of specific sexual exercises involving nongenital and genital touching) and behavioural counselling.

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 both the physical and psychological aspects of sexual functioning. You can ask them for information on medical treatments for particular problems, or they can help you work through any emotional and relationship difficulties. Again, 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 30 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 combine discussion about the difficulties you are facing with a clinical examination.

If you've been experiencing sexual problems since the onset of your Parkinson's symptoms, this suggests they are related. But the professional examining you will also look for other underlying causes, which could include heart disease, smoking or medication history.

If you are experiencing erectile problems, your GP or specialist 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 automatically assumed to be related to emotional factors. The healthcare professional you see may ask you a number of questions to assess your sexual function and evaluate the impact of any treatment.

Many of the treatments for sexual problems are the same as for those without a neurological condition.

Difficulties with sex in people with neurological conditions is common, but is 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.

Support from Parkinson's UK

You can call our free confidential helpline for general support and information or to speak to one of our helpline nurses. 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 information and support workers, 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

Local groups

While you may not be ready to talk about these issues openly, you can get general support and meet others who may be experiencing similar issues at your Parkinson's UK local group. Visit parkinsons.org.uk/localgroups or call our helpline for details of your nearest meeting.

Useful contacts

British Association for Counselling and Psychotherapy (BACP)

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

01455 883 316
bacp@bacp.co.uk
www.bacp.co.uk

College of Sexual and Relationship Therapists (CORST)

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

020 8543 2707
info@corst.org.uk
www.corst.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.

Sex and Disability Helpline
0707 499 3527
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

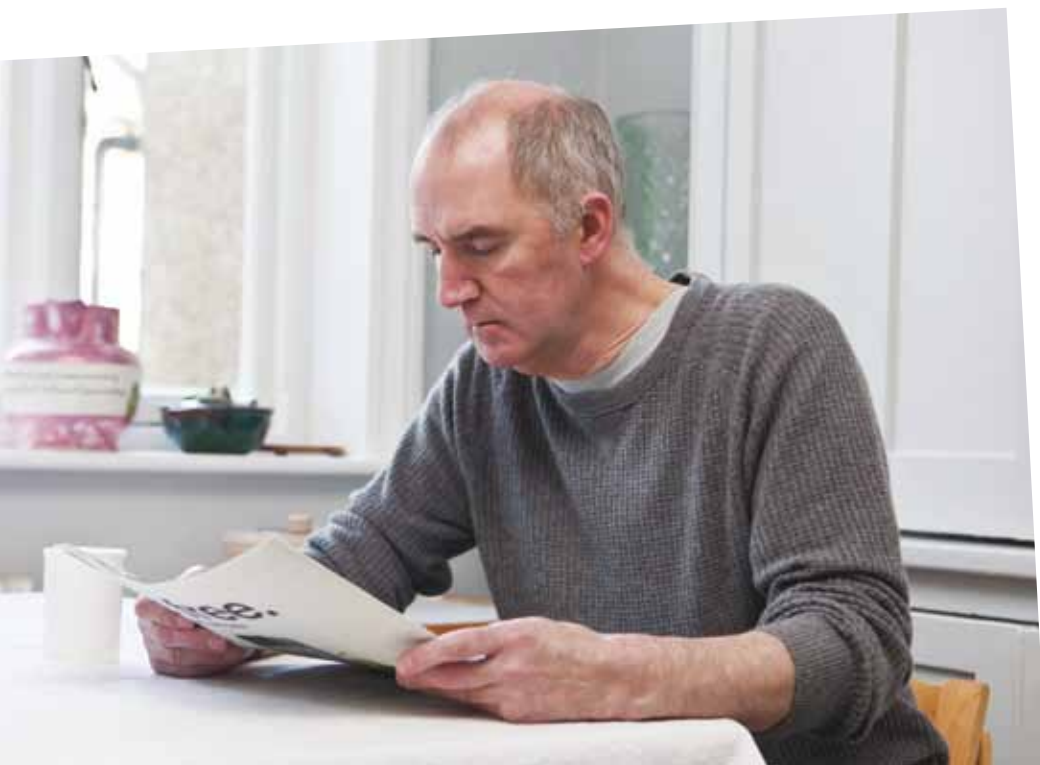
by the American Parkinson's Disease Association.

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 and Parkinson's

If you have comments or suggestions about this booklet, we'd love to hear from you. This will help us ensure that we are providing as good a service as possible. We'd be very grateful if you could complete this form and return it to:

**Resources and Diversity, Parkinson's UK, 215 Vauxhall Bridge Road
London SW1V 1EJ.**

Or you can email us at publications@parkinsons.org.uk. Thanks!

Please tick...

- I have Parkinson's. When were you diagnosed?
- I'm family/a friend/a carer of someone with Parkinson's
- I'm a professional working with people with Parkinson's

Where did you get this booklet from?

Please tick...

- GP, specialist or Parkinson's nurse
- Parkinson's UK local group or event
- Our website
- Information and support worker
- Ordered from us directly
- Other

How useful have you found this booklet?

(1 is not useful, 4 is very useful) 1 2 3 4

Has this resource given you information that might help you manage your condition better?

NA It hasn't helped It has helped a little It has helped a lot

Have you found the publication easy to read/use? Yes No

Continued over the page



What aspects did you find most helpful?

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Were you looking for any information that wasn't covered?

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Do you have any other comments?

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If you would like to become a member of Parkinson's UK, or are interested in joining our information review group (people affected by Parkinson's who give us feedback on new and updated resources), please complete the details below and we'll be in touch.

- Membership Information review group

Name

.....

Address

.....

Telephone

Email

What is your ethnic background?

Please tick...

- Asian or Asian British Black or Black British Chinese Mixed
- White British White other Other (please specify)



Thank you to everyone who contributed to and reviewed this booklet:

Clare Fowler, Professor of Uro-neurology; Principal Clinical Research Associate, National Hospital for Neurology and Neurosurgery, London

Paula Hall, Relationship Psychotherapist

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

We make every effort to make sure that our services provide up-to-date, unbiased and accurate information. We hope that this will add to any professional advice you have had and will 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.

References for this booklet can be found in the Microsoft Word version at **parkinsons.org.uk/publications**

How to order our resources

01473 212 115

resources@parkinsons.org.uk

parkinsons.org.uk/publications

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 **020 7932 1303** or visit our website at **parkinsons.org.uk/support**.

Thank you.

Every hour, someone in the UK is told they have Parkinson's. Because we're here, no one has to face Parkinson's alone.

We bring people with Parkinson's, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson's.

As the UK's Parkinson's support and research charity we're leading the work to find a cure, and we're closer than ever. We also campaign to change attitudes and demand better services.

Our work is totally dependent on donations. Help us to find a cure and improve life for everyone affected by Parkinson's.

Parkinson's UK

Free* confidential helpline **0808 800 0303**

(Monday to Friday 9am–8pm, Saturday 10am–2pm). Interpreting available.

Text Relay **18001 0808 800 0303**

(for textphone users only)

hello@parkinsons.org.uk

parkinsons.org.uk

*calls are free from UK landlines and most mobile networks.

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