

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

RELATIONSHIPS, SEX AND PARKINSON'S



Parkinson's may affect sex and your relationships whether you have Parkinson's or care for someone who does.

This information is for you if you're sexually active or not, and if you're single or in a relationship.

It looks at relationships in general, at the challenges couples may face, starting new relationships and how the condition may affect your sexual functioning, both physically and emotionally. In each section there is information 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 MY RELATIONSHIPS?

First reactions

How you handle the issues Parkinson's presents can have a big effect on your relationships. For example, how you and your partner react to a Parkinson's diagnosis can affect how you feel.

Your reaction will be personal to you and people can go through a range of emotions, including anger, frustration, denial or guilt.

You may even experience relief at finally knowing what's been causing your symptoms. It's 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 this period of adjustment to take place.

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's 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 possible

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

Find out more: we have lots of information about all aspects of Parkinson's on our website, parkinsons.org.uk, or available to order (see the end of this information).

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 like 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. A Relate counsellor can help you both talk about the problems you're facing together (see the end of this information for contact 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 condition 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 main earner 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 give emotional or intellectual support
 - find mutual activities, like 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 on communication and Parkinson's](#).



HOW CAN STRESS, ANXIETY AND DEPRESSION AFFECT MY RELATIONSHIPS?

Adjusting to life with Parkinson's may be stressful, whether you have the condition yourself or you care for someone who does. Some people may experience feelings of depression. This can 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 can also see the end of this information for the details of the Parkinson's UK helpline who can support you over the phone.

Relax

It's easier to say than do, but it's important to relax. To lift your mood, you could try having a bath, going for a stroll, reading a book or just chatting with friends.

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 in the day when you won't be interrupted. It can be encouraging to look back over the weeks and see how much you've 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 eating 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 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 joke.

Find out more: see our [information on 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 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.

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 best activities for helping you bond
- 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 effects 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 could 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're 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 holds. 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. You can find their

contact details at the end of this information. Your Parkinson's local adviser can also offer emotional support to you and your family. See the end of this information to find out more.



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 like low mood or depression. Parkinson's doesn't 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. 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 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, it 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 most relationships 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 CAN CONTRIBUTE TO SEXUAL PROBLEMS?

Difficulties with sex can often happen when something disrupts your sexual responses. Causes of sexual problems include movement problems, fatigue and depression. These difficulties are common in people with and without Parkinson's, so it may not be easy to tell whether a problem is a result of your condition or not.

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

Some Parkinson's symptoms may affect sexual activity. Below we look at these and what you can do to help treat and improve these issues.

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Movement problems

The physical symptoms of Parkinson's, like 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. If it is an issue, try being intimate or having sex at a different time of the day when you have more energy.

Bowel and bladder problems

Fear of incontinence may make you or your partner nervous about sexual activity.

If you experience urinary incontinence, certain drug treatments may be helpful. Using the loo before intercourse may also help. For some people, 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 can help.

The Bladder and Bowel Community can offer more information. See the end of this information for their contact details.

Find out more: see our [information on bladder and bowel problems and Parkinson's](#).

Medications

Any medications you're taking should be reviewed for side effects that may affect sex. Some drugs for depression can cause a reduction in sexual desire, problems with arousal and delayed, or lack of, orgasms.

It's best to speak to your specialist or Parkinson's nurse about the options available for you so you

can continue to get the most benefit from your medication.

Hypersexuality

Some people who take a type of medication known as 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's also a risk that someone will behave in a way that's 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.

If this side effect is mild, then some couples may find they enjoy the extra sex. But 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're 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're having. But remember they'll have spoken to others with similar problems before and everything you tell them will be confidential.

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's 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. In most cases 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. You can find details of

organisations where you can find psychosexual therapists at the end of this information.

Find out more: see our information on impulsive and compulsive behaviour in Parkinson's.

Lowered sex drive

Many people with Parkinson's and their partners have a 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 video 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. Then the outcome will happen more naturally.

Problems with sexual arousal

Both men and women can struggle with becoming aroused sexually. 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 to 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're experiencing a lack of sexual interest or desire.

Orgasm problems

Both men and women may experience reduced or absent orgasms.

Some men may experience problems with premature or delayed ejaculation.

Treatments for problems orgasming may include therapies like psychosexual therapy or cognitive behavioural therapy. These can help individuals or couples find better ways to communicate sexually. If you have problems reaching orgasm the following things might help:

Try to minimise any 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 orgasm – you'll enjoy the time 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're doing won't help you achieve orgasm, so try to 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 you approach sex in a more relaxed and exploratory way, orgasm may follow more naturally.

Sex aids

Sex aids including vibrators and vacuum devices may be useful to help with stimulation and orgasm. The Family Planning Association has its own e-commerce website, Desire and Pleasure (www.fpa.org.uk/shop/86/product-list), which 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, which can help with orgasms. These exercises can be tricky, but a physiotherapist,

nurse or GP will be able to explain how to do them properly.

Ask for 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?

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 any problems you might have aren't necessarily as a result of your condition. There may be other causes such as enlargement of the prostate gland.

The prostate is a small gland found only in men. It's 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 flow 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.

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.

You should talk to your GP if you begin to experience symptoms. They can assess you and refer you to a urologist (a doctor specialising in problems with the bladder, kidneys and male reproductive organs) if necessary.

Erectile dysfunction

Research has shown one of the sexual problems that affects men is not being able to get aroused. When a man is struggling to get aroused, he'll 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 like high blood pressure or diabetes.

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

If you're having erectile problems, speak to your GP or specialist. They'll ask about how much response you have to stimulation, or when problems happen, such as when you wake up in the morning, or when you're 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's 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 before taking it. There's a range of alternative drugs now available that work in different ways, but are still effective at producing an erection.

Self injection or pessary

A drug is available that can be injected into the penis, or inserted in the end of the penis as a pessary,

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.

A vacuum pump device

Vacuum constriction devices are an option for men who don't want to or are unable to take medication. These can be put around the penis to produce an erection. 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's normally a last resort, however.



WHAT SEXUAL PROBLEMS MAY AFFECT WOMEN?

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 they can include hormonal treatments, psychosexual therapy and treatments for any 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 have are necessarily a result of your condition. There may be other causes. We've listed some below.

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 childbirth. Lack of tone in pelvic floor muscles can increase this risk. Pelvic organ prolapse can have a negative effect on sexual function.

Pelvic floor prolapse can be corrected in a number of ways, including vaginal pessaries to support the vaginal walls and organs, or surgery. Talk to your healthcare professional about what options are available to you.

Menopause

The menopause can affect vaginal lubrication and sexual sensations. If you're experiencing these symptoms and are of menopausal age, you should talk to your GP, who will be able to suggest treatments including hormone replacement therapy (HRT).



WHERE CAN I GO FOR 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're having, but remember, they'll have spoken to many others with similar problems before. They'll need to take your particular needs into account when talking to you, including your attitude towards sex and cultural influences. The medical profession is governed by strict privacy laws though, so anything you do share with a healthcare professional will remain totally confidential.

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's essential for your partner to get the support they need too. Parkinson's nurses and Parkinson's local advisers 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. See the end of this information to find out more.

Relationship counselling

If you've tried talking to each other about your relationship problems and you feel that you're not getting anywhere, couples 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. This means 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'll 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 the end of this information for their 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 a person or couple's beliefs about what is 'normal' are contributing to the sexual problem. Also, treatments focusing on relationship problems result in a better outcome than approaches that only focus on problems with the physical side.

Psychosexual therapy

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

Many psychosexual therapists are also relationship therapists and can address practical problems and 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 the end of this information for contact details).

At your appointment

When you speak to a specialist in sexual problems, they should combine discussion about the difficulties you're facing with a clinical examination, if necessary.

If you've been experiencing sexual problems since the onset of your Parkinson's symptoms, this suggests they're 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 are 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.



MORE INFORMATION AND SUPPORT

Bladder and Bowel Foundation

This charity can help provide support for people who experience issues with their bladder or bowels.

0845 345 0165

info@bladderandbowelfoundation.org

www.

bladderandbowelfoundation.org

British Association for Counselling and Psychotherapy (BACP)

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

01455 883 300 (Monday–Friday,
8.45am–5pm)

bacp@bacp.co.uk

www.bacp.co.uk

Relate

Relate provides counselling for people with sexual or relationship difficulties.

0300 100 1234

enquiries@relate.org.uk

www.relate.org.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

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

Outsiders provides information and support to disabled people on personal and sexual relationships.

Sex and Disability Helpline

07074 993 527

sexdis@outsiders.org.uk

www.outsiders.org.uk

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

Parkinson's nurses

Parkinson's nurses provide expert advice and support to people with Parkinson's and those who care for them. 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 tell you about local services.

You can find out more at
parkinsons.org.uk/nurses

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

You can also visit
parkinsons.org.uk/forum to chat to other people with similar experiences on our online discussion forum.

Relationships, sex and Parkinson's (PKB034/2019)

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. 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



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



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

Martin Burrow (Relate)

Jalesh Panicker, The National Hospital for Neurology and Neurosurgery

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

All of the photographs in this booklet feature either people affected by Parkinson's, health and social care professionals involved in caring for people with Parkinson's or Parkinson's UK staff. Thank you to everyone involved for letting us use their photograph.

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**. Thank you.

Our information

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

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**

hello@parkinsons.org.uk
parkinsons.org.uk

Order code: **PKB034**

Last updated March 2019. This information will be reviewed within five years.

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