Sex and relationships

Everyone has their own experiences of how <u>Crohn's Disease</u> or <u>Ulcerative Colitis</u> affects, or does not affect, sex and relationships. This information is here to help you think and talk about sex, intimacy and relationships. Even if you are not having sex or don't want to have sex, you may still find this information useful.

This information is meant for everyone – whatever your gender, sexuality or relationship status.

We have separate information on **<u>Reproductive health and fertility</u>** and <u>**Pregnancy and**</u> <u>**breastfeeding**</u>.

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Key facts about sex and relationships

- Many people living with Crohn's or Colitis are in intimate, loving and sexual relationships.
- There's no right or wrong way to tell someone about your condition.
- There are some practical things you can try if symptoms are getting in the way of sex.
- People with Crohn's or Colitis can have anal sex, but there are some things to consider.
- Many people experience a loss of sex drive at some point in their lives.
- Support is available if you're having difficulties with sex or relationships.

Dating and new relationships

Telling a partner about Crohn's or Colitis

Dating someone new can be an exciting but nerve-wracking time. And it can have extra challenges if you are living with Crohn's or Colitis.

There's no right answer for when to tell someone about your condition. You may find it comes naturally. Maybe the other person brings up the topic of illness. Maybe they are

living with a chronic condition themselves. With other people, it might not be so easy and it could take you longer to feel comfortable telling them.

You may feel better telling them early on and getting it out of the way. Having them know about a key part of your life could be a relief. If you do get a negative response from them, you may feel better knowing this sooner rather than later. Telling someone early could mean less worrying about hiding symptoms or medicines. You may feel less pressure to explain why you only eat certain foods, or don't drink alcohol, for example.

On the other hand, you could wait until you know someone a bit better before you tell them. This way you may feel more confident being open with them.

If you're struggling to find the right words, our **<u>Talking Toolkit</u>** may help.

I found that getting to know my new partner before any intimacy took place was the best way to find out what kind of person he was and whether I felt as though I could trust him. Due to my previous fears, I wanted to make sure that I felt comfortable and this was really important for me.

Georgie

Living with Crohn's

You may feel that your condition is not a big enough part of your life to tell them. If it's someone you're only going to see once or twice, you may wonder if you need to tell them at all.

I have found opening up about my Colitis quite hard, so I tend not to tell dates early on. But I've been in remission for a couple of years now so I don't feel like I need to tell people – especially if I know it's only a fling!

Rose

Living with Colitis

Even if there are times when you feel overwhelmed or embarrassed by your Crohn's or Colitis, it's only one part of who you are. Your best relationships will be with people who see and love you as a whole.

> It will feel like a big deal to bring up because it is a part of who we are, but people who care about you will be understanding and want to do whatever they can to support you. And in terms of getting to know new people - romantic or otherwise - if you are worried that they may react with insensitivity or immaturity then maybe they aren't someone you want to let into your life.

Elliot

Living with Colitis

Telling a partner about your stoma

There's no right or wrong way to tell someone about your stoma. You may decide to tell them early on, maybe even before you meet them. This could give you more control over when they find out. And if someone acts insensitively because of your stoma, then you know early on.

On the other hand, telling someone later could show them that there's more to you than your condition.

You could practise how you'd tell them. See our <u>Talking Toolkit</u> for inspiration on how to talk about your stoma.

The person you're telling may seem shocked or upset – but try not to take this as a rejection. They may be surprised that you've been through such a big life event, and don't know what to say. Maybe they don't know what a stoma is, why you have it, or what it means for your future. You could show them our information on <u>stomas</u>. Give them time to try to understand. If you feel comfortable, let them ask you questions about your stoma.

Take it at your own pace. For some people, the physical signs of Crohn's or Colitis are a reminder of a time when they were very unwell. It's not ok for anyone to make you feel uncomfortable about your body or condition. Don't feel pressured to talk about the details of your stoma if you don't feel happy to.

I felt pressure to fit into a box within the gay community. My box 'gay man with a stoma and lots of scarring' came with its own set of problems. I no longer had the body I thought men wanted and how I had sex would need to change to deal with my new way of life.

Dean Living with Crohn's

There may be some people who can't see past the stoma. It can be extremely difficult to face rejection. Try not to take it to heart. If someone cannot accept you for who you are and what you've been through, then they may not be the right person for you.

Telling a partner about your fistula

Having a fistula can affect some people's confidence. And it can be hard to explain to a new partner why you may look a bit different around your bottom or genitals. You could

practice how you would tell someone. If you're nervous about telling them face to face, you could show them our information on <u>fistulas</u>.

Your partner may be very understanding or they might not even notice. You may find some people are less understanding. If someone makes you feel bad because of your fistula, or any other part of who you are, they may not be someone you want to be with.

> The first sexual partner I told about my fistula decided they didn't want to see me anymore because of it. It was very upsetting and massively knocked my confidence. However, as I got through the situation with support from my friends, I realised it was a huge blessing in disguise - why would I want to be with someone like that?! Other people I've told have been so much kinder and understanding. Unfortunately, you might meet some not very nice people on your Crohn's journey, but there definitely some good ones.

Sophie

Living with Crohn's

Body image worries

When you first start dating or getting intimate with someone, you may worry about what they think of your body. This is a common worry, and living with Crohn's or Colitis may make you focus on your body image even more.

These worries may come from outside ideas of what a body should look like. But everyone's body is unique, beautiful and desirable in its own way. Your body may have been through a lot. You may feel like it has let you down at times. However, you may also feel a sense of pride about how far you've come and what you've been through.

The person you're being intimate with will probably be worrying about what you think of their body too. Reassure and compliment each other so you both feel more confident being intimate together.

Some people find wearing loose clothing, or more comfortable underwear or lingerie helps them feel more body confident.

If you're going to have sex, you may feel better talking to the other person about your body image worries beforehand. You could tell them if you don't like being touched in certain places, or let them know which positions help you feel most confident.

See the section on **Body image and self-esteem** for more information.

Dating tips

Having Crohn's or Colitis doesn't have to stop you going on dates. But to help you feel more confident you could try:

- Checking the menus of any restaurants you're going to beforehand.
- Taking your **Can't Wait card and Radar key** with you.
- Making sure your date happens in a location with toilets nearby.
- Wearing comfortable clothes to help with bloating or tummy pain, or clothes that you can easily take off if you need the toilet urgently.
- Suggesting a time of day that works best for managing your symptoms, such as earlier in the day if fatigue is worse for you in the evenings.
- Exploring date ideas that involve something other than eating and drinking, such as a walk in the park, or watching a film.
- Taking emergency supplies with you spare underwear, wet wipes, air freshener, or perfume.
- Taking spare medicines with you just in case you go back to the other person's place after the date.

Casual sex and relationships

Many people enjoy casual sex and relationships at some point in their lives. Lots of the things mentioned in this information, such as telling a partner about your condition or

your stoma, also apply to casual relationships. If you are having casual sex, it's important to use protection to lower your risk of catching sexually transmitted infections (STIs). See the section on **Sexual health** for more information.

You may find your doctor or nurse makes assumptions about your sexual practices. But there's no shame enjoying casual sex. See the section on **Talking to your healthcare professional about sexuality**.

Long-term relationships

Many people living with Crohn's or Colitis are in secure and loving relationships. For some people, their condition can make their relationship feel stronger. But for other people, living with Crohn's or Colitis can put a strain on their relationship. It may sometimes feel like there's three of you in the relationship – you, your partner, and your Crohn's or Colitis. There is no right way to navigate relationships, but this information is here to support you to explore what is best for you.

Feeling embarrassed to talk to your partner about your condition

Talking about poo can be hard at the best of times, and even harder if you're trying to create a bit of romance! But being honest with a partner can build connection and a sense of intimacy. If you're finding it hard to think of the right words, our <u>Talking Toolkit</u> may help. You could also show your partner our information on <u>supporting someone with</u> <u>Crohn's or Colitis.</u>

Not everyone will make the effort to learn about other people's experiences and difficulties. If your partner makes you feel bad or embarrassed about your condition, you may want to ask yourself if they are the kind of person you want to be with.

Feeling uncertain about the future

Uncertainty of how your condition will be in the future is a major worry for many people living with Crohn's and Colitis. You may think 'Does my partner know what they're getting themselves into?'.

Being open about your worries may help. You could show them our information on <u>Crohn's</u> and <u>Colitis</u> so they can better understand your condition.

Supporting someone with a long-term condition can be hard. Your partner may worry about being honest about their feelings too. Our information on <u>supporting someone with</u> <u>Crohn's or Colitis</u> has tips for partners on how to support you, but also themselves.

See the charity <u>Relate</u> for more information on relationships and how to find relationship counselling services.

Feeling like a burden

It may feel hard to have your partner look after you when you're unwell. You may feel guilty or embarrassed about the things they are helping with. Or you may feel sad that you have lost some of your independence. Try to be honest about your feelings and worries, and encourage your partner to be open too. Have a look at our <u>It Takes Guts</u> campaign or <u>Relate</u> for more ideas on how to be honest with your partner.

If your partner is struggling with extra responsibilities arising from your Crohn's or Colitis, you may be able to look for extra support together. This could mean asking for help from friends and family, or you may be eligible for other help. See <u>Carers UK</u> for more details.

Financial issues

Living with Crohn's or Colitis can sometimes mean extra costs such as prescriptions or higher water bills. Financial strain may be worse if you can't work because of your condition. See our information on <u>finances and benefits</u> for tips on how to manage this. The charity <u>Relate</u> also has information how to talk to your partner about money problems.

Abusive relationships

No one should feel unsafe in their relationship. If you feel like you are being controlled or pressured by your partner or ex-partner – whether it's about your healthcare, finances or friends – this is not ok.

Research has shown that people living with a physical or mental disability, or long-term illness have a higher risk of experiencing domestic abuse.

There are many forms of abuse and they can be hard to spot. See the <u>UK government</u> <u>website</u> for more information on how to spot the signs of domestic abuse, and how to get support. If you are in immediate danger, call 999.

Body image and self-esteem

Body image is how we think we look and present ourselves, as well as how we think others see us.

Self-esteem is how we feel about ourselves as a whole. It's feeling confident about who we are, our abilities and our self-worth.

Having poor body image and low self-esteem can affect intimate relationships. If you don't feel good about yourself or how you look, you may find it hard to be intimate emotionally or physically with someone else.

Living with Crohn's and Colitis can affect your body image and self-esteem. You may find some symptoms of Crohn's and Colitis embarrassing, such as experiencing diarrhoea, incontinence or wind. And this could make you feel less confident. Bloating, weight changes, and surgery can all affect how we see our bodies too.

Some of the medicines used to treat Crohn's and Colitis can have side effects that change how your body looks. For example, steroids can cause weight gain, acne, 'moon face', and stretch marks.

Other aspects of living with a chronic condition, like being unable to work, exercise or socialise at times can also impact how you feel about yourself.

It can be a long and hard process, but there are ways that you can build up your body image and self-esteem.

These tips were collected from a range of sources. They may not all work for you, but you could try some of them to see if they help:

- Think of all the positives about yourself 'I'm funny', 'I'm good at drawing', 'I'm a good listener', 'I can make a great curry', 'I have a great sense of fashion'.
- Write down the things you like most about yourself so you can look over them when you feel low about yourself.
- Think back to when you last felt good about yourself what helped you feel good?
 Was it doing a hobby, wearing nice clothes, taking the time to make your favourite foods?
- Challenge negative thoughts are they rational?
- Imagine you are a friend what would you say to a friend if they felt bad about themselves?
- Look after yourself physically by doing some physical activity or getting outside.
- Limit or avoid unhealthy habits such as smoking or drinking alcohol.

By doing things which make you feel good as a whole, you may feel more confident going into situations like dating or being intimate with someone.

I realised my fear around my illness and my body image was mostly in my head. If your other half loves you, they will love everything about you, regardless of Crohn's or Colitis, scars or sexual mishaps. Our bodies are wonderful and should never be shamed. I have realised that if you accept yourself, other people will too. You may meet the odd person who doesn't but they won't be perfect either! Guaranteed.

Georgie

Living with Crohn's

The charity, Mind has a <u>guide to self-esteem</u> with lots of tips which may help you. NHS Scotland also has a <u>self-help guide</u> focusing on self-esteem.

For some people, obsessive and distressing thoughts about their body can be a symptom of **Body Dysmorphic Disorder** (BDD). If you are worried by how your thoughts are affecting you, speak to your GP.

Sex and consent

Sexual consent is fully understanding and agreeing to have sex or take part in sexual activities. In the UK, you have to be 16 years old or older to consent to sex or sexual activities. This is the law and is the same for all genders and sexualities. No one should ever feel pressured in to doing something sexually that they don't want to. See <u>Brook</u> for more information on consent.

Sex and intimacy

Some people find that living with Crohn's or Colitis causes problems with their sex life. If you find that your Crohn's or Colitis makes having sex difficult, it does not mean your sex life is over forever. It may take time, but there are things you can try to get your sex life back on track.

When I was growing up with Colitis, there was very little information about sex. But I think things are changing and there are a lot more people talking about sex and body positivity now.

Rose Living with Colitis

Not feeling like having sex (low libido, desire or sex drive)

Low sex drive in people with Crohn's or Colitis could be due to:

- Fear of experiencing symptoms during sex.
- Symptoms during a flare-up affecting how attractive you feel.

- Lower testosterone levels in men taking steroid or opiate medicines, or with inflammation.
- Low body image and self-esteem.
- Depression or anxiety.
- Side effects of medicines used to treat depression and anxiety.
- Fatigue.

Let's talk about low sex drive

A low sex drive is relatively common in the general population. A large survey looking at sexual behaviours in the UK showed:

- 1 in 4 people who were in a relationship had a different level of sex drive to their partner.
- 1 in 5 people who are in a relationship said that their partner had experienced sexual difficulties in the past year.
- 1 in 6 people reported having a health condition that affected their sex life in the past year.

Many people experience a noticeable loss of sex drive at some point in their lives. This could be due to relationships issues, stress or other big life changes. Often it just takes some time for your sex drive to return to what is normal for you. If a change in sex drive is lasting longer than you expect and is worrying you, speak to your GP. They can help you explore possible causes and help you find solutions.

Being intimate without being sexual

There are ways to still feel close with someone even if you're unwell, in a flare-up or experiencing a low sex drive. You could try:

• Cuddling

- Hair stroking
- Massage
- Back rubs
- Holding hands
- Napping together
- Kissing
- Sharing baths or showers
- Lying next to each other

Orgasm issues

You may want to have sex, but find it difficult to orgasm when you do. There can be many reasons for this, both physical and mental. This may be due to starting new medicines, recent surgery, pain, anxiety, or depression.

The NHS has information on <u>orgasm issues</u>. The charity Brook also has information on <u>orgasms</u> and what can affect them.

You may be able to discover, or rediscover, ways to orgasm through <u>masturbation</u>. This can help you explore new positions and tricks to help enjoy being physically intimate with someone.

Even if you're finding it difficult to orgasm, there are lots of other ways to enjoy being intimate with someone. You could try:

- Oral sex
- 'Outercourse' rubbing, touching,
- Mutual masturbation
- Nipple play
- Sensual massage
- Watching porn together
- Playing with sex toys together

Erectile and ejaculation problems

If you have a penis and live with Crohn's or Colitis you may experience problems with getting an erection, keeping hard, or ejaculating. This is called erectile dysfunction. There are many <u>causes of erectile dysfunction</u>. Specific risk factors for people living with Crohn's or Colitis include:

- Anxiety or depression this is the biggest risk factor for erectile dysfunction
- Stress
- Certain types of surgery, such as pouch surgery
- Some medicines such as steroids
- Being in a flare-up

If you are struggling with erectile problems, speak to your GP or local sexual health clinic. They can help you explore possible causes and treatment options.

Your partner has stopped having sex with you

Your partner may be less sexual with you for many different reasons. They may be worried that you don't want sex, or that they may hurt you. Talk to your partner and encourage them to be open about their feelings. See <u>Relate</u> for more information. The charity <u>Brook</u> also has tips on how to talk about sex. There are other ways you can be intimate together – see the section above on **Being intimate without being sexual**.

Being spontaneous

There are many things that can get in the way of spontaneous sex – such as work or having kids. You may find that living with Crohn's or Colitis takes away from having that spur-of-the-moment intimacy. Having to think about where the nearest toilet is, or what to do if you get symptoms can make it hard to be spontaneous.

Be kind to yourself and your partner, and avoid comparing your sex life to others. Try to be prepared as much as you can. You could carry some supplies like extra underwear, wet wipes, or pain relief when you go out with your partner. Or you may even decide to leave some supplies at your partner's place.

Taking medicines

The way you take some medicines for Crohn's and Colitis may affect sex. Some medicines, like mesalazine and steroids, may be given as topical treatments by enema or suppository.

Enemas use a specially designed applicator which contains the medicine as a liquid or foam. Enemas are inserted into the bottom and apply the medicine directly into the rectum. Suppositories are small 'bullet-like' capsules of medicine. They are inserted into the rectum through the bottom.

Your IBD team may suggest you take these just before you go to sleep, which could affect when you have sex. You might want to have sex at a different time of day. Speak to your IBD team if you have any questions about taking enemas or suppositories and sex.

Sex after surgery

Your IBD team may give specific advice about when they think it's safe for you to have sex after surgery. Getting back to sexual activity when you feel ready may mean exploring new ways of being intimate.

After surgery, you may find certain positions don't feel as comfortable as they did before. Research shows that around 4 in 10 people changed their usual sex positions after colorectal surgery.

Sex positions may feel different for a number of reasons:

- You may have scar tissue (adhesions) inside the pelvis which may cause pain.
- Surgery may damage nerves which can affect how things feel when you have sex. It can also make your skin more or less sensitive.
- If you have a penis, you may have difficulty getting and keeping erections after pelvic surgery.

These changes may be temporary and may improve after some time. If they don't, speak to your IBD team or visit a sexual health clinic to find ways to help.

Sex and stomas

If you have, or are going to have a stoma, you may worry whether it may get in the way of sex. But having a stoma could make you feel more in control. If you're worried about the stoma bag leaking during sex, empty or change it beforehand.

Some companies sell stoma covers and lingerie designed for stomas which may help you feel more confident.

Do not use your stoma for sex. Bowel tissue is very fragile and can be easily damaged.

See our information on **living with a stoma** for more tips. Stoma nurses can also give lots of practical advice on living with a stoma. **Colostomy UK** also offers information on living with a stoma. You could also try some of the tips in the **diarrhoea and incontinence** section below.

Anal sex

Anal sex means any sexual activity involving the bottom, also called the anus. Many people enjoy anal sex, regardless of their gender or sexuality.

Anal sex includes:

- You or someone else using fingers in or around your bottom
- Having someone put their penis in or around your bottom
- Having someone licking in or around your bottom (rimming)
- You or someone else using sex toys in or around your bottom

There's no right or wrong answer about anal sex with Crohn's or Colitis. But that there are some risks associated with anal sex. This is because the lining of the bottom and rectum is very thin, and can be easily damaged. Your risk of catching or passing on an infection from anal sex is higher if there is an open wound, like a cut, in your bottom or rectum.

If you have inflammation in your bottom or rectum due to your Crohn's or Colitis, your risk of damage or infection may be even higher. This is because you may already be ulcerated or bleeding in this area. Some people with Crohn's can develop strictures, which cause

tightening in the bottom. This may make anal sex more difficult. Having perianal fistulas, abscesses or anal fissures may make anal sex more difficult and could cause further damage.

To help lower your risk of damage during anal sex:

- Use plenty of lubricant. This can help reduce friction and the risk of cuts and tears.
- Foreplay is important. Being turned on will help you relax and make the area more sensitive to pleasurable sensations.
- Be gentle to avoid accidental damage. If you're having something put into your bottom (receiving), try going on top so that you are in control.
- Try other positions or ways of being intimate while your bottom or rectum is healing.
- If it's painful, that's probably a sign that there's some damage and you should stop.

There is very little research into anal sex and Crohn's and Colitis. This makes it difficult to know if anal sex could make your inflammation worse or trigger a flare-up. However, any pain or bleeding is probably a sign of damage. In this case, you may want to stop and give your bottom a chance to heal before attempting it again. Cuts in your bottom can take longer to heal, as they stretch every time you go to the toilet.

Douching

Some people douche before anal sex. Douching means cleaning out the bottom and rectum. It may help you feel more confident about avoiding accidents, but it has been linked to inflammation, especially in people who douche regularly. Try to be mindful of this if you do try douching.

Anal sex after a proctocolectomy

A proctocolectomy is an irreversible type of **surgery** where the whole large bowel, including the rectum and anal canal, is removed. This may be incredibly difficult for you if you enjoy anal sex above other forms of sex. How you enjoy sex may have to change, but it doesn't need to end.

If you're finding it hard to come to terms with these changes, psychosexual counselling may help. Speak to your GP, IBD team, or local sexual health clinic about accessing this support.

Sexually transmitted infections (STIs) and anal sex

Proctitis means inflammation of the rectum. Both Crohn's and Colitis can cause proctitis.

Infectious proctitis is inflammation of the rectum caused by an infection. STIs that can cause proctitis include chlamydia, gonorrhoea, syphilis and herpes.

If you enjoy receiving anal sex, be aware that some STI symptoms are very similar to symptoms of Crohn's and Colitis. If you start to get symptoms like bleeding, discharge, itchiness, or pain in your bottom it's worth visiting your local sexual health clinic or letting your IBD team know. This is so they can check for STIs as well as the usual Crohn's and Colitis tests.

Crohn's and Colitis symptoms and sex

The symptoms of Crohn's or Colitis may get in the way of your sex life. Here are some common issues and ways to cope with them.

Navigating a new relationship with my now wife, when I had first been diagnosed, I was self-conscious about physical symptoms such as being gassy and bloated. I was paranoid about having an accident or not being clean enough. I found the best thing to do was to be honest about how I was feeling so that my partner understood.

Phoebe

Living with Colitis

Pain during sex

Pain can be your body telling you something isn't right. So, if you have pain during sex, stop and let the other person know.

Crohn's and Colitis can cause pain in many places including your tummy (abdomen), joints, mouth and genital area. Let your partner know when and where you feel pain. Together you can find ways to enjoy yourselves without causing or worsening pain.

Pain during sex seems to be more common in women living with Crohn's. Pelvic, vulval or vaginal pain may increase during a flare-up. Pain during sex may be in part due to the pelvic floor muscles contracting. These muscles contract when trying to control incontinence, diarrhoea and tummy pain. Pelvic floor muscles contracting can also affect sensation and orgasms.

Many things can cause painful sex. These include physical problems such as infections, as well as psychological issues. See the NHS's information <u>'Why does sex hurt?'</u> for more on the causes of painful sex in men and women. If your pain is not going away, speak to your GP or local sexual health clinic.

If you experience pain during sex, try:

- Foreplay feeling aroused is important in making sex pleasurable and not painful.
- Using lubricant to ease friction and help arousal.
- Exploring different positions to find ones that work for you.
- Going on top for penetrative sex, so you are in control of the pressure, speed, and depth.
- Slower more shallow movements.
- Using support aids to help you get into more comfortable positions. You can use normal pillows or cushions. Some companies sell more supportive 'sex wedges' and 'sex pillows'.
- Talking to your doctor about pain relief medicines.

If penetration is too much, there are plenty of other ways to be intimate. Sex isn't just about penetration – it's about what feels good for you. Explore your body to find out where you like to be touched. These places are called <u>erogenous zones</u>.

I was diagnosed with Colitis before I started having sex, so it's always been at the back of my mind when meeting new people. Symptoms have got in the way at times, but I've learnt to just be honest and take control of the situation. I now feel more confident exploring different positions or roles so that we both have a good time.

Rose

Living with Colitis

Bloating and wind

Feeling bloated can be very uncomfortable and can make the thought of sex very unappealing. Worrying about wind during sex may mean you avoid getting intimate with someone.

Our information on <u>bloating and wind</u> includes things you can try to reduce these symptoms. It may help to talk to your partner about these symptoms and your worries. You could suggest that you try less impactful movements, such as avoiding deep thrusting.

Eating earlier in the day, or avoiding large meals before sex may help you feel more comfortable. Wearing loose fitting clothes or underwear may also help you feel more confident being intimate.

People who do not have Crohn's or Colitis also pass wind during sex. So don't feel too embarrassed if it happens to you – it can happen to anyone!

Diarrhoea and incontinence

If you have diarrhoea or incontinence, you may be thinking:

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- Do I smell?
- Have I cleaned myself properly?
- What if they go down on me (oral sex)?

If you're worried about having an accident during sex, you're not the only one. It's a common fear for people living with Crohn's and Colitis. You may find that you avoid getting into intimate relationships because of this worry. It can be very off-putting and may make it harder for you to orgasm. If you have a penis, you may find this anxiety can lead to erection problems.

It's understandable to be nervous – sex is supposed to be fun, pleasurable, and empowering. And the thought of poo can be the last thing you want. Talking about these fears with your partner may help.

There are some things you can try to lower your risk of having an accident:

- Going to the toilet to have a poo before sex.
- Having a wash or shower before sex.
- Suggesting the other person uses a dental dam when they go down on you (oral sex). A dental dam is a piece of latex that you can put between your mouth and the other person's skin or genitals. You could also use a cut out bit of condom.
- Using an <u>antidiarrhoeal medicine</u>, such as loperamide (Imodium/Arret), before sex. However, these sorts of medicines are not suitable for everyone with Crohn's or Colitis and should not be taken during a flare-up. Check with your IBD team before using these medicines.
- Having sex at the times of day when your bowel is less active.
- Some hospitals have continence specialists who can help with incontinence issues. Speak to your GP or IBD team to see if this may be suitable for you.
- See our information on diarrhoea and incontinence for more tips.

Ultimately, accidents may still happen and it's good to be prepared. You could have some towels or wet wipes close by so you can quickly clean up. You could put towels on the

bed just in case. Some people do this for other reasons, such as protecting the bed sheets from period blood, semen or lubricant.

Depending on your relationship, you may want to pretend it didn't happen and get back to having sex. Or acknowledge it, embrace it and laugh about it!

If someone makes you feel bad or embarrassed about having an accident, you may want to ask yourself if they are someone you really want to be intimate with again.

> By voicing my fears, it opened up vulnerability for both of us. We are now so comfortable with each other that on days where my IBD is playing up I'll joke and say that my underwear has to stay on today, but my partner's doesn't! I see it as an opportunity to be playful and treat my partner.

Phoebe Living with Colitis

Fatigue

Fatigue is a common symptom of Crohn's and Colitis. Fatigue can make it hard to keep both physical and emotional relationships.

If you don't feel like sex, that's ok. You shouldn't feel pressured to have sex just because the other person wants it.

If you do want sex but get tired easily, you could try:

- Positions that require less energy from you
- Using support props such as cushions
- Using sex toys, such as vibrators or dildos, to do the work
- Using massage
- Going slow and sensual
- Mutual or solo masturbation
- Taking breaks

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• Having sex at times of the day when you have more energy

You don't have to climax – sex is not just about reaching orgasm; it's about feeling good. So, take it slow and do what feels good for you. Read our information on <u>fatigue</u> for more tips on managing fatigue.

> We always talk about how we are feeling in relation to sex, and at times where I'm having a lot of fatigue or discomfort, I always take care to show my partner that I love them and am attracted to them in ways that I can whilst feeling unwell.

Phoebe Living with Colitis

Fistulas

A <u>fistula</u> is a narrow tunnel that connects an organ to another part of your body. Fistulas are a complication of Crohn's (and more rarely Colitis). Perianal fistulas connect the anal canal or rectum to the surface of the skin near the bottom where poo leaves the body. These are the most common type of fistula. Some people can develop fistulas between their bowel and their vagina.

Having a fistula may mean that have to find what feels good for you sexually. But it's still possible to have a healthy sex life with a fistula.

Scarring, sores, and setons can make your genital area look a bit different. This may make you feel nervous about sex. Worrying about leakage or smells from a fistula can also be a distraction for some people. Fistulas and scarring may make your genitals feel tight or dry. Keep lubricant nearby to help make sex more comfortable for you.

If you find penetrative sex too painful, there are many other ways to be sexually intimate with someone. See the section **Orgasm issues** above for other ways to be intimate. You could also ask your IBD team for advice on sex with a fistula.

You may want to avoid penetrative sex while you are recovering from fistula surgery. Your IBD team can tell you when it's safe to have sex again.

Sexual health

There are some things to consider to help you stay safe and healthy when having sex.

Sexually transmitted infections (STIs)

Using condoms is the most effective way of protecting yourself from STIs. Having regular STI tests helps to keep yourself and others safe. Not all STIs give you symptoms so don't wait until you feel unwell. See the NHS's <u>advice on STIs.</u>

Some STIs have similar symptoms to Crohn's and Colitis. If you think you may have an STI or are having <u>symptoms of an STI</u>, speak to a sexual health clinic. They provide tests and treatments for STIs. Find your nearest sexual health clinic:

- England
- <u>Scotland</u>
- Wales
- Northern Ireland

There are many websites advertising private STI tests for a fee. But you may be able to get a free STI sent to your home. Brook has information on <u>finding free STI tests</u>.

Anyone can get an STI, but using condoms can help protect you. If you have Crohn's or Colitis, there may be other factors that increase your risk of catching STIs:

- Having open, sore skin. If you are regularly wiping your bottom this can make it sore. Diarrhoea and incontinence can also irritate skin and make it sore. Help your skin heal by using warm water to wash around your bottom and pat dry with toilet paper. You can also use barrier cream to help the skin heal. See our information on <u>diarrhoea</u> for more tips on skincare.
- Some medicines can lead to vaginal dryness which can increase your risk of cuts and tears during sex. You can lower this risk by using lubricant.

 If you use condoms, be aware that lotions or oil-based creams can make condoms weaker and more likely to break. If you are using creams, ointments, or any medicines in or around your genitals or bottom (such as barrier creams) ask your IBD team or pharmacist for further advice.

Herpes

Herpes Simplex Virus (HSV) commonly known as herpes, is a common infection. There are two main types – oral (cold sores) and anogenital (around the bottom and genitals). In England, around 1 in 5 adults have a genital herpes infection by the age of 25.

Herpes spreads easily, mainly through skin to skin contact. You are most infectious when you have **symptoms**, such as blisters and sores. But Herpes can still be infectious even if you don't have symptoms yet. Once you've been infected symptoms can come back – this is called an outbreak.

If you are taking <u>immunosuppressant medicines</u> your risk of having an outbreak is higher. However, there are antiviral treatments available to help with symptoms. If you're having lots of outbreaks your doctor may recommend taking daily antivirals to prevent outbreaks.

If your partner has genital herpes, help protect yourself by avoiding sexual contact until they are well again and their symptoms and sores have gone. Using condoms can help, but cannot protect you completely.

The <u>Herpes Viruses Association</u> has more detailed information on what herpes is and how to manage it.

Thrush (candidiasis)

Thrush is a yeast infection you can get on and around your genitals. Thrush is not an STI. It can make your genitals feel very itchy and sore. It can make having sex uncomfortable. Having a weakened immune system or taking antibiotics can increase your risk of developing thrush. If you think you have thrush, speak to your GP, IBD team or local sexual health clinic. There are over-the-counter medicines for thrush, but they may

interact with your Crohn's or Colitis medicines. Check with your IBD team or pharmacist before taking an over-the-counter medicine for thrush.

Taking PrEP

PrEP (pre-exposure prophylaxis) is a medicine to stop you catching HIV. PrEP is free in the UK for people who are at greater risk of getting HIV, such as men who have sex with men. See <u>Terrence Higgins Trust</u>, or speak to your local sexual health clinic for more information on what PrEP is and how to access it.

None of the common medicines used to treat Crohn's and Colitis have major interactions with the medicines used in PrEP. But it's always best to check with your IBD team or pharmacist before taking any new medicines.

I'm HIV positive – do I have to tell my IBD team?

You do not have to tell other healthcare professionals, such as your GP or IBD team, about your HIV (or any other STI) status. You may feel that you want to keep this information private. However, your IBD team may need to carry out HIV screening before starting some medicines. This is to make sure you aren't taking a medicine that could be harmful to you. See <u>Terrence Higgins Trust</u> for more information.

Contraception

Be aware that:

- If you take contraception pills and are vomiting or have diarrhoea, <u>you may not be</u> protected against pregnancy.
- Condoms are the only form of contraception that can help protect you from STIs.

For more on contraception, see our information on *reproductive health*.

Talking to healthcare professionals about sex

Sex is often not asked about at your appointments. And you may feel anxious to bring it up, especially if you only have a short time with your doctor or nurse. Here are some ideas to try:

- If you usually go into an appointment with a family member, partner, or friend, it might help you to go alone so you can be completely open.
- On the other hand, you may find having your partner there helps you bring up things that can be difficult to talk about.
- You could write down your problems then show your doctor or nurse, so you don't have to say it out loud.
- If you have an IBD nurse you could email them, or email your doctor.
- Use words that feel comfortable to you, whether that's slang or medical terms. Whatever helps you get the message across.
- Look at our **appointments journal** to help you prepare for your appointment.

If problems with your sexual wellbeing are causing you distress, let someone know. It's a valid problem and you should not be dismissed.

Talking to healthcare professionals about sexuality

Living with Crohn's or Colitis means contact with lots of different healthcare professionals including doctors, nurses, pharmacists, radiographers and surgeons.

You may find that people make assumptions about your gender, sexual practices or sexuality. This can be hard, not only to listen to, but having to correct them too.

You may feel nervous about being open about your sexuality, especially if being unwell also makes you feel vulnerable. But letting the people involved in your care know these details means they can get you the right tests and treatments. It may also help you feel more comfortable involving your partner in discussions about your care.

If you are lesbian, gay, bisexual, transgender or non-binary, you have the same rights to healthcare as anyone else. Healthcare staff receive training in LGBTQ+ care and rights, but we know that some LGBTQ+ people still face discrimination in healthcare. If you feel you are being or have been discriminated against because of your gender or sexuality, see <u>Citizen's Advice</u> for <u>information</u> on how to make a complaint.

Other organisations

Age UK

www.ageuk.org.uk

Advice line: 0800 678 1602

Brook (A charity promoting sex education and wellness. Mainly support young people, but information for all ages, genders and sexualities)

www.brook.org.uk

British Association for Counselling and Psychotherapy

www.bacp.co.uk

01455 883300

College of Sexual and Relationship Therapists (Professional body with a register of therapists)

www.cosrt.org.uk

020 8106 9635

Colostomy UK

www.colostomyuk.org

24-hour free helpline: 0800 328 4257

Galop LGBT+ (Charity supporting LGBT+ victims and survivors of domestic abuse, sexual violence, hate crime, and other forms of abuse including honour-based abuse, forced marriage, and conversion therapies)

www.galop.org.uk

LGBT+ Domestic Abuse Helpline: 0800 999 5428

Herpes Viruses Association

www.herpes.org.uk

Helpline: 0845 123 2305

Ileostomy and Ileoanal Pouch Association

www.iasupport.org

0800 0184 724



Mind (Mental health charity)

www.mind.org.uk

Helpline: 0300 123 3393

Refuge (Charity supporting people affected by domestic abuse)

www.refuge.org.uk

National Domestic Abuse Helpline: 0808 2000 247

Relate (Offer relationship support, including counselling and sex therapy, in England and Wales)

www.relate.org.uk

Switchboard (LGBT+ helpline for support with sexuality, gender identity, sexual health and emotional well-being)

www.switchboard.lgbt

LGBT+ Helpline: 0300 330 0630

Terrence Higgins Trust (Charity supporting people impacted by HIV and poor sexual health)

www.tht.org.uk

0808 802 1221

Young Minds (Mental health support for young people)

www.youngminds.org.uk

Helpline for parents: 0808 802 5544

Help and support from Crohn's & Colitis UK

We're here for you whenever you need us. Our award-winning information on Crohn's Disease, Ulcerative Colitis, and other forms of Inflammatory Bowel Disease have the information you need to help you manage your condition.

We have information on a wide range of topics, from individual medicines to coping with symptoms and concerns about relationships and employment. We'll help you find answers, access support and take control.

All information is available on our website: crohnsandcolitis.org.uk/information

Our Helpline is a confidential service providing information and support to anyone affected by Crohn's or Colitis.

Our team can:

- Help you understand more about Crohn's and Colitis, diagnosis and treatment options
- Provide information to help you live well with your condition
- Help you understand and access disability benefits
- Be there to listen if you need someone to talk to
- Help you to find support from others living with the condition

Call us on 0300 222 5700 or email helpline@crohnsandcolitis.org.uk.

See our website for LiveChat: crohnsandcolitis.org.uk/livechat.

Crohn's & Colitis UK Forum

This closed-group community on Facebook is for everyone affected by Crohn's or Colitis. You can share your experiences and receive support from others at:

facebook.com/groups/CCUKforum.

Help with toilet access when out

Members of Crohn's & Colitis UK get benefits including a Can't Wait Card and a RADAR key to unlock accessible toilets. This card shows that you have a medical condition, and will help when you need urgent access to the toilet when you are out. See <u>crohnsandcolitis.org.uk/membership</u> for more information, or call the Membership Team on 01727 734465.

Crohn's & Colitis UK information is research-based and produced with patients, medical advisers and other professionals. They are prepared as general information and are not intended to replace advice from your own doctor or other professional. We do not endorse any products mentioned.

About Crohn's & Colitis UK

We are Crohn's & Colitis UK, a national charity fighting for improved lives today – and a world free from Crohn's and Colitis tomorrow. To improve diagnosis and treatment, and to fund research into a cure; to raise awareness and to give people hope, comfort and confidence to live freer, fuller lives. We're here for everyone affected by Crohn's and Colitis.

This information is available for free thanks to the generosity of our supporters and members. Find out how you can join the fight against Crohn's and Colitis: call **01727 734465** or visit <u>crohnsandcolitis.org.uk</u>.

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We hope that you've found this information helpful. You can email the Knowledge and Information Team at <u>evidence@crohnsandcolitis.org.uk</u> if:

- You have any comments or suggestions for improvements
- You would like more information about the research on which the information is based
- You would like details of any conflicts of interest

You can also write to us at Crohn's & Colitis UK, 1 Bishops Square, Hatfield, Herts, AL10 9NE or contact us through the Helpline: 0300 222 5700.

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Patient Information Forum