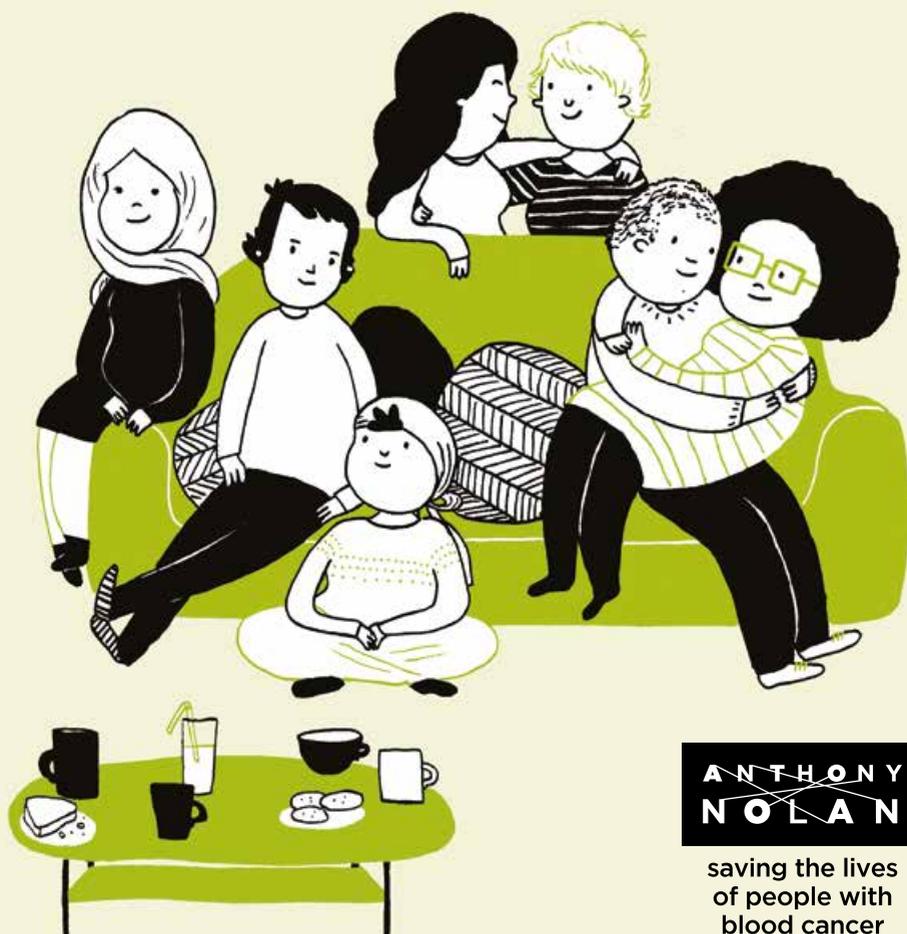


LIFE AFTER TRANSPLANT: AN ESSENTIAL GUIDE TO SEX AND RELATIONSHIPS



**ANTHONY
NOLAN**

saving the lives
of people with
blood cancer



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saving the lives
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ANTHONY NOLAN
PATIENT SERVICES

WHAT'S IN THIS BOOKLET?

We've put together this booklet for anyone who is having concerns about their relationship or sex life after their stem cell or bone marrow transplant.

It has been written with guidance and advice from our remarkable patients, their partners and healthcare professionals, to help you come to terms with your current situation and what can be done to help.

If you need to ask us any questions, or you would like some more advice, please get in touch with the Anthony Nolan Patient Services team at:
patientinfo@anthonymolan.org
or on **0303 303 0303**.

'Very few people are happy to talk openly about sex, libido and relationships, so it's even more important that I try to bring this topic into conversation.'

Hayley, Anthony Nolan Lead Nurse

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INTRODUCTION



For a lot of people, their primary concern after their stem cell transplant is feeling better. Understandably during this time, focus is placed on recovery – and some of the important things that help us to enjoy life can get forgotten about.

Whether you are in a relationship or not, sex is an important factor in this. It provides pleasure, relieves stress and helps create a deeper intimacy with your partner. Since your stem cell transplant you may be experiencing physical or emotional difficulties that mean you are not as comfortable having sex as you once were; it might even be painful to have sex. These changes can cause anxiety and emotional distress that can sometimes put a strain on your relationship and affect your mental wellbeing.

This guide will give you a better understanding of the physical problems that can affect your sex life following your stem cell transplant and the treatments that can help.

It will explore some of the emotional concerns you might have surrounding your existing relationship or when thinking about starting a new one. There is also a section for your partner, explaining how your current medical situation might affect your relationship from their perspective.

Your sex life and your relationship are not the easiest things to talk about with your medical team. Often the hardest part is finding a way to start the conversation. Perhaps take this booklet with you to your appointments and use it as a way to introduce the topic of sex with them. Your transplant team is used to talking to people about all aspects of stem cell transplant treatment and will be able to provide you with the support that you and your partner need.

'People don't seem to see sex as something to talk about, which I don't necessarily think is a good thing. We have this concept that it's a bit icky to think of someone else having sex, don't we? And yet it's all over TV and in the media.'

Emma, recipient of two stem cell transplants

'I think people have to do what's right for them, but I'd say having good communication with your clinicians about the ways in which your body will change can be helpful. Let your team know if there are things concerning you.'

Louise, who had a transplant in 2014



KEY FACTS



We know from talking to our patients who have had a transplant that there are some important questions relating to sex that are best answered straight away. They may not all be relevant to your situation right now but hopefully they will help to put your mind at ease about certain issues.

WHEN IS IT SAFE TO HAVE SEX AFTER MY STEM CELL TRANSPLANT?

Your transplant team will be able to give you personalised advice about when it is safe to have sex after your stem cell transplant. In general, the right time will be when both you and your transplant team feel you are comfortable and able to have sex.

DO I NEED TO TAKE ANY SPECIAL PRECAUTIONS WHEN HAVING SEX?

The chemotherapy agents you were taking before your transplant can be passed on to your partner during sex - this includes oral sex. To protect your partner during this time, it's important that you use a condom until one week after chemotherapy has stopped. You should also avoid any sexual practices that put you at risk of infection.

HOW COMMON IS IT TO HAVE PROBLEMS WITH YOUR SEX LIFE AFTER A TRANSPLANT?

If your stem cell transplant is affecting your sex life, you are certainly not alone. Approximately half of all patients experience issues with their sexual health after their transplant. It's very common to experience loss of libido, erectile dysfunction and vaginal dryness, for example.

CAN MY SEX OR RELATIONSHIP PROBLEMS BE TREATED ON THE NHS?

All of your prescribed medications are free through the NHS. If you are referred for any counselling services, these are also available on the NHS - but there may be a waiting list. These services can also be paid for privately, if that is an option for you.



PHYSICAL SYMPTOMS AND TREATMENTS



CAUSES

Prior to your transplant you will have undergone intensive chemotherapy and potentially full body radiation as well. This can leave you with side effects and fatigue in the short term that can make sex more difficult to enjoy.

Following your transplant you might have developed graft versus host disease (GvHD) related side effects that hinder your ability to have and enjoy sex. High dose steroids that are used to relieve GvHD can also suppress the production of sex hormones, which lowers your sex drive.

Even if you are not particularly affected by GvHD, your stem cell transplant can still leave you fatigued during your recovery. This can make the most basic of daily activities difficult to achieve, let alone summoning up the energy for sex.

SIDE EFFECTS

Depending on your situation, you may have experienced one or more of the following side effects that could affect your enjoyment of sexual activity. They usually appear between six and 12 months after your stem cell transplant:

WOMEN

- Genital GvHD can cause vaginal dryness and irritation, as well as narrowing of the vagina and even ulceration in severe cases.
- Decreased libido (desire to have sex).
- Difficulty achieving orgasm and reduced satisfaction from sex.
- Pain during sex and bleeding afterwards.
- An irregular or absence of your menstrual cycle and other symptoms of early menopause, such as hot flushes and vaginal dryness.

MEN

- Difficulty in achieving and sustaining a full erection, known as erectile dysfunction.
- Decreased libido (desire to have sex).
- Inflammation or a rash on the penis and/or scrotum caused by GvHD. This often leads to pain or discomfort during sex.
- Narrowing of the urethra, the tube in the penis that carries urine and sperm, which can cause discomfort.
- Inability to ejaculate.

‘Symptoms that develop after one year post-transplant are called “late effects”. At this point, we tend to see patients begin to discuss loss of libido and sexual function.’

Hayley, Anthony Nolan Lead Nurse

TREATMENTS

Your transplant team will provide you with the best possible treatment based on your medical situation. If you are unsure about anything, feel free to ask your transplant team for more information, they will be happy to help. It is likely that your treatment plan will include a combination of the following medications:

MEN AND WOMEN

All patients can be given a range of treatments to target the localised immune responses leading to painful inflammation, including:

- Immuno-suppressants that can be applied to areas of the skin showing signs of inflammation.
- Steroids are often given in response to inflammation and then reduced over a few weeks.
- Calcineurin inhibitors can also be given to replace long term steroid use.

'I'm covered in rashes, and it makes you really self-conscious about wearing nice clothes.'

Emma, recipient of two stem cell transplants

WOMEN

- Oestrogen, the female sex hormone, causes the lining of your vagina/vulva to thicken and become more resilient. It can be given in the form of creams, capsules or release rings.
- Conditioning therapy prior to your transplant can cause women to go through the menopause much earlier than expected. You can discuss treatment options with your doctor and will probably be offered HRT (Hormone Replacement Therapy) to alleviate hot flushes and other symptoms. HRT may also make sex less painful and can increase your sex drive. If you would like more information about early menopause, see our guide *The Seven Steps, The Next Steps*.
- You may be referred to a gynaecology specialist who will examine and treat you. If you would like more information about what to expect during a gynaecology appointment, see our 'Meet the expert - Women's health' section on p27.

MEN

- You may be offered a course of testosterone, the male sex hormone, to increase your libido.
- PDE-5 inhibitors are a class of drugs you may not have heard of before although you probably know one of their commercial names: Viagra. These oral tablets are used to increase blood flow to the penis, which helps to sustain an erection when required.
- Other possibilities (although much less common) include the use of vacuum erection devices, an Alprostadil injection or in some cases penile implants. These options can be discussed in more detail at an erectile dysfunction clinic which you can be referred to via your transplant team. The 'Meet the expert - Men's health' section on p31 has more information on how these problems are treated.

TIPS FOR EASING SYMPTOMS

While some treatments need to be prescribed by your transplant team, there are also a few things you can try to help ease any discomfort you might be experiencing:

- Bathe in warm water to avoid chemical or physical irritation, and try not to use perfumed lotions and soaps.

- Wear loose fitting clothes and cotton underwear. If your skin is particularly sensitive, consider washing your clothes in a mild detergent.
- When symptoms arise they can sometimes be relieved by sitting in a sitz bath (warm water that covers up to the hips) for five to 10 minutes.
- Moisturisers or emollients should be applied to the skin to prevent dryness.
- Barrier creams – such as bacteriostatic gels, petroleum jelly or lanolin cream – can be applied to lock in moisture after a bath or wash.
- Vaginal moisturisers and lubricants can make intercourse more comfortable. If you are using condoms, make sure the lubricant is water-based rather than oil-based because oil-based lubricants can tear condoms.
- If women experience narrowing of the vagina, it can be eased by regularly inserting dilators of varying sizes. Having regular intercourse with your partner can also help, but only try it if you both feel comfortable.



HEALTHY LIVING AND WELLBEING



The way you feel and your general outlook on life can be lifted by following a healthy lifestyle. This is true for your sexual wellbeing too, and could lead to your sex life returning to normal more quickly. Incorporating some of these ideas into your daily routine could help you to feel more positive.

DIET

- Eat five portions of fresh fruit or veg a day.
- Limit the amount of red meat you eat and avoid processed meats.
- Cut down on the amount of salt in your diet.
- Keep yourself hydrated by drinking at least two litres of water per day.
- Avoid sugary drinks.

If you require more detailed advice about your diet, talk to a member of your transplant team. They will be able to put you in contact with a dietician.

ALCOHOL

Try to limit alcoholic drinks so that you are not drinking more than 14 units per week. See [nhs.uk/livewell/alcohol](https://www.nhs.uk/livewell/alcohol) for more info.

EXERCISE

It might feel like the last thing you want to do, but even a small amount of physical activity can help reduce fatigue and improve your physical strength. It's important to find

a balance and not overdo it because your fitness, endurance and muscle strength will have reduced during your treatment. Even light housework or a walk around the block each day can make a big difference.

SMOKING

Not only will quitting smoking improve your general health but it also improves circulation, which can help prevent erectile dysfunction.

SLEEP

Everybody's mood is affected by a lack of sleep, so try to get into a regular sleeping pattern that your body is comfortable with. It will also help you to manage the effects of fatigue on your lifestyle. For more information and handy tips on how to get a better night's sleep, visit anthohnolan.org/fatigue

REDUCE STRESS

Make time to do things that you enjoy. Catch up with friends, go out for a meal or try a relaxation technique such as yoga or meditation; it doesn't matter what it is, as long as it puts a smile on your face.



MEET THE EXPERTS: MEN'S HEALTH & WOMEN'S HEALTH



In the coming months you could be referred to various healthcare teams who you have not visited before. Attending a specialist clinic or therapist consultation for the first time can be a cause of concern for some patients. To help put your mind at ease we've asked three expert healthcare professionals to provide some insight into the services they provide and what you can expect during your visit.

MEET THE EXPERT - WOMEN'S HEALTH



Dr Nivedita Reddy is a gynaecologist and fertility specialist at Guy's and St Thomas' Hospital in London. Here she talks about the potential impact of a stem cell or bone marrow transplant on

women's sexual health, and the treatments available in her clinic.

Why do women come to see you?

The women that enter my clinic can have a range of problems that have arisen from their stem cell transplant and the treatment they have had. This includes:

- Symptoms such as hot flushes, sweats, tiredness and disturbed sleep that is often related to menopause.

-
- Lack of libido, vaginal dryness or pain during sex.
 - Difficulty in having a cervical smear.
 - Wishing to discuss hormone therapy.
 - Possible genital GvHD.

Improvement in some conditions can be achieved more easily than others, which may need prolonged treatment.

Do I need to do anything before I visit your clinic?

You are likely to be referred to my clinic from your haematology clinic, transplant team or your GP. Bringing a list of your medications will be helpful, and you can also ask a friend or relative to come along to the appointment with you if you want.

How do you put women at ease?

I ask them to tell me about their problems and I try to assess how much they are affecting them. Women may mention their symptoms to their consultant, but often don't because they feel he or she may not understand, or else they feel it isn't appropriate to talk about it with a haematologist. Others are embarrassed to discuss personal issues.

Patients will say to me that in the big picture of cancer and transplants, sexual health concerns may be looked upon as not so important, so they don't mention them to their haematologist. But it's alright to do so because they are known side effects of the treatment and the haematologist can then refer you to the appropriate doctor.

What will happen?

I start by asking a few questions to establish my patient's gynecological history, their current issues and their recovery following the transplant. This helps me to prioritise their needs and treat the most pressing issue first. I may need to perform a physical examination and/or blood tests to obtain information and advise suitable treatment.

Some patients may be anxious or unprepared to be examined at their first visit. A pelvic ultrasound may also be performed to complete the examination. It's important that cervical smears are up to date. This can be problematic for some women because of vaginal dryness, discomfort or occasionally due to genital GvHD. In these cases it's often possible to prescribe medication to make it less uncomfortable to complete a cervical smear at a later appointment.

What happens next?

Most women will need a couple of visits, depending upon whether the symptoms have improved. If hormone therapy has started, usually one or two appointments are needed, followed by an annual visit. Treating sexual dysfunction and GvHD often takes longer and can vary in different women.

Can the issue of fertility be talked about?

Yes, fertility is a common question with young women. Preservation of fertility is usually undertaken prior to the transplant. Some women may have had a fertility discussion but unfortunately due to the urgent need to proceed to chemotherapy there may not have been sufficient time to complete fertility preservation. This can impact upon relationships or future plans. Support from fertility counsellors is available.

If fertility preservation (storage of eggs or embryos) was previously undertaken, fertility treatment can be commenced when the woman has completed her treatment and is well enough to attempt a pregnancy. Where preservation was not possible, treatment with donor eggs can be discussed. A small proportion of young women may resume fertility and conceive naturally.

MEET THE EXPERT - MEN'S HEALTH



Dr Isabel White is a clinical research fellow in psychosexual practice at the Royal Marsden Hospital, London. Here she talks about how she helps men who have had a stem cell transplant to

overcome their sexual concerns in her clinic.

Why do men come to see you?

Their most common sexual difficulties are persistent loss of sexual desire and erectile difficulties or dysfunction. This is commonly caused by a mixture of physical and emotional reasons such as persistent fatigue, weight gain, body image difficulties, low self-esteem, loss of sexual confidence, general anxiety and fear of disease recurrence or low testosterone (hormone) levels.

In general, the men who visit my clinic have been recovering from their stem cell transplant for at least 12 months. This is because when people feel their life is threatened, or they are coping with significant treatment side effects, any sexual concerns may not be a priority for them at that time. However, as they recover people are more likely to try to resume their sexual

relations and may need help to talk about any persistent or distressing difficulties they are experiencing.

What happens before I visit your clinic?

You will probably be referred to my clinic by a member of your treatment team or GP, but I accept self-referrals too. Usually your treatment team will have requested that the level of testosterone (and possibly other hormones too) is measured from a sample of your blood. This is to check that your endocrine system is working properly to stimulate the testes that produce testosterone.

You will be asked to bring a summary of your current medications, so we can check to see if any of the drugs you are taking might affect your sexual wellbeing, such as antidepressants or high blood pressure medication. It is also helpful for us to know your past medical history and if you have had any help for sexual difficulties before your transplant.

Can I bring someone with me?

It is always helpful to meet partners because sexual difficulties usually affect more than one person in the relationship. However, if you are single and would like to bring someone along for moral support that is fine

too. The consultation will include questions of a personal or sensitive nature, so make sure you are comfortable discussing this type of information with them in the room.

What will happen?

I try to put men at ease first by reassuring them that what they discuss will be treated confidentially. Specific details about the sexual concern or difficulty will only be shared (with your permission) on a 'need to know' basis with your GP or treatment team. I usually ask patients to start talking about things they feel more comfortable with. People normally find it helpful to talk briefly about when they were first diagnosed, how their treatment has affected them and their partner and what is important to them during their recovery. I think it's important that men know that sexual difficulties are common in the general population, even among younger adults. I help them to understand the factors causing their sexual concerns and together aim to find the best way to manage them.

As a psychosexual therapist I do not perform a physical examination at any point. I take a detailed past medical, sexual health and relationship history only. Some other erectile dysfunction clinics or your GP may ask to perform an examination of your penis and testes if it is appropriate.

What happens next?

I usually arrange to see men for at least three to four sessions, depending on the underlying reasons for their sexual difficulties, the treatments proposed (medication alone and/or brief psychosexual counselling) and their response to treatments. Some men may need up to 10 sessions to support them while they overcome their sexual difficulties and adapt to changes associated with their transplant or treatment.

Are the needs of single men different to those in a relationship?

Loss of sexual desire and erectile dysfunction can contribute to men losing their confidence and make them feel less masculine because they cannot fulfil aspects of their role in life or in their relationship. Single men are sometimes reluctant to start a new relationship because of the 'fear of failure' when it comes to being sexual with a new partner. This can lead to social isolation for some men. Men in a relationship tend to fear how the lack of a sex life will affect the stability of their relationship, which can then cause friction in the couple.

What would be your one 'take home' message about sex and relationships during and after a stem cell transplant?

It is understandable that people with sexual concerns are not used to talking about something that is usually a very private aspect of their lives. However, always remember that your sexual recovery after your transplant is just as legitimate an aspect of your recovery as any other.



A FEW OTHER THINGS TO THINK ABOUT



Your stem cell transplant treatment could have raised other concerns relating to aspects of your sexual health that need to be addressed. If you are concerned by any of the issues raised here, please talk to a member of your transplant team or contact the Patient Services team at Anthony Nolan on **0303 303 0303** or via email: **patientinfo@anthonymolan.org**.

HPV VACCINATION

At the age of 12 to 13, schoolgirls in the UK are vaccinated against human papilloma virus (HPV) to prevent the development of cervical cancer in later life. As you may be aware, the conditioning treatment you had before your transplant causes you to lose the immunity you had from your old vaccinations. This means that you will need to have the HPV vaccine again, along with any others you had previously. It normally happens 6-12 months after your transplant and will be organised by your medical team.

BREAST CANCER SCREENING

If you received total body irradiation (TBI) before your stem cell transplant, there is an increased risk of developing breast cancer in later life. This means that you will need a check-up more regularly than other women of the same age. It's recommended that you are screened annually over the age of 25 or if

it's been eight years since your TBI. Although your risk is increased, it does not mean that you will develop cancer. If you are screened yearly it will be found earlier, giving you the best chance of treating it successfully.

EARLY MENOPAUSE

The chemotherapy and radiotherapy associated with your transplant is likely to damage your ovaries. This means your body is very likely to go through the menopause earlier than expected. You can be referred to a gynaecologist for advice and treatment to relieve your symptoms. The Daisy Network charity also provides support for women who are experiencing premature menopause (see 'other useful contacts' on p62).

YOUR FERTILITY

It is not 100% certain but it is highly likely that the chemotherapy associated with a stem cell transplant means that you will not be able to have children. This can cause distress and feelings of loss of femininity or masculinity for some patients, depending on their age and personal circumstances. For more information about your fertility, you can read our guide *The Seven Steps, The Next Steps* or talk to a professional counsellor about your concerns.

CONTRACEPTIVE PILL

Some women still experience regular periods after their transplant, so using a method of contraception may need to be considered. Your medications and other complications could interfere with the effectiveness of the pill. Your transplant team or GP will be able to discuss the different options available to you.

UNPROTECTED SEX

If you are in a sexual relationship it is important that you practice safe sex and always use a condom, even if you or your partner is taking the contraceptive pill. This is because of the risk of picking up an infection. This also applies to oral sex. If you are entering into a new relationship, it's advisable to always use a condom to reduce the risk of getting a sexually transmitted disease.

THRUSH AND CYSTITIS

Both women and men who have had a stem cell transplant can be more susceptible to thrush and cystitis (infection of the urinary tract). It's important to wash and go to the toilet after sex to try to prevent these infections. Treatments are also available from your local pharmacist. For cystitis, drinking plenty of water can help flush the infection from your system and cranberry juice will ease your symptoms too.

YOUR FEELINGS



The last few months have probably been a whirlwind of emotions for you. You will have a lot of things on your mind, so it's understandable if feelings surrounding your sex life have been pushed to one side. You may have had to come to terms with many different changes to both your physical appearance and how people react to you.

Your stem cell transplant has probably resulted in your body image changing; you will have had to cope with losing your hair, how your central venous catheter (CVC) looks and any changes to your weight. Many people worry about how this may affect their sex life or that people will not find them as attractive as they once did. This can in turn affect their self confidence and desire to be sexually active. You can read patient stories about body image change on the Anthony Nolan blog: **blog.anthonynolan.org**

'Changes in how someone's body looks can have a knock-on effect on their confidence - for men and women. A positive body image is key to self-esteem, confidence, and maintaining relationships.'
Hayley, Anthony Nolan Lead Nurse.

It can take time for you to get used to some of these changes but many patients talk about their sexual desire returning as their recovery progresses. During this time it's a good idea to take stock of everything that you have been through recently and how you feel about yourself. If you are not comfortable with the thought of having sex, there is no need to rush things. You should focus on your own feelings and not on the needs of somebody else. Only attempt to have sex when you feel ready.

'In my experience, one of the things that helps patients and loved ones is accepting that the illness and the transplant have changed the person who's had it. These can be both positive and negative changes, but there is a difference.'

Philip Alexander, counsellor and cognitive behavioural psychotherapist

'I started to put myself out there more. I started to feel more confident about my body and a bit more confident about who I am. I felt like I'd beaten the MDS and it was behind me.'

Emma, recipient of two stem cell transplants

You may find that you are struggling with your emotional wellbeing and that you would prefer to discuss this in more detail with a professional. You can talk to your transplant team about being referred to a counsellor or therapist, either with or without your partner if you prefer.

YOUR PARTNER

This section is for anyone whose partner has had a stem cell transplant. It focuses on your feelings and the support available to you.

HOW ARE YOU FEELING?

Helping your partner recover from their transplant has probably become the most important thing in your life because of how much you care for them. Although you are probably happy to do it, it can still be difficult and demanding, especially if you also have to juggle it with earning a living and your family.

Just as your partner has had to get used to being less independent, it can take time for you to adjust to your new supportive role. It's understandable that you might find it hard to cope with this responsibility, while also worrying whether they are getting better.

Many partners feel guilty about admitting to their stress because they feel they have to always be strong for the person who has been unwell. However, it's perfectly OK to

talk to them about feeling this way and it will benefit your relationship in the long term.

'I felt overwhelmed by everything that was happening. No-one could say, "It's definitely going to be OK," and there was nothing I could do to change that.'

Una, whose husband, Val, had a stem cell transplant in 2007

'Often the partner takes on the role of being the strong one. They are managing everything and reassuring the patient and the family, being everything to everybody and protecting their partner. But they don't always feel they can be honest and say - "I thought I was going to lose you."

Krystal Woodbridge, psychosexual and relationship therapist

ENJOY A BIT OF 'ME' TIME

It's really important that you find the time and space to enjoy things independently from your partner. This might be simply phoning a friend for a chat or re-starting a forgotten hobby. Nobody will judge you for taking some time for yourself; it will reinvigorate you and give you fresh energy to tackle the challenges ahead. You need to look after yourself as well as your loved one.

If this has been lacking in your life recently, talk to your partner about how you are feeling - because they love you, and will understand.

'The trouble was that I was never one to say, "I need this time for myself," maybe to meet up with friends one night in the week. I just couldn't do it. I just wanted to be next to George. This is not something I recommend - because meeting up with people outside of this situation every couple of weeks is a good thing to do, to keep you connected to the world.'

Mariacristina, whose husband, George, had a stem cell transplant in 2014

YOU NEED SUPPORT TOO

If you would prefer to talk to somebody else about how you are feeling, there are options available. Your partner's transplant team will be able to put you in contact with a counsellor or therapist. Alternatively you may benefit from sharing your story with people going through a similar experience. Your hospital and various charities organise local support groups you can get involved with. You can also get advice from our online community, the Anthony Nolan Patients and Families Forum:

[anthonynolan.org/forum](https://www.anthonynolan.org/forum)

RELATIONSHIPS: NEW AND OLD



STARTING A NEW RELATIONSHIP? BODY CONFIDENCE

Your stem cell transplant and ongoing medication may have changed your appearance or your feelings about it. This could be causing you some concern and you might be anxious about how a new partner reacts to it. Many people find that these feelings are temporary and they regain their confidence as they recover. However it still might help to talk about your concerns with a friend or family member in preparation for starting a new relationship.

'Be patient and your confidence will come back and your sex life will improve - but seek help as soon as you feel you need it!'
Simon, who had a bone marrow transplant in 2014

DATING

Going on a date with someone you hardly know can be stressful at the best of times, but if you want to get back into the dating game after your transplant you can at least control how you go about it:

- Meet new people through social activities such as a new hobby or volunteering for a charity. You will find this is a more relaxed situation in which to get to know somebody. You can then progress

any potential new relationship at your own pace.

- Look to your friends for inspiration – hopefully they will be able to set you up with someone who you can get along with easily. They might be able to talk to your date about your situation so that you don't have to worry about bringing up the subject yourself, if that's what you want.
- Get involved with people who are experiencing a similar situation. You will find that they have a better understanding of what you are going through which can enable you to open up more easily. Your hospital/transplant centre and charities such as Macmillan organise a number of different support groups that you can join.

'If it's someone you know, it's a bit different – if it's a friend of a friend, someone who knows some of your backstory, it's not too much of an issue. But if it's a new person, at what point do you tell them about this baggage you've got?'

Emma, recipient of two stem cell transplants

WHEN AND WHAT TO TELL PEOPLE

As your new relationship develops there might not be an obvious time to tell your partner about what you're going through. It's probably better to say something before things get too serious, especially if concerns such as fertility need to be talked about. Unfortunately there's no right or wrong time to start the conversation but if you feel comfortable and you trust them to act in a supportive way, it's probably OK. Remember that a loving partner will accept you for who you are. If they can't do that, they are probably not the right person for you.

'I don't want to talk about myself like the treatment is my life. I want to talk about my job and my gym stuff, because that's who I am, and what I'd be doing if I could.'

Emma, recipient of two stem cell transplants

Don't forget that if you would like to talk to a professional about any issues, there are lots of options available. For more information read 'Getting some extra help' on p52.

IF YOU ARE IN A RELATIONSHIP

The worry surrounding your stem cell transplant could make your relationship more complicated. For some couples, a situation like this brings them closer together but

for one reason or another your relationship might become strained or even break down. Many people find it difficult to talk about sexual issues, often finding it embarrassing. However it's the most natural thing in the world and if you bottle up your feelings it could make things worse in the long run. It will be important for you to talk to each other about how you are feeling so there are no misunderstandings. If your partner appears distant, help them open up about their feelings; they could be hiding their concerns because they don't want to burden you with extra worries.

'My girlfriend decided not to see me for a couple of weeks as she didn't recognise me and needed some time to adjust. That had quite a big impact.'

Rob, who had a stem cell transplant in 2014

THE ESSENTIALS

- As the old saying goes 'laughter is the best medicine' – humour can often be used to express how you are feeling in a more manageable way.
- Decide on set times to talk about certain issues. This will allow you to keep control of your feelings.
- If you need to talk to your partner about a sensitive issue, try to bring it up when

you are both engaged in an activity such as cooking. It will give you both something else to focus on if things get tough.

- To reduce the chance of arguments, try to stay calm, understand the other person's point of view and suggest some compromises.

'Try to talk about how you feel, rather than making any assumptions about how your partner might be feeling. Sit down with them and say, "I'm feeling this about my body, I wonder how this is affecting you?" You could start by talking more generally – about how you're feeling about treatment and your relationships – before diving straight into talking about your sex life.'

Krystal Woodbridge, psychosexual and relationship therapist

ALTERNATIVES TO SEX

If you feel uncomfortable about having sex for whatever reason, there are still plenty of ways for you and your partner to feel close. Find time to enjoy each other's company, talk about things that make you both happy and try to forget about your situation for a while. Holding hands, cuddling, kissing and massaging each other are all types of physical contact that can help you feel close.

Some people find it helps if they ‘reset’ their relationship following their transplant by going back to dating their partner. This removes the immediate pressure of having sex and allows intimacy to grow at a pace that is more comfortable. It’s still possible to feel close to your partner without the physical act of having sex.

‘Life is good. Life is a little bit different. We make the most of every little thing – things that we used to take for granted, we don’t anymore.’

Mariacristina, whose husband, George, had a stem cell transplant in 2014

GETTING SOME EXTRA HELP

You may feel that you (and your partner) would benefit from working through some of your concerns with the help of a counsellor. They will help you to explore the cause of your problems and suggest ways of resolving them. Everything you say is strictly confidential and will not be discussed with anyone else.

If you would like to try a talking therapy, your transplant team or GP should be able to refer you. It’s also possible to access free

treatment through the Improving Access to Psychological Therapies (IAPT) programme. This NHS service allows people with stress and anxiety problems to refer themselves directly to services in their local area. Details of the IAPT programme are available in ‘Other useful contacts’ on p62.

If you have never used this kind of therapy before it can seem a little strange at first, so we have invited a fully qualified psychosexual therapist to talk about her work in the ‘Meet the expert’ section on p54.

‘There were good days and bad days, and we got through it one day at a time. We’re now out the other side and we are stronger than ever before.’

Helen, whose partner, Nilush, had a cord blood transplant in 2013



MEET THE EXPERT: PSYCHOSEXUAL THERAPY



Krystal Woodbridge is a qualified psychosexual and relationship therapist and trustee of the College of Sexual and Relationship Therapists (COSRT), offering support to individuals and couples.

She is a former winner of the COSRT national post-graduate award for her work in the field of psychosexual therapy. Here she talks about the potential impact of a stem cell or bone marrow transplant on sex and relationships, and how therapy can help.

What is psychosexual therapy?

Psychosexual therapy is a talking therapy that helps individuals and couples to better understand themselves sexually. We talk in detail about the issues patients are experiencing and the factors that are causing them, so that they can work through their problems. We can deal with anything to do with sex and relationships – from erection problems, to low sexual desire or avoidance of sex or general relationship issues.

Talking about such sensitive and intimate issues with a stranger can feel very difficult at first, and as psychosexual therapists we completely understand this. Everything discussed in our sessions is confidential,

and hopefully once you meet with your therapist you will feel safe and comfortable enough to discuss your concerns. Just know that you can be completely open, and you won't shock us – we've heard it all before!

What will happen?

An initial assessment session will be set up where your therapist will explain the therapy process in detail with you. There is no physical or medical examination involved and the therapist will ask you questions about your current problems, how long they have been troubling you, your medical history and medications as well as any other relevant issues in your life. Your therapist will then be able to help you decide how you would like to move forward and what it is that you would like to achieve from therapy, setting goals as necessary. Some people are very clear about what they want to achieve from the process, while some just want to talk to someone who will understand and listen.

If you decide that you are happy to work with your therapist for regular sessions, you will normally decide to meet at the same day and time every week. You will decide with them how many sessions you will need and if you and your partner will attend all sessions. This can be reviewed on an ongoing basis.

What will we talk about?

Your stem cell transplant can have a huge impact on your body, and people can feel different about themselves before and after treatment. Men and women may have changed sensitivity in their genitals: what was arousing before treatment may have changed; there may be a sense of loss around this. I find that people can feel less connected to themselves sexually, as well – they might have just been focused on surviving and getting through their treatment.

Psychosexual therapy can help people understand and come to terms with themselves physically – re-learning how to connect with their body and sexuality. We can help you explore what is different, and how you can accept the changes.

An important element of psychosexual training is thinking about the medical and physical aspects of sexuality – there's no point doing weeks of emotional work in therapy without also addressing physical difficulties! So if you're dealing with side effects like pain or hormone changes we can also liaise with GPs and help get treatment prescribed. The therapist may also give you specific exercises to do outside of the sessions.

Can psychosexual therapy help single people too?

I normally have an equal split in my caseload between single people and those in relationships. I find that single people are often worried about the 'disclosure' aspect of their situation – at what point do you tell someone you've had cancer or a transplant? I think it is very personal and individual, and something you must judge for yourself. There also seems to be more of an expectation in our dating culture nowadays that you should have sex early on – perhaps before you're ready. A good rule of thumb is if you don't feel comfortable enough to be open and authentic with the person, then you might need to question whether you are ready to have sex with them.

What would be your one 'take home' message about sex and relationships during and after a stem cell transplant?

Don't bottle things up! Don't leave things until you're really struggling. Find a therapist you trust that you can be open with. Right from diagnosis, it's important to know that cancer and treatment can affect relationships.

For more help and support, you can visit the College of Sex and Relationships website cosrt.org.uk or Relate relate.org.uk



ANTHONY NOLAN CONTACT DETAILS

WHERE CAN I GET MORE INFORMATION AND SUPPORT?

If you or a loved one is affected by a stem cell or bone marrow transplant, there are many ways we can support you:

NEED TO TALK?

The Patient Services team at Anthony Nolan is here for you. Call us on **0303 303 0303** or email: **patientinfo@anthonymolan.org**

GET CONNECTED

Find support from other patients and their families by joining our patient and families forum at: **anthonymolan.org/forum**

FIND INFORMATION

Our website has lots of helpful information about what it's like to go through a transplant. Download or order our booklets for free, and find links to other places where you can get support at:

anthonymolan.org/patientinfo

OTHER USEFUL CONTACTS

British Association for Counselling and Psychotherapy

itsgoodtotalk.org.uk

01455 88 33 00

Information about counselling and therapists in your area.

College of Sexual and Relationship Therapists (COSRT)

cosrt.org.uk

020 8543 2707

Provides information and support on sexual problems.

The Daisy Network

daisynetwork.org.uk

A large support group for women suffering with Premature Ovarian Insufficiency (POI), also known as the early menopause.

Improving Access to Psychological Therapies (IAPT)

england.nhs.uk/mental-health/adults/iapt/

Allows patients to self refer to NHS-funded counselling and therapy services available in their local area.

Macmillan Cancer Support

macmillan.org.uk

0808 808 00 00

Practical, financial and emotional support for people with cancer, their family and friends.

Mind

mind.org.uk

020 8519 2122

Mental health charity which offers information, advice and support to anyone experiencing a mental health problem.

NHS Choices

nhs.uk

Information about treatments, conditions and lifestyle. Support for carers and a directory of health services in England.

The Institute of Psychosexual Medicine

ipm.org.uk

020 7580 0631

Lists all UK doctors that are trained in psychosexual medicine.

LLGS

switchboard.lgbt

0300 330 0630

Free and confidential support and information for lesbian, gay, bisexual and transgender people in the UK.

Look Good Feel Better

lookgoodfeelbetter.co.uk

01372 747 500

Providing practical and effective free services for patients struggling with the visible side effects of cancer treatment.

Relate

relate.org.uk

0300 100 1234

Information, advice, relationship counselling and sex therapy.

The Samaritans

samaritans.org

helpline: 0845 790 9090

Confidential, non-judgemental emotional support 24 hours a day, by telephone, email, letter or face-to-face.

Self Management UK

selfmanagementuk.org

0800 988 5560

Free self-management courses to help you take control and manage your condition.

Teenage Cancer Trust

teenagecancertrust.org

020 7612 0370

Support to improve the lives of teenagers and young adults with cancer.

Terrence Higgins Trust

tth.org.uk

helpline: 0808 802 1221

Information, support and advice on all aspects of sexual health and HIV.

'I wish that I had asked for support at the time. It wouldn't have made Cheryl better but it would have made things easier for both of us.'

***Richard**, whose wife, Cheryl, had a stem cell transplant in 2007*

'I AM BEGINNING TO
RECOGNISE THE BODY
IMAGE AND SEXUAL DESIRE
CHALLENGES UNDERPINNED
BY HOW I FEEL ABOUT MY
BODY. THIS BOOKLET HELPED
ME TO RECOGNISE WHAT I'VE
NOT BEEN ABLE TO SEE.'

*Tom, who had a stem cell
transplant in 2015*



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saving the lives
of people with
blood cancer