
Sex and Leukaemia

**A Guide for
Patients**

Leukaemia Care
YOUR Blood Cancer Charity

Introduction

As long as you are fit and well to do so, you can still have sex. You cannot catch leukaemia through sex.

There may be times when you don't want sex. You may feel differently about sex after treatment. For some people, achieving a fulfilling sex life after you've had treatment (or if you are living with leukaemia) means finding new ways of giving and receiving pleasure.

The aim of this booklet is to be honest and open with patients and your loved ones. We have tried to answer many of the common questions online. The following material is very sexually explicit. It is extremely frank and uses a fair amount of direct phrasing and descriptions of specific sexual acts and practices.

This booklet has been written by

Nurse Fiona Heath, Nicole Scully and Fergus Metcalf. We're very grateful for the valuable patient reviews by Julie Quigley and Nick York.

If you would like any information on the sources used for this booklet, please email communications@leukaemiacare.org.uk for a list of references.

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About Leukaemia Care

Leukaemia Care is a national charity dedicated to ensuring that people affected by blood cancer have access to the right information, advice and support.

Our services

Helpline

Our helpline is available Monday - Friday 9am until 5pm. If you need somebody to talk to, ring 08088 010 444.

Nurse service

We have two trained nurses on hand to answer your questions and offer advice and support, whether it be through emailing nurse@leukaemicare.org.uk, over the phone on **08088 010 444** or via LiveChat.

Patient Information Booklets

We have a number of patient information booklets like this available to anyone who has been affected by a blood cancer. A full list of titles – both disease specific and general information titles – can be

found on our website at www.leukaemicare.org.uk/support-and-information/help-and-resources/information-booklets/

Support Groups

Our nationwide support groups are a chance to meet and talk to other people who are going through a similar experience. For more information about a support group local to your area, go to www.leukaemicare.org.uk/support-and-information/support-for-you/find-a-support-group/

Buddy Support

We offer one-to-one phone support with volunteers who have had blood cancer themselves or been affected by it in some way. You can speak to someone who knows what you are going through. For more information on how to get a buddy call

08088 010 444 or email
support@leukaemicare.org.uk

Online Forum

Our online forum, **www.healthunlocked.com/leukaemia-care**, is a place for people to ask questions anonymously or to join in the discussion with other people in a similar situation.

Patient and carer conferences

Our nationwide conferences provide an opportunity to ask questions and listen to patient speakers and medical professionals who can provide valuable information and support.

Website

You can access up-to-date information on our website, **www.leukaemicare.org.uk**, as well as speak to one of our advisers on our online support

service, LiveChat (9am-5pm weekdays).

Campaigning and Advocacy

Leukaemia Care is involved in campaigning for patient well-being, NHS funding and drug and treatment availability. If you would like an update on any of the work we are currently doing or want to know how to get involved, email **advocacy@leukaemicare.org.uk**

Patient magazine

Our quarterly magazine includes inspirational patient and carer stories as well as informative articles by medical professionals: **www.leukaemicare.org.uk/communication-preferences/**

Introduction to sex and leukaemia

Issues with sexuality are one of the most important quality of life concerns for people undergoing treatment for blood cancer. Sexuality is complex, as it includes intimacy, body image, sexual desire and the ability to have sex, and is linked to our need for caring, intimacy, closeness and touch.

Sexuality is a very personal matter and means different things to different people. Physical changes caused by chemotherapy such as weight loss or gain, changes in skin colouring, hair loss, hormonal changes, energy levels, fatigue and the functioning of sexual organs all influence feelings about sexuality and sexual appeal.



Treatment and sex

Can I have sex whilst being treated with chemotherapy?

You may still be able to have sex during chemotherapy if you are feeling up to it. If you are being treated with chemotherapy, your medical team will advise you to avoid unprotected sex. Using protection is not only advised for the avoidance of pregnancy, but to avoid any traces of chemotherapy being transferred in bodily fluids.

Typically, chemotherapy is excreted in the bodily fluids for 48-72 hours. Some chemotherapy drugs can be found in bodily fluids for up to seven days after treatment. Some doctors may recommend using barrier protection for 72 hours post chemotherapy treatment, while some may advise it for longer. Chemotherapy can be transmitted through bodily fluids and is known to irritate the skin.

Types of barrier protection

Many guides will talk about using barrier methods or protection or barrier contraception. Barrier methods of contraception can also prevent the transfer of infections

The main types are:

The male condom

Worn on the penis, the condom can be worn for penetrative sex (anal, vaginal) or for receiving oral sex.

The female condom, or femidom

The femidom is an internal device much like the male condom equivalent. It is inserted before sex and can be put in place up to six hours before sex happens. Female condoms are not a reliable method of contraception if you are preventing pregnancy.

Do not use female and male condoms together. Using both types of condom together can cause friction, which leads to

splitting of the latex. Using both methods can also make one slip out of place.

Dental dam

A dental dam is a thin piece of latex or silicone. Typically, they are rectangular in shape. They can be used during various forms of oral sex including:

- Used to cover female genitalia during oral sex
- Used to cover the anus for a partner receiving anilingus/ analingus. This is a sex act where one partner stimulates the other's anus using their tongue.

How to make a dental dam

You can make your own dental dam using a condom. Cut off each end of the condom and cut down the side of the tube that remains. This piece of material can then be used as a dental dam. For this purpose, you may want to avoid condoms that have lubrication or even flavoured lubricants because they may taste unpleasant.

Effective birth control methods

Some forms of treatment may affect a developing baby should you become pregnant. Therefore, it may be recommended that you seek birth control. These methods may include:

- combined pill
- contraceptive implant
- contraceptive injection
- contraceptive patch
- intrauterine device (IUD)
- Mirena (intrauterine system or IUS)
- progestogen-only pill (mini-pill)

Birth control is something you can talk about with your medical team to discuss what is right for you. However, birth control is free on the NHS should you seek to use it.

Treatment and sex (cont.)

Hand jobs and chemotherapy

A hand job is a sexual act involving a partner stimulating the male's penis with their hand.

If the male patient has been receiving chemotherapy, you may have concerns about whether you need to use condoms for hand jobs.

If you are within 2-3 days of receiving chemotherapy, there may still be some of the drugs present in the ejaculate. These drugs may cause irritation to the skin, so you may want to be cautious and use a condom during those times.

Oral sex and chemotherapy

Many doctors will advise that patients use barrier methods of contraception following treatment with chemotherapy drugs. Some may recommend avoiding unprotected sexual acts for 72 hours post treatment, some may recommend longer.

This would also include oral sex. Therefore, men receiving oral sex would need to use a condom and women receiving oral sex would be advised to use a barrier method such as a dental dam.

Chemotherapy and infections

A common cause of infections for patients receiving chemotherapy is due to yeast or fungus. You are more likely to be susceptible to an infection of this type if you have low white blood cell counts (neutropenia).

Herpes simplex virus (HSV)

If you have ever had herpes simplex virus in the past, you may experience a flare up due to a weakened immune system caused by chemotherapy treatment.

It is a virus that can be passed onto a partner and is diagnosed with a blood test which can see if you have ever been exposed to the virus. Alternatively, they can also take a swab from the areas to look

at under a microscope.

If you are undergoing active treatment and have a flare up of herpes, speak to your healthcare team who will be able to give you treatment to make the lesions heal.

Yeast infections

A yeast infection can make you feel very uncomfortable. Yeast infections are very common. There are many types of candida (yeast) that live in various areas across your body. They do not pose a problem as the growth is managed by bacteria. However, when something happens to kill off bacteria (in this case chemotherapy), it can multiply and cause mild to serious infections in the body. One place where these yeast infections can manifest is in the genitals.

In the vagina, symptoms may include:

- Itching and burning of the vagina. The area may appear red and inflamed.
- You may have abnormal discharge. Some people describe it as looking a little like cottage cheese (white and thick). Some women may not have this discharge.
- A yeast infection can cause pain or discomfort during sex.

Men can also get yeast infections. Symptoms may include:

- A red rash on the penis.
- Sometimes, you may see patches of white, shiny skin on the penis.
- The skin of the penis may be moist.
- A thick white substance may be found under the foreskin or other folds of skin.
- Itching or burning feeling of the penis.

Treatment and sex (cont.)

Managing a yeast infection:

- Ensure your genitals are dried properly after a bath or shower.
- Avoid wearing tight clothes or underwear.
- Wear underwear that has a high percentage of cotton.
- Avoid scented lotions or potions in this area.
- Don't use Vaseline as a lubricant as it can increase the chances of a yeast infection.
- If you or your partner has a yeast infection, use a condom during sexual activity.

Sexually transmitted infections (STI's) and treatment

With a lowered immune system, you may be more susceptible to catching an infection or being exposed to a sexually transmitted disease. The usual advice would apply: use protection and ask any new partners whether they have been tested for an STI.

If you are a little older and have met a new partner, do not be shy about asking the question. In 2016, the topic made the national news as England's Chief Medical Officer revealed that STI diagnoses in people aged 50 to 70 had risen by a third over the last decade. Some people may think that contraception is there just to prevent pregnancy. However, contraception and sexual health checks will keep the spread of diseases such as chlamydia and gonorrhoea at bay.

Other types of infection

Urinary tract infections can be avoided by urinating soon after sex has finished, as this can wash away much of the bacteria. To make it easier to have a wee after sex, you may want to consider drinking a glass of water beforehand.

With low white cell counts, you are susceptible to infection. Before any sexual contact, ensure that you and your partner's hands and genitals are clean before engaging in any types of sex and are thoroughly washed after.

Treatment and sex (cont.)

Love bites

A love bite is essentially a bruise caused by sucking on a partner in a sexual way. Blood cancer patients are susceptible to bruising because of low platelet counts. Therefore, it would be generally recommended for patients affected by a leukaemia to not allow this to happen to themselves.

BDSM

BDSM is an abbreviation for Bondage, Discipline (or domination), Sadism, and Masochism. It is a sexual practice that some people choose to engage in. A masochist is somebody that enjoys physical or mental pain during sex.

Some people may not realise they are partaking in BDSM; however, many people would consider the following activities to be BDSM: domination, submission, pain play, dressing up and role playing.

BDSM and radiotherapy

If you enjoy taking part in BDSM, and are being treated with radiotherapy, you should be aware

of the changes that radiotherapy can do to your skin. These can include:

- A skin reaction which may be sore like a sunburn
- A darkening of the skin

While being treated with radiotherapy, you should be gentle with any sore areas of skin. You may want to avoid perfumed products on the area. In terms of sexual practice, you may want to avoid scented lubricants which could further irritate these delicate areas. Although you may enjoy receiving pain, due to your reduced platelet levels and heightened risk of infection, you should try to avoid this during active treatment.

You may enjoy dressing up or sexual role play as part of your BDSM play. However, during radiotherapy treatment you may want to avoid this altogether to prevent further irritation to delicate skin.



Sex and chronic leukaemias

CML

Patients with a chronic leukaemia, such as chronic myeloid leukaemia, may be treated with a tyrosine kinase inhibitor, also known as a TKI.

While many people may refer to a TKI as a form of chemotherapy, a TKI is a targeted therapy which will be taken for many years.

You may find mixed information online as to whether you should use a condom if you or your partner is being treated with a TKI and this information can be very confusing.

Many of the key CML experts both in the UK and worldwide say that a condom isn't necessary as the levels of treatment in secretions such as semen or vaginal fluids would be very low and would not interfere with a partner.

Although this booklet is not necessarily about fertility, it is important to raise the issue of contraception with female CML patients of a child bearing age.

Studies show no suggestion of any problems in pregnancy,

delivery or any increase in congenital abnormalities when the father is being treated for CML. For male patients, fathering children could be achieved without interruption of treatment.

For a female patient being treated with TKIs, this is not the case. TKI's are teratogenic drugs which means they can disturb the development of the embryo or foetus. Therefore, pregnancy in women with CML is closely monitored by a consultant. Women with CML who aren't actively trying for a baby should use a form of contraception to prevent pregnancy. Having CML does not mean you shouldn't get pregnant, however, it should be discussed with your consultant.

There are a number of resources online that discuss pregnancy and CML. Leukaemia Care have a video on their YouTube channel from a world-renowned expert on the subject, Professor Jane Apperley. The charity has been allowed to share the footage by the CML advocates network and can be found on their YouTube channel at <http://www.youtube.com/c/leukaemiacare>

CLL

85% of patients with chronic lymphocytic leukaemia (CLL) have issues making antibodies. This difficulty in producing antibodies can lead to a rise in infections.

To combat any infection risk, increase hygiene strategies that you may already have in place such as handwashing or using barrier contraception if you are susceptible to thrush. You may find some of the information from pages 11-13 which cover different types of infection useful.

Fatigue can also impact on your sex life. Fatigue can impact on your libido (as detailed on page 21) or your ability to have sex in certain positions. We have suggested some sex positions or sexual acts which may be appropriate for when you feel fatigued from pages 32 to 44.

The CLLSA (Chronic Lymphocytic Leukaemia Support Association) run an online forum which is frequented by over 13,000 CLL patients. Sex is a topic which is discussed fairly regularly.

Their forum has the ability to sign up anonymously if you wish to discuss the topic of sex and CLL and to share patient experience on the topic.

The CLLSA healthunlocked forum can be found at:

**[healthunlocked.com/
CLLSupport](https://healthunlocked.com/CLLSupport)**

Orgasms

Some chemotherapy treatments may cause toxicity to the pelvic blood supply or nerves. In men, this could change the feeling of your orgasms and they may not feel the same as they did before treatment.

According to research conducted on the general public in 2017, up to 80% of women cannot orgasm through penetrative sex alone. One in seven women experienced pain when climaxing and 3% of those surveyed had never had an orgasm.

The causes of sexual dysfunction in women that have undergone cancer treatment are both physical and psychological.

For any patient, you may find that:

- You may have difficulties in reaching orgasm.
- You have decreased pleasure at orgasm.
- You have no changes at all.

As well as being cancer related side effects, these issues can also be attributed to ageing.

Decreased sexual sensation

If you feel that your sexual sensation has diminished, you could use a vibrator to help increase the sensation in these areas. This works by stimulating nerve endings.

It may be that you need a stronger vibration if your sensation has decreased. Instead of using a vibrator, you may wish to try a body massager instead which has stronger vibrations. A body massager can be used on all areas of the body and could be used to ease any aches you have across your body.

Vibrating toys can be used by men too where achieving an erection is difficult. Vibrating toys can be placed around the head of the penis and they will produce sexual stimulation.

Difficulties in reaching climax

You may find that you are not able to achieve orgasm in the way you were used to.

As we age, it can be harder to achieve orgasm or it may take longer. This is also true for patients that have been treated for a cancer.

You may need to spend more time in foreplay or try touching new areas on your body to see what you respond to.

In some cases, it may be beneficial to talk to a psychosexual counsellor to look at strategies for achieving or improving orgasms.

Loss of libido

Before you were told you had leukaemia, you had a libido. Some people have a high libido, some have a lower libido. Only you will know what your libido was like before treatment.

A key question following diagnosis will be, "Do you have desire, to have desire?". If the answer is yes, the likelihood is that you do have libido, it is just that your body is not doing what it used to do.

Hormones and libido

Some cancers or treatments alter the hormones that the body produces. Some cancer cells cause hormones that will create symptoms.

Some treatments can stop the body making certain types of hormone altogether. In terms of sex and cancer, the main hormones that may be affected are oestrogen, progesterone and testosterone.

These alterations in hormone levels can lead to a loss of libido. Doctors may want to measure your hormone levels to see if your

levels have dropped and then treat this.

Mental health and libido

The Leukaemia Care patient survey revealed that some leukaemia patients felt constantly depressed or anxious since their diagnosis. Depression and anxiety are both common responses to being diagnosed with a leukaemia as well as the treatment you have faced. For some CLL patients, living on "watch and wait" can cause depression or anxiety too.

Signs of depression can include:

- Signs of extreme sadness that don't go away.
- Feeling low or hopeless.
- Losing interest or pleasure in doing things you used to enjoy.

You should speak to your GP if you think you may be depressed. They may be able to prescribe you antidepressants or refer you for counselling. This may help to alleviate symptoms of depression

and help to resolve your libido issues.

However, if you are taking antidepressants, a lowered libido can be a side effect of this treatment. Most prescribed antidepressants are SSRI's, this stands for selective serotonin reuptake inhibitors. The drugs work by raising levels of serotonin in the body. Serotonin plays an important role in regulating your mood and low levels of serotonin have been linked with depression.

Some people are more sensitive to the effects of these treatments than others. Therefore, some people taking antidepressants may have a lowered libido because of the treatment but some may not.

Pain, nausea and libido

You may feel nauseous as a result of chemotherapy treatment and the result of this is that you do not feel like you want sex. For some leukaemia patients, such as those diagnosed with chronic myeloid leukaemia, the side effect of the tyrosine kinase inhibitor

treatment may also include nausea.

Over time, you may learn when you're likely to experience nausea and you could plan your sex to avoid these times.

You may be prescribed an anti-nausea medicine to deal with nausea as a side effect; however, these could also lead to a loss of libido. If this is something you are worried about, you should talk to the medical professional that is recommending the medication to discuss your worries and to work towards a solution.

Fatigue and libido

Fatigue is one of the most common consequences of cancer and related treatments. Its cause, however, is not yet fully understood. Cancer related fatigue is thought to affect the majority of people who have had a cancer episode and may be defined as:

"A distressing, persistent, subjective sense of tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent

Loss of libido (cont.)

activity and interferes with usual functioning."

Given the subjective nature of fatigue, it may feel different from one person to the next. Most people however, will experience a degree of fatigue which feels invasive in that, it affects them both physically and cognitively. This means that it is different to the tiredness you might usually have experienced prior to becoming ill or as a consequence of doing something pleasurable.

It is common for patients to sometimes find it difficult to adequately explain how cancer related fatigue actually feels due to its invasive, fluctuating and troublesome nature.

Your cancer episode and associated fatigue can negatively impact on all aspects of your day to day life. This may include disruption to your usual and taken for granted activities such as personal care, including showering and dressing; leisure and social activities, such as keeping fit or going out with family and friends; and others

may experience disruption to work and educational attendance and performance. Relationships of an intimate nature may also be affected by the presence of cancer related fatigue and you may feel too tired to participate in sexual intercourse. Additionally, your partner may be cautious to do so and worry that they may make your fatigue symptoms worse.

The first step in self-managing your fatigue symptoms is acknowledging that you have cancer related fatigue. Secondly, being self-compassionate and not expecting yourself to perform all the activities you did before you became ill will help if fatigue is an issue.

Congratulate yourself on what you do achieve rather than what you don't, regardless of how little it seems, and do not compare yourself with others or past performance.

If you accept that your available energy is not currently what it used to be, you can then begin to think about how much energy you have in 'your battery', how you are

using this and whether you would like to use it differently. This self-management approach will hopefully help you to regain some control over your daily activities, roles and responsibilities.

If you are looking to have sex, we have included a section in this booklet which looks at sexual positions which may be of use when you are fatigued. They can be found on pages 32 onwards.

Remember the fatigue you are currently experiencing may well go away over time. In the meantime, however, self-managing your fatigue will help you feel more in control and add to your sense of wellbeing.

Ways to increase libido

Watching pornography together

Before being treated for a leukaemia, you may or may not have watched pornography by yourself or with your partner.

Some people do not feel comfortable watching pornography. Some people feel uncomfortable with the idea of their partner watching pornography. Only you know what your personal feelings are on the subject.

Communication is key on issues such as pornography. Talk to your partner about what they are comfortable with and make sure you both know what one another's feelings on porn are.

Relate, the relationship charity, commissioned a survey in 2012 that revealed that 41% of women watched pornography once a month or more, while 76% of men admitted watching it. 19% of women watched once a week, with 58% of men saying they also watched it once a week. These figures may indeed be higher,

as some respondents said they would prefer not to say whether they used porn.

A study published in the journal Sexual Medicine revealed that men that watched porn had a marked increase in sexual desire compared to those who did not. However, the men in the study were all in their 20s so the report did not offer insight on older males.

Being diagnosed with a leukaemia does not mean you have to change your opinion on pornography. However, if you are comfortable in watching pornography either on your own, or with your partner, it may help to improve your libido.

Reading erotic novels/ listening to erotica

Some people would argue that the brain is the biggest sexual organ, as desire begins in the mind.

Over the past five years, reading erotic fiction has become increasingly popular. Some would call it the "Fifty shades" effect!

In 2015, a study was conducted which looked at women with low sexual desire. Half of the women in the study were given self-help books to read, whilst the other half were given erotic fiction. The study revealed that both groups made equal gains in the following: sexual desire, sexual arousal, lubrication, satisfaction, orgasms, pain reduction and overall sexual functioning.

The term erotica is used for written words that arouse and excite the reader and could be consumed in the following formats:

- Fiction, from short stories to novels
- Nonfiction essays and retellings of true experiences
- Romance novels
- Fan fiction
- Web content and e-books

There is a stereotype that men need visual stimulus, whilst women prefer reading about sex. Most studies suggest that men are just as turned on by the

written word as women, and many women enjoy porn as much as men.

There are thousands of books available that would be classified as erotica with many subcategories from erotic romance to erotic BDSM. Many are available on popular book websites such as Amazon, Waterstones or your local independent book shop. Your local library is likely to have its own section of books that you could borrow or even e-books that you could download to your e-reader.

Ways to boost libido (cont.)

Podcasts

Podcasts are increasingly popular too. There are over half a million podcasts that exist and the number rises daily.

To find an erotic podcast, simply search erotica in the podcast device that you use such as Castbox, Spotify or iTunes. These shows are typically free so you could try a few shows to see what you like. The advantage with Podcasts is that it is private; you simply pop in your headphones and nobody would know what you are listening to!

Both books and podcasts are something that you could try as an individual or you could involve your partner. This could involve listening or reading the same piece at the same time. If you are reading, you could choose to read passages to one another.



Treatment related side effects that may affect your sex life

Written by Nurse Advisor Fiona Heath

Graft Versus Host Disease (GVHD) and Sex

Patients may develop GVHD after their transplant; this can affect women and men in different ways. High dose steroids are often used to treat GVHD and these can also suppress the production of sex hormones, which may decrease a person's sex drive.

For information specific for men and women, please see the relevant sections of this booklet.

Transplants and sex

Sexual dysfunction is one of the most frequently described issues experienced by bone marrow transplant patients. Impairment of sexual functioning, interest in sexual thoughts or feelings and satisfaction with personal sexual appeal are common issues. Approximately half of all patients experience issues with their sexual health after their transplant.

Sexuality and sexual function

Organic sexual dysfunction in bone marrow transplant patients is thought to be caused by systemic therapies, particularly the alkylating agents and total body irradiation, which are known to damage the endocrine and sex organ pathway responsible for sexual maturation and function, resulting in very low sex hormone levels and low or absent function of sex organs.

Sexuality

Changes in sexuality after a transplant are common. Issues with sexuality and sexual dysfunction are one of the most important quality of life concerns for people after a transplant. Sexuality is complex and involves more than just having sex. Sexuality includes intimacy, body image, sexual desire and the ability to have sex and it is linked to our need for caring, intimacy, closeness and touch. Physical changes caused by transplant such as weight loss or gain,

changes in skin colouring, hair loss, hormonal changes, energy levels, fatigue and the functioning of sexual organs all influence feelings about sexuality and sexual appeal.

Relationships

A transplant can also place a huge strain on the intimate relationship you have with your partner. It is sometimes hard to make the switch from being the patient or caregiver back to seeing your partner as a sexual being. The most important thing is to maintain honest, open communication with your partner about what both of you need and can achieve. You may need to get to know each other again in a sexual sense. Going on dates, massage, cuddling, showering or bathing together may be helpful with this. Activities such as touching, hugging, and kissing provide feelings of warmth and closeness even if intercourse is not involved. Professional sex therapists can recommend alternative methods. Emotions can also affect sexual functioning,

including stress, marriage problems, or depression.

If you are having sexual problems, talk to your healthcare professional. Don't be afraid to ask questions and seek answers. Many of these problems can be treated.

Guidelines for resuming sex

Your transplant team will be able to give you personalised advice about when it's safe to have sex after your stem cell transplant.

- You should have a single partner rather than multiple partners in order to minimise the risk of getting an infection.
- Your partner should be well, that is, they should not have cold sores, influenza, a cold or a sexually transmitted disease.
- Your platelet count should be more than $50 \times 10^9/L$.
- Use condoms for three months after your transplant

Treatment related side effects that may affect your sex life (cont.)

- because they lessen the risk of getting an infection
- You may receive oral sex but shouldn't give it for three months after your transplant or while you are on immunosuppressive drugs
- Anal sex should be avoided while on immunosuppressive drugs or if skin breakdown is present
- Use birth control until your fertility status has been assessed and confirmed.

If your desire to become more sexually active does not increase as your recovery proceeds, bring this up with your doctors on your follow-up visits. It is important to remember that as with everything else after a bone marrow transplant, getting back to normal in terms of sex will take time. Try to be patient with yourself.



Sex positions when you are fatigued

As a leukaemia patient, you may well want sex but find a barrier to becoming intimate is your ongoing levels of fatigue. This fatigue may affect before, during or after treatment. You may also feel fatigued if you are on 'watch and wait'.

One solution is to find positions with your partner where your partner is willing to do the more strenuous activity during sex. Alternatively, you can choose positions where the sex is more gentle but both partners are active in the act. You could also consider having sex at the times in the day where you feel the least fatigued, for example, this may be in the morning rather than in the evening.

We have listed a number of positions below with a brief description and we've tried to include diagrams where possible. We have listed positions which may be suitable for those in a heterosexual relationship (male and female) or gay relationships (male and male, female and female).

Points to keep in mind for all of these activities:

Penetrative sex (anal or vaginal) may need to be avoided if you have a low cell count or a low platelet count. This is because you might be at risk of bleeding or infection. If in doubt, ask your consultant or CNS or ring the Ward or department that looks after you (don't be embarrassed, they are here to answer your very normal question about sex!).

If it hurts at any time, stop. If you are worried about mild pain during sex, take painkillers about 30 minutes beforehand.

Chemotherapy can be excreted in semen for a period of time after treatment; therefore, you will need to use condoms. Women may need to use dental dams.

Your partner should be well, that is, they should not have cold sores, influenza, a cold or a sexually transmitted disease.

Treatment for cancer can cause problems in climax. Don't worry if you don't manage to climax. Similarly, being the partner of a

person diagnosed with a blood cancer can cause anxieties and stress which can manifest in problems with orgasming. Achieving orgasm does not have to be the 'end goal' of sex. Concentrate on enjoying what you are doing.

Spooning

In some cases, when people refer to spooning they are referring to the act of sleeping with one partner behind the other. Both partners are facing the same way. The name refers to the way that spoons fit together if placed facing the same way.

A variation on this position is for both partners to bring their knees towards their chest. It is super comfortable - and there is something to be said for gentle sex!

The way this position is performed depends on the partner that is fatigued.

Alternatively, the partner that is behind (also known as in the 'big spoon position') could use their free hand to masturbate their partner.



Sex from behind

In this position, one partner is on the bed typically on all fours. The other person positions themselves behind the person on the bed and penetrates them from behind. The position is also known as doggy style and the name is taken from the way in nature that dogs have sex. There are modifications that can be made to this position to take pressure off knees for both partners.

If you struggle with kneeling, the position can be performed standing up. A modification to make this position easier for the partner receiving penetration is to lie on the stomach and prop up the bum using a pillow.



Sex in a seated position

In this position, the partner that is being penetrated straddles their partner. This allows the partner on top to control the speed of the sex, as well as controlling the depth of penetration.

The position could be performed by leaning against a wall too to take pressure off the back.



Missionary

The best known sexual position of them all.

In this position, the partner that is penetrated is on the bottom.

You can make modifications to the missionary position including placing a pillow underneath your bum to lift the pelvis and to allow deeper penetration.

If the partner on top gets an ache in their arms, they could lean forward onto their forearms rather than leaning onto their hands.



Other sexual acts you may want to consider when fatigued

Outercourse, or non-penetrative sex, is any sexual activity which doesn't involve sexual penetration. This could include the following activities:

- Frottage - the act of rubbing any part of the body against the sexual organ of another person either naked or clothed
- Mutual masturbation
- Kissing
- Cuddling
- Erotic massage
- Masturbation or ejaculation onto a partner's body part or parts



Anal sex

Anal sex is very normal in both heterosexual and homosexual relationships.

When white blood cell counts are low, you are at risk of infection so you may want to avoid partaking in anal sex during that time. If your platelet count is low, you will need to be gentle during sex.

If you regularly partake in anal sex, talk to your healthcare team to ensure you are safe to do so.



Sex toys

You may or may not have used sex toys before the diagnosis but after a diagnosis, you may want to consider using sex toys.

According to a survey conducted in 2017, almost three million people in the UK confessed to owning at least one sex toy.

The most popular form of sex toy was a vibrator, followed by cock rings and butt plugs.

If you've never used a sex toy, this doesn't mean you need to start. Simply, sex toys are an option for engaging in various sexual acts. As always, communication is key so talk to your partner if you'd like to explore sex toys for the first time.

Some gynaecologists are even looking to sex toys as a way of increasing natural oestrogen in the body. A natural way of increasing moisture in the vagina is to increase blood flow into the pelvis, and a sex toy such as a vibrator can be a natural way of doing this and an option for women that do not want to take synthetic oestrogen.

Cleaning sex toys

If you wish to continue or begin to use sex toys, it would be advised to keep them very clean - especially when you are prone to infection.

Tips for keeping your sex toys clean include:

- Use mild soap to clean your toys. Harsh materials can actually damage the surface of the toy. Using a mild, fragrance free soap should also avoid causing irritation to delicate skin.
- Don't submerge any toy that is motorised.
- For toys made from a durable material, such as glass or silicone, you should submerge them in boiling hot water.
- Once cleaned or washed, dry sex toys using a clean dry towel.
- Wash all toys before and after use.

You may have never used sex toys and you may not feel comfortable visiting a shop to buy these items. The internet now has a wealth of websites where you can buy

products of this type. The items will arrive in plain packaging so nobody will know what you are buying. There are toys available for people to use alone or as a couple.

Many of these online stores will have the ability to chat with an employee. If you don't feel comfortable sharing your email to ask questions, simply set up an email address which is completely different from your own to answer those questions. Remember - your questions are normal!

Lubricants

Using lubricants can not only make sex more comfortable but it can also make sex more fun. There are many lubricants that you can purchase nowadays for different uses or with different flavours, the choice is seemingly endless.

Lubricants help to ease friction during sex. They may be particularly helpful if you have vaginal dryness, for example, after treatment which has sent your body into a menopausal state.

You could use lubricant as a part of foreplay. As a woman, you may want to spread it over the labia, clitoris and over the vagina to make penetration easier. It can also be spread onto your partners genitals or on sex toys too. You may need to apply further lubricant later during sex.

If you don't like putting on lubricant with your hands, you could wear surgical gloves but you may find that this kills the mood. Some lubricants also come with an applicator.

When buying a lubricant, look for one that is water based rather than oil based. If you are using contraception such as condoms, oil-based lubricants can actually

damage condoms and reduce their effectiveness.

You should also be aware that some lubricants include the ingredient glycerin. Glycerin can actually promote the growth of thrush. Another ingredient that can cause issue is parabens, as they can cause imbalances in the vagina and make existing problems worse.

Many lubricants are advised with qualities such as "tingle", "heat", perfumed or flavoured. These can cause irritation to the genitals and should be avoided.

Keep your lubricants near places where you're likely to have sex, for example in the bedroom. This will stop you fumbling around when you need them!

There is a fantastic website run by a former nurse which includes many articles looking at the wider issues of sex after cancer, including fantastic practical tips on sex. The website can be found at: JoDivine.com



Advice for men

Men and Genital GVHD

Chronic GVHD may affect your penis and sexual function. It may cause:

- A decreased desire to have sex
- Redness/rash on your penis
- Ulcers on the penis
- Inflammation of the penis and/or scrotum
- Narrowing of the urethra
- An inability to ejaculate

If you experience any of these symptoms, it is important to let your transplant team know. You may want to ask if they can test your testosterone levels to see if there has been a decrease.

Treatments for genital GVHD may include some of the following medications:

- Steroids are the most common treatment given
- Calcineurin inhibitors are sometimes given as an alternative to avoid long term

steroid use

- Topical immunosuppressants
- Testosterone may be prescribed – this may help to increase your libido
- PDE-5 inhibitors – e.g. Viagra

If you experience any of these symptoms of GVHD it is important to inform your medical team so that the appropriate treatments can be given.

Genital GVHD can be a difficult and uncomfortable subject to talk about; however, it is important to discuss any issues with your transplant team as genital GVHD can become severe if not treated and can have a devastating effect on quality of life.

Priapism

Priapism is defined as a long-standing and painful erection that lasts longer than four hours without sexual stimulation and is unrelieved by ejaculation.

The word "Priapism" has its roots in Greek mythology. The term is named after a Greek god of fertility called Priapus, who is said to be a son of Zeus. A jealous female cast a spell over Priapus' mother whilst she was pregnant, causing her son Priapus to be born with this affliction for which he was disowned by his mother. Priapus is often represented in ancient statues and paintings with a disproportionately large and permanent erection.

In reality, priapism is a very serious condition and is considered to be a medical emergency that requires immediate treatment. An erection that lasts too long can cause permanent damage to the penis, with the risk of impotence being as high as 50% in males affected by priapism.

Priapism and leukaemia

Priapism in its own right is a very rare disease, and so for priapism to be caused by leukaemia is extremely uncommon. About two thirds of adult cases of priapism are caused by the use of agents to treat erectile dysfunction and, in children, the major cause of priapism (67%) is sickle cell anaemia. Generally speaking, leukaemia is only responsible for around 20% of all the cases of priapism, and the incidence in adult leukaemic patients is as little as 1-5%. Approximately half of these have chronic myeloid leukaemia (CML) as it is far more common to have priapism with chronic leukaemia than acute leukaemia.

There are three different types of priapism, all of which vary in the underlying biological cause:

Low-flow priapism (ischemic)

Low-flow priapism occurs when blood becomes trapped in the erection chambers, meaning it is not able to leave the penis after an erection. This is the most

Advice for men (cont.)

common and represents over 95% of cases.

Symptoms of low-flow priapism include:

- Erection lasting over four hours or at times unconnected to sexual interest or stimulation.
- Pain in penis that gets progressively worse.
- Rigid penile shaft, but the tip of the penis (glans) remains soft.

It is low-flow priapism that can present in men affected by leukaemia (as well as sickle-cell disease and malaria).

How does leukaemia cause low-flow priapism?

Priapism in leukaemia is caused by an abnormally high number of white blood cells in the blood, which can occasionally cause the blood to thicken and clog up the small veins, leading to decreased blood flow out of the penis and stagnation of the blood. When blood becomes stagnant, it cannot replenish oxygen, which

means that the penile tissue becomes deprived of oxygen, often leading to long term damage.

Another contributing factor to the congestion of blood flow out of the penis is the result of physical pressure upon the abdominal veins by an enlarged spleen (splenomegaly), a comparatively common symptom of leukaemia.

Stuttering priapism

Stuttering priapism is a more uncommon type of low-flow (ischemic) priapism. It is a recurring form of low-flow priapism which is identified by episodes of unwanted and/or painful erections that last for three hours or more. It occurs repeatedly with intervening periods where the penis relaxes and subsides from its swollen state. This type of priapism is more likely in males who have inherited a genetic disorder which changes the shape of their red blood cells (e.g. sickle cell anaemia) as these abnormally shaped cells can temporarily block the blood vessels.

High-flow priapism (non-ischemic)

This type of priapism is rarer than low-flow and is usually not as painful. The cause of this type of priapism is usually from an injury to the penis or the perineum (the area between the scrotum and anus). This then prevents the blood in the penis from circulating normally.

Symptoms of high-flow priapism:

- Erection lasting over four hours or at times unconnected to sexual interest or stimulation.
- Erect but not fully rigid penile shaft
- Often painless

How is priapism treated?

Treatment of priapism depends on the type and the cause. Your doctor will evaluate your symptoms and run tests to decide whether it is ischemic or non-ischemic, as well as the possible cause.

If the erection has lasted for four to six hours, decongestive

medication in tablet form is usually effective as an immediate relief method.

However, if this doesn't work, other treatments to help reduce your erection might be:

- Decongestive medications injected directly into your penis.
- Aspiration - where the penis is numbed with local anaesthetic, using a needle to drain the excess blood.
- Surgery whilst you are asleep under general anaesthetic to draw out the blood through a small incision.

Due to the relative rarity of priapism occurring as a symptom of leukaemia, there are currently no standard protocols for its treatment or management in leukaemia patients, and there is still debate over what method is most effective. However, all methods look to reduce the excess burden of white blood cells in the blood causing the blockage (hyperleukocytosis).

A rather out-dated technique

Advice for men (cont.)

used in the past included local radiotherapy, with or without open surgical shunting (using a long needle to create a bypass around the obstructed portion of the vein in the penis).

More recent therapies include:

- Chemotherapy to kill the excess white blood cells clogging the veins of the penis.
- Leukapheresis to temporarily reduce the number of leukaemia cells in the blood.
- In the case of CML, initiation of TKI therapy with agents such as imatinib to selectively kill the cancer cells.

Changes to your sperm

Due to treatment such as radiotherapy or chemotherapy, men may find that their semen is a different colour; typically, orange or brown. Some men may also feel pain in the testicles upon orgasm. The colour of the ejaculate will be temporary, as will the pain.

If you have been treated with any form of radiotherapy, for example, in preparation for a stem cell transplant, you may find that the volume of semen when you ejaculate (come) has decreased. Towards the end of the radiation treatment, some men may feel pain as they ejaculate. This is caused by irritation in the tube that carries urine and semen (the urethra). This should dissipate as treatment ends. However, if the pain continues and you are worried about it, speak to your nurse.

Managing infection

Men who have had a stem cell transplant can be more susceptible to thrush and cystitis (infection of the urinary tract). It is important to wash and go to the toilet after sex to try and prevent these infections. For cystitis, drinking plenty of water can help flush the infection from your system and cranberry juice may ease your symptoms too.

Treatments for men

Erectile dysfunction

Being diagnosed with a cancer like leukaemia can cause issues to your sex life, either directly or indirectly. Erectile dysfunction can be the result of cancer treatment such as chemotherapy.

A study published in 2016 revealed that 60% of male cancer patients in the United States had sexual problems following treatment. Just 20% of male patients in this study had sought advice for their cancer-related sexual problem.

Erectile dysfunction is the inability to obtain an erection which can be maintained (kept firm enough) for sex.

Although physical side effects can affect the ability to maintain an erection, psychological effects of having cancer can also impact on this.

Treatments for erectile dysfunction include:

- Tablets taken before sex, such as 'viagra': We have covered this in greater depth in this booklet and why this may not always be suitable for leukaemia patients.
- Injections into the penis: This is generally for men that have erectile dysfunction due to nerve damage in the penis.
- A pellet or cream that you put into the opening of the penis.
- Vacuum pumps: This involves putting your penis into a tube and the vacuum effect of the pump creates an erection. To maintain the erection, you place a constriction ring around the base of the penis which means the erection can be maintained for up to 30 minutes.
- Sex therapy.

For some men, it may be a combination of treatments that work rather than one in isolation.

Men who are older, or who have experienced erectile dysfunction before a diagnosis are more likely to experience erectile dysfunction after treatment.

Viagra

Since April 2018, Viagra has been available "over the counter" in pharmacies and even in some supermarkets. Here we look at what Viagra is and its availability for leukaemia patients.

Before the "little blue pill" was made available without a prescription, men had to visit their GP and have a full examination before being able to access the drug on prescription. For men who didn't want to speak to their GP, many were accessing the treatment online which came with its own problems including counterfeit tablets.

Now, men can speak to a pharmacist and buy tablets over the counter (without a prescription) costing approximately £20 for four.

What is Viagra?

Viagra is a treatment for men, over the age of 18, that are experiencing erectile dysfunction (ED). This dysfunction could include difficulties in getting an erection during sex, trouble maintaining an erection. Some men also take this drug because

they have a reduced libido.

'Viagra' is common name for referring to a tablet that helps to treat erectile dysfunction. The medication's actual name is Sildenafil. It was launched in 1998 by drugs company Pfizer and was originally formulated to treat high blood pressure. Since its launch in 1998, it is claimed that 62 million men have tried the drug.

How does Viagra work to treat ED?

Sildenafil increases blood flow to the penis to help men get or maintain an erection. According to the NHS website, 2/3 men have an improvement when using this treatment.

Men who are taking Sildenafil must take the treatment up to four hours before sex, ideally around an hour before. The medication alone will not cause an erection and a man must be aroused for it to work.

How do you take it?

Although the common image for this treatment is a little blue pill, Sildenafil can also be supplied in a liquid format.

Treatments for men (cont.)

Can men treated for a blood cancer buy Sildenafil over the counter?

If you are a man seeking treatment for erectile dysfunction after the diagnosis of a blood cancer, such as a leukaemia or myeloma, then you should speak to your GP or consultant first.

For some men that are diagnosed with a leukaemia, they may be more susceptible to a condition called priapism. Priapism is defined as a long-standing and painful erection that lasts longer than four hours without sexual stimulation and is unrelieved by ejaculation.

Priapism in its own right is a very rare disease, and so for priapism to be caused by leukaemia is extremely uncommon. About two thirds of adult cases of priapism are caused by the use of agents to treat erectile dysfunction and, in children, the major cause of priapism (67%) is sickle cell anaemia. Generally speaking, leukaemia is only responsible for around 20% of all the cases of priapism, and the incidence in adult leukaemic patients is as little as 1-5%. Approximately half of these have chronic myeloid

leukaemia (CML) as it is far more common to have priapism with chronic leukaemia than acute leukaemia.

Talking to your doctor about erectile dysfunction

While sex may not be the first thing on your mind upon diagnosis, it is a key part of many people's lives and therefore it is important that you feel comfortable in asking for support in this area of your life.

To ensure you get the most of this important conversation, there are a number of steps you could take:

- Prepare for your visit. Preparation would include making lists of all the medications you take. If you take supplements such as vitamins or herbal remedies, ensure that you list these too.
- Keep a diary about your symptoms. Key information will include when the symptom started (or a rough approximation of time). Does it happen every time you want sex or is this intermittent?
- Make a note of any personal information. Other than your

diagnosis, is there anything else affecting your life right now?

- You'll probably be asked questions on the following subjects so it's important to be honest about whether you drink heavily, use cocaine, smoke cigarettes or use opioids for recreational use.

You may find it useful to take a partner; however, some people may be more comfortable discussing these subjects alone.

There are a number of questions you may want to ask your doctor which include:

- What is the cause of my erectile dysfunction?
- Can it be treated? Is it temporary?
- What treatment options are available to me?
- What happens if that doesn't work?
- Will I be referred to a specialist?
- What lifestyle changes may help my erectile dysfunction?

Other factors that affect sexual function

Other factors that affect sexual function

There may be other reasons why your ability to function sexually has decreased.

These can include:

- Being overweight
- Smoking, alcohol or drug consumption
- Stress and anxiety
- Age related causes
- High blood pressure
- High cholesterol
- Diabetes

The wide range of reasons for issues with sexual function means its important to talk to your GP or consultant about the issues in case they are something else other than your blood cancer.



Advice for women

Women and Genital GVHD

Chronic GVHD may affect your vaginal and genital area. It may cause:

- Vaginal burning
- Vaginal tightness
- Discomfort or pain with sexual intercourse
- Abnormal vaginal discharge
- Narrowing of the vagina
- In severe cases the vagina may become ulcerated.

Women who have genital GVHD may have a decreased desire to have sex. They may find it difficult to achieve an orgasm and experience pain or bleeding during or after sex.

There are a few things that can be done to help prevent vaginal GVHD and its symptoms.

- Avoid using chemical irritants when washing and try not to use perfumed lotions and soaps
- Wear cotton underwear
- If you have very sensitive skin

use a very mild detergent

- Apply moisturisers to avoid dry skin
- Vaginal lubricants can make sexual intercourse more comfortable. However, make sure they are water-based lubricants as oil-based lubricants can tear condoms

If you get any symptoms of vaginal GVHD such as vaginal burning, vaginal tightness, discomfort or pain with sexual intercourse and abnormal vaginal discharge, let your transplant team know immediately.

Treatments for women experiencing vaginal GVHD:

- Oestrogen cream, capsules or release rings may be prescribed. This should be inserted into the vagina 2-3 times a week as prescribed. Oestrogen cream will help to increase the moisture and elasticity of the vagina.
- The transplant team may encourage you to use vaginal dilators or sexual intercourse two to three times a week to help keep your vagina healthy. If you don't currently

feel ready for sexual intercourse then vaginal dilators should be inserted two to three times a week.

- Hormone replacement therapy: Chemotherapy given as part of the transplant conditioning regimen can cause women to go through the menopause much earlier than usual. Hormone replacement therapy may help to alleviate the symptoms of menopause such as hot flushes and it can help to increase sex drive.

If you experience any of these symptoms of GVHD it is important to inform your medical team so that the appropriate treatments can be given.

Genital GVHD can be a difficult and uncomfortable subject to talk about; however, it is important to discuss any issues with your transplant team as genital GVHD can become severe if not treated and can have a devastating effect on quality of life.

Hot flushes

Why do people get hot flushes after treatment?

Some women will get hot flushes after treatment because the cancer treatment has placed them into the menopause.

The menopause is when a woman stops having periods. Usually, the menopause will happen over the age of 45 but cancer treatment may put some women into the early menopause. Some patients mistake their leukaemia symptoms for the menopause as the hot flushes and night sweats could be attributed to either condition.

Hot flushes can interfere with quality of life. One of the most basic ways that hot flushes can interfere with your life is when you share your bed with another human being.

Medications can be prescribed to help with the hot flushes, and these would need to be discussed with your healthcare team.

There may be some homeopathic approaches that you might like to try such as acupuncture, and there has been some evidence to show that this can help to

reduce hot flushes. If you plan to try acupuncture, you should talk to your consultant to ensure that this is the right thing to do.

Other tips for managing hot flushes at night include avoiding hot drinks before bed, avoiding exercise before intimacy or even taking a cool shower before you become intimate. You could also try having a fan on your side of the bed to help you to cool down.

Physical arousal can also trigger hot flushes. If this happens, take a moment to explain to your partner what is happening and that you need to cool down before continuing.



Vaginal dryness

Symptoms of vaginal dryness include:

- Feeling sore or itchy in or around your vagina
- Pain, soreness or discomfort during sex

Vaginal dryness is very common for women and will be something that your GP will discuss regularly, so try not to feel embarrassed about discussing it. There are options available that you can try to alleviate the dryness, including:

Avoid scented products in your intimate areas

Many products will advertise using phrases such as "balancing" the natural PH in this area or phrases of this type. While some people may want to use washes like this, they aren't necessary at all, and in some cases can cause imbalances in the delicate system down there. Avoid scented products too, as this could cause infections. If there was a need for you to use a dedicated wash in this area, it would be something that was prescribed by your GP.

Vaginal moisturisers

There are many vaginal moisturisers available to patients and your GP or healthcare team will be able to recommend a suitable product. A vaginal moisturiser is used inside the vagina to keep the area moist. They differ to lubricants as you use them outside of times where you have sex. Typically, you would apply a vaginal moisturiser once every couple of days.

Vaginal lubricants

Typically, you would apply a vaginal lubricant to your vulva, vagina and any part of your partner during sexual acts. The relief for the dryness is short term and typically only lasts during sex. If you are looking for longer term relief, it's worth discussing a moisturiser with your healthcare team.

Vaginal oestrogen

If you have entered the menopause, your oestrogen levels will drop which can cause the dryness.

Vaginal oestrogen is prescribed as pills that you place inside your vagina (pessaries), creams

or vaginal rings. You may prefer one type over the other and you may have to try all three to find out what you're most comfortable with.

Compared to moisturisers or lubricants, it is not a fast-acting option and you may need to use it in conjunction with another option until the oestrogen takes effect. This is a long-term option as the symptom typically returns if the treatment stops.

HRT

HRT stands for hormone replacement therapy. After entering the menopause, the ovaries stop producing oestrogen which causes symptoms such as hot flushes, mood swings and vaginal dryness.

There are two types of HRT: Combined HRT which is oestrogen and progesterone together, as well as oestrogen only HRT.

There are other forms of HRT that are less commonly used too and these may be discussed with your GP.

HRT can prove beneficial for some women experiencing side effects; however, there are other risks to

consider.

Vibrator therapy

There are some US based gynaecologists who have begun to prescribe vibrator therapy to those experiencing vaginal dryness. The theory behind this is that to increase vaginal moisture, you need to increase blood flow to the area and using a vibrator can do just this. In this setting, it doesn't necessarily matter whether you orgasm or not through using the vibrator but orgasms will help with the production of natural oestrogen. They can also help a person to feel better about themselves and a partner. They can also reduce stress and help you to relax.

Pain during vaginal penetration

Research published in 2016 revealed that nearly one in 10 women experience painful sex, also known as dyspareunia. Despite there being treatments to help combat painful sex, the research also revealed that many women find the topic too difficult to talk about and therefore are suffering in silence.

Vaginal dryness (cont.)

There are ways that pain can be managed including:

- Taking pain medication 30 minutes – 1 hour before sex. Although this might take some of the spontaneity out of sex, you will feel more comfortable knowing that you have taken pain medication.
- Lubrication: Some pain can be caused from a lack of lubrication. This lack of lubrication can make having sex difficult. See our sections on lubrication and vaginal dryness on more information about how this can be managed.
- You may find certain positions painful. This may mean you need to experiment with different positions thinking about positions where penetration isn't so deep. You could also control the depth of penetration by having sex in a position where you are in control, such as the woman going on top of the partner.
- You may find sex painful if you are not fully aroused. Take time to engage in foreplay

before attempting penetrative sex.



Your relationship with yourself and others

Body image and self-esteem

How can low self-esteem affect my sex life?

Low self-esteem can manifest itself in a number of ways, including:

- Not wanting to be seen naked or semi-naked
- Only willing to have sex in the dark or under covers
- Inability to become aroused
- Lack of desire to have sex

Improving your body image and self-esteem

Body image is how you feel about your body. Self-esteem is how you feel about yourself. These terms are very closely linked. Negative body image or self-esteem can have an effect on your sex life or how you feel about sex after you are diagnosed.

Some people worry that the appearance-related side effects of treatment will draw attention to the fact that they have cancer, which can affect their self-esteem. The psychological distress of

being diagnosed with a blood cancer can also have an effect on an individual's self-esteem. You have been through a life changing event. In the case of acute leukaemia, you've been given news about an illness that needs treating very quickly. In the case of chronic leukaemia, you have been given a diagnosis that will be a part of you for the rest of your life. Studies have shown that many cancer patients display the signs of post-traumatic stress disorder (PTSD).

If you are a patient that has undergone chemotherapy, you will know the effects that this can have on the body including hair loss, changes to your nails or skin.

Some of these effects will be temporary. Some will become the new-normal. You may feel that you are grieving your 'old' life, or 'old' body or even just the 'old' you.

You may want to adopt one of the following coping strategies to help you work through these issues:

Improving your own self-esteem

There are a few strategies that you could employ to try and improve how you feel about yourself and how you feel about your body.

Mind, the mental health charity, have some fantastic guides on their website for improving self-esteem. These tips include:

Being kind to yourself

Instead of focusing on the negative about yourself, find something that you like. For example, you may dislike a certain part of your body after treatment. Instead, try and focus on one thing that you like about your physical body. When thinking about yourself, try not to compare yourself to others.

You may want to keep a diary where you write one nice thing about yourself each day. When you are having a day where you are struggling with how you feel about yourself, you could then look through your diary and remember those things that you do like about yourself.

Remember, there are many

qualities about you that your friends, family and loved ones really like about you, even if you struggle to see it.

There is a full guide on the Mind website <https://www.mind.org.uk>.

Talking to others

You may find it useful to be open with your loved ones with how you are feeling.

You may want to talk to a partner, loved one or trusted friend about the feelings you have been or are experiencing.

It may help you to write down these feelings too so you can talk about them during the conversation.

The person you are speaking to might not be able to give you all the answers you need but saying these feelings out loud may help you move towards rebuilding your self-esteem and body issues.

You may also consider joining a support group for those with or who have had a blood cancer diagnosis. In a support group, you can talk with others in a similar situation knowing they are facing situations like you are. There

Your relationship with yourself and others (cont.)

are a number of blood cancer support groups across the UK. Alternatively, there are a number of online forums or private groups where you can discuss your feelings with people that understand.

We will list all the relevant groups at the end of this section.

Talking to a professional

You may want to seek professional support to help you psychologically. This may include talking therapies, such as counselling, where you may or may not want your partner to attend with you.

You may be able to get a referral to a counsellor through the NHS.

Although you may want to talk to your GP, a GP referral is not always needed to access counselling services. The NHS has launched a new service which will help to self-refer to services that are available in your area. To start this process, you need to go to <https://beta.nhs.uk/find-a-psychological-therapies-service/> and type in some details about where you live so they can find the support most

relevant to you.

Counselling services are in high demand and there can be very long wait times to access the support you need. If you feel like you would benefit from speaking to a trained professional a little sooner, you may want to consider paying for a counselling service.

Relate is a charity that offers low-cost, or in some cases, free counselling. They can offer support on relationships, sex or even talking about sex with others. Each Relate centre has their own rate for charging. They do offer a live chat service through their website where you can message a trained counsellor and this is a free service. You can find out more about Relate on their website <https://www.relate.org.uk>

You may be able to get support in funding for relationship counselling. A member of the team at Leukaemia Care is available to talk and help with signposting for relevant counselling services.

Support groups

Leukaemia Care online forum

<https://healthunlocked.com/leukaemia-care>

The Leukaemia Care online forum is open to anybody affected by a blood cancer diagnosis. You can sign up with an anonymous username if you so wish.

The forum is moderated by the team at Leukaemia Care.

Leukaemia Care Facebook groups

The Leukaemia Care facebook groups are open to anybody affected by a blood cancer diagnosis. There are a number of sub-groups according to diagnosis type.

Facebook groups will show off your real name, so these are not suitable for those people who wish to ask anonymous questions.

Leukaemia Care Facebook groups can be found by going to the Leukaemia Care facebook page, <https://www.facebook.com/LeukaemiaCare/> and click on the groups tab.

Lymphoma Action

Lymphoma Action are the UK's only dedicated lymphoma charity. They run a number of support services which include in-person support groups. To find out about the full range of support available, go to their website at

www.lymphoma-action.org.uk

CML-UK

CML-UK is a dedicated charity for anybody affected by a chronic myeloid leukaemia diagnosis. They run a forum which can be found on their website at cmlsupport.org.uk. There is also a very active Facebook group which can be found by searching "CML Support - UK" on Facebook.

CLLSA Forum

The CLLSA forum is hosted on the HealthUnlocked platform and has over 10,000 members and rising. This is an international platform with members from across the globe. It is a fantastic way to share experiences and you have the ability to be completely anonymous. There is also the ability to "lock" your posts so that they cannot be indexed by a Google search.

Your relationship with yourself and others (cont.)

You can access the CLLSA forum at: <https://healthunlocked.com/clsupport>

Macmillan forums

Macmillan host their own online community for cancer patients of any type. Although it is not necessarily leukaemia specific, the forums offer a chance to ask questions that are common across all cancer diagnoses and you will find many members on that site that have been affected by a leukaemia diagnosis. To access the Macmillan online community, go to <https://community.macmillan.org.uk>



Useful contacts and further support

There are a number of helpful sources to support you during your diagnosis, treatment and beyond, including:

- Your haematologist and healthcare team
- Your family and friends
- Your psychologist (ask your haematologist or CNS for a referral)
- Reliable online sources, such as Leukaemia Care
- Charitable organisations

There are a number of organisations, including ourselves, who provide expert advice and information.

Leukaemia Care

We are a charity dedicated to supporting anyone affected by the diagnosis of any blood cancer.

We provide emotional support through a range of support services including a helpline, patient and carer conferences, support group, informative website, one-to-one buddy service and high-quality patient information. We also have a nurse on our helpline for any medical queries relating to your diagnosis.

Helpline: **08088 010 444**
www.leukaemicare.org.uk
support@leukaemicare.org.uk

Bloodwise

Bloodwise is the leading charity into the research of blood cancers. They offer support to patients, their family and friends through patient services.

020 7504 2200
www.bloodwise.org.uk

Cancer Research UK

Cancer Research UK is a leading charity dedicated to cancer research.

0808 800 4040
www.cancerresearchuk.org

Macmillan

Macmillan provides free practical, medical and financial support for people facing cancer.

0808 808 0000
www.macmillan.org.uk

Maggie's Centres

Maggie's offers free practical, emotional and social support to people with cancer and their families and friends.

0300 123 1801
www.maggiescentres.org

Citizens Advice Bureau (CAB)

Offers advice on benefits and financial assistance.

08444 111 444
www.adviceguide.org.uk

Turn2Us

Help with finding financial assistance. Website with a benefits calculator and a search tool for local benefits advisors and grant-awarding charities by location or occupation.

<https://www.turn2us.org.uk/>

Look good, feel better

Organisation that runs skin care and make up workshops for people with cancer.

01372 747 500

www.lookgoodfeelbetter.co.uk

info@lgfb.co.uk

British Association for Counselling and Psychotherapy (BACP)

Professional association for counsellors and psychotherapists that provides information about talking therapies and a find a therapist finding service.

01455 883300

www.bacp.co.uk/

bacp@bacp.co.uk

British Complementary Medicine Association

Member organisation for complementary therapists that offers information and a therapist finding service.

0845 345 5977

office@bcma.co.uk

www.bcma.co.uk/

Complementary and Natural Healthcare Council

Maintains a register of complementary therapists and set standards for practice. Provides a therapist finding service on their website.

020 3668 0406

info@cnhc.org.uk

www.cnhc.org.uk

Learn mindfulness

On line course run in partnership with the Mental Health Foundation and recommended by the NHS.

<https://www.bemindfulonline.com/>

Notes

Leukaemia Care is a national charity dedicated to providing information, advice and support to anyone affected by a blood cancer.

Around 34,000 new cases of blood cancer are diagnosed in the UK each year. We are here to support you, whether you're a patient, carer or family member.

Want to talk?

Helpline: **08088 010 444**

(free from landlines and all major mobile networks)

Office Line: **01905 755977**

www.leukaemicare.org.uk

support@leukaemicare.org.uk

Leukaemia Care,
One Birch Court,
Blackpole East,
Worcester,
WR3 8SG

Registered charity
259483 and SC039207

Leukaemia Care
YOUR Blood Cancer Charity