

This booklet has been provided as an informative guide for people living with renal disease and those close to them.

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Maintaining a healthy sex life

Information for people living
with kidney failure



Contents

Understanding the changes	4
Talking can be difficult	4
What problems should I be aware of?	4
What causes sexual problems?	6
Physical causes	6
Anaemia • Chronic illness • Diet • Fluids • Hormones Blood pressure medication • Transplant rejection Blockage of arteries • Neuropathy • Vitamin and trace metal depletion	
Psychological causes	8
Adjustments • Appearance and self-esteem • Depression • Anger	
Social causes	10
Lifestyle adjustments • Sexual attitudes	
Sexual function, contraception and fertility	10
For dialysis patients and their partners For transplant recipient patients and their partners For Polycystic Kidney Disease patients and their partners	
HIV, Hepatitis B and Hepatitis C	12
Advice for partners	13
The way forward	13
Talk with your doctor • Dealing with your emotions Look after yourself • Your attitudes and expectations Sex education • Talk with your partner • Change your habits	
Professional help	18
What next?	18
Suggested reading	19

Understanding the changes

Throughout our lives, many of us experience changes that can affect our sex lives. This booklet is written with the needs of people with kidney disease and their partners in mind. It aims to help you understand changes you may have noticed in your sexual feelings or functioning. It also sets out to provide advice you may find useful in improving the quality of your relationship - and life.

The reality is that many people experience problems in this area of their lives. Sexual difficulties may also occur for people with kidney disease, both men and women. These difficulties can affect your enjoyment of life, your relationships and your response to treatment.

Whether you are in a stable relationship, are single, divorced or widowed, it is important to understand the possible effects of your illness on your sexual interest and functioning.

For partners of people with kidney disease, it can also help to be aware of the possible difficulties. While many people with kidney disease will maintain healthy relationships and sex lives, it's reassuring to know that if difficulties occur, professional help is available to help resolve them.

Talking can be difficult

Everyone finds talking about sex awkward. You may find it especially hard to talk to your doctor, nurse or social worker about such a personal subject. Reading this booklet should answer many of your questions and help you to talk about the issues you need to discuss.

It's worth remembering that your hospital staff will always be understanding, helpful and confidential. Once you start to talk with someone who understands and can help, you should begin to feel better. However difficult, it is important to communicate your concerns with your partner, because together you can overcome many of the problems you are facing.

What problems should I be aware of?

Many men and women with kidney failure and undergoing dialysis treatment experience a change in their sexual lives. These changes vary in intensity and can occur at different times. It's worth remembering that each individual is affected differently.

Men may notice changes in their interest in sex, in their ability to have an erection or in their ability to have an orgasm. Women may also notice a change in their interest, in their ability to become sexually aroused or have an orgasm.



If you have noticed any of these changes, you are not alone. For some people, a decrease in interest or activity does not pose a problem, but for others it does, leading to doubts about their self worth and tensions, or even conflict in their relationships.

Discussing the changes with your partner and their reaction to them is the first step in working out whether they are even regarded as a problem, and if so, what can be done to improve the situation.

What causes sexual problems?

The causes can be physical, psychological, social and may even be a mixture of all of these.

Physical causes

Anaemia: Kidney failure can cause reduced production of a hormone called erythropoietin (EPO). EPO is produced in the kidneys and stimulates the bone marrow to produce red blood cells which carry oxygen to every cell in your body. A depletion in the number of red blood cells results in reduced haemoglobin (the oxygen carrying pigment in red blood cells) levels. Low haemoglobin (Hb) levels cause anaemia.

Red blood cells carry oxygen to every cell in your body and a depletion in these results in anaemia. The main symptoms of anaemia are breathlessness, tiredness, pale skin, poor appetite, irritability and low sex drive. So you may find that many activities, including sex, are an effort.

The good news is that the anaemia associated with chronic kidney failure can now be treated with artificially produced EPO or with recombinant forms of human erythropoietin. These treatments are effective in restoring red cell counts and haemoglobin to normal levels.

These changes bring about a feeling of physical and emotional well-being and can result in improved sexual function.

Chronic illness: Having a chronic illness may mean that you feel less than perfectly healthy. It is difficult to feel interested in sex if you are not feeling well.

Diet: If your kidneys are not working as well as they should and you are relying on dialysis to do their work, you may find that some wastes that the kidneys should remove from the blood builds up between treatments. This is why you are on a special diet. If you follow your diet, it will help to keep the level of waste products in your blood at a lower level. When the level is high, you will feel nauseous, lack energy and be unable to concentrate. Keeping the level of toxic waste products low by sticking to your diet and medications will help you feel much better.

Fluids: Many people undergoing dialysis treatment must limit their fluid intake. If there is excess fluid in your system, you will feel unwell. Your energy will be reduced, your heart will have to work harder, your blood pressure will rise and you will be breathless and feel bloated. The excess fluid may also contribute to feelings of depression. Keeping to your fluid restriction will help improve the way you feel.

The chemical and fluid changes that dialysis causes may make you feel exhausted; it is also time-consuming, often inconvenient and relentless. You have probably found that there seem to be fewer hours in the day and that you have less time for yourself.

Hormones: We know that hormones influence our sexual interest. The level of hormones in people with kidney failure often changes and as a result, you may notice changes in your body. Menstrual periods may become irregular or stop altogether. A man's sperm count and motility may be lowered and both men and women may notice a decrease in their libido or sexual interest.

Blood pressure medication: Some medications used to treat high blood pressure can diminish the sexual interest of both men and women and affect men's ability to have an erection. A change to another medication may help. Your doctor is the best person to advise you which medication is likely to be right for you.

Transplant rejection: If you have had a transplant and feel well, then your interest in sex usually improves. When you are being treated for a transplant rejection, your interest in sex, as well as your ability for sexual activity may decrease. The anxiety and depression often associated with a bout of rejection can also contribute towards your reduced libido.

Blockage of arteries: Cholesterol or fatty deposits called atheroma can block the arteries throughout the body. If the arteries to the genital organs are narrowed or blocked, the blood flow will be reduced during periods of sexual arousal. When this occurs, sexual functioning can be affected.

Another issue some people with renal disease face is calcification of arteries. This results from calcium and phosphate imbalances and can also cause reductions in blood flow. This is a major reason why it is so important that phosphate levels be controlled by medication and diet.

Neuropathy: Neuropathy, or nerve damage, can occur in patients with diabetes who also have chronic renal failure. If the nerves to the genital organs are affected, then sexual functioning may be impaired.

Vitamin and trace metal depletion: During dialysis, vitamins and trace metals can be removed. Evidence suggests that the depletion of zinc may contribute to sexual dysfunction. However, the use of zinc supplements and their effectiveness has not been proven by clinical trials.

Psychological causes

Adjustments: The degree to which your illness has affected your life and that of your family will vary, but it is likely you have had to make some adjustments. You may have needed to change jobs or stop work altogether, your income may be reduced, you may have moved house, you may have decided against having children in the short or long term, and your participation in sports or heavy physical activity may have decreased or ceased altogether. All of these changes are stressful and take their toll of your emotional resources and those of your partner.

Appearance and self-esteem: The way you feel about yourself will affect your sex life. Many people with kidney disease find their appearance changes. You may also have lost weight, and be less physically fit or attractive.

Your fistula or peritoneal dialysis catheter is a constant reminder that you are on dialysis and this may affect the way you think you look, your partner's reactions and maybe the way you make love.

Other changes can include a paler complexion and a slight difference in the thickness of your hair. Some people also find they have a bad taste in their mouth or their breath smells of ammonia.

Depression: A common response to all the changes you are experiencing in your life is depression, and this can significantly affect your enjoyment of all aspects of life, including sex.

The reality is that everyone feels down from time to time, but because of your extra physical problems, you may find you are depressed more often. Part of what can make this time so difficult is having to come to terms with the changes in your body and your concept of yourself.

For some men, no longer urinating represents the loss of an important bodily function and can affect their feelings of masculinity. This can also adversely affect a man's self-esteem and contribute towards feelings of depression.

One thing to remember is that it is important that you share your feelings with your partner. This way both you and your partner can start facing the new hurdles together.

Anger: Feeling angry at times is understandable and can even be constructive. If you channel your anger through some form of physical activity such as hitting a ball, walking, swimming, weeding the garden or even punching the pillows when making the bed, you should feel a little better for it.



Social causes

Lifestyle adjustments: Your dialysis routine, dietary and fluid restrictions, restless nights and tiredness all contribute to the need for adjustments in your lifestyle.

A significant adjustment is that you have less time to spend doing what you enjoy – mixing with friends, playing sport, spending time with the family or going to the movies. As well as limited time, you may also feel that eating out and going to parties may not appeal to you anymore. Many people find it frustrating that their familiar ways of relaxing and enjoying themselves become more difficult.

It is easy to fall into a rut where you feel everything becomes too much trouble, including sex. You might have even started sleeping in another bed because restlessness keeps your partner awake.

Remember, each one of us has a need for physical closeness and comfort, especially when times are tough.

Sexual attitudes: It can be comforting to remember that your sexuality embraces far more than the act of intercourse. Closeness, tenderness, warmth, caring, consideration, cuddling, touching, laughing and holding hands are all aspects of our sexuality.

It is important to remember that your sexuality is part of you and that even if intercourse is difficult for you, it is only part of sex. You can still share and enjoy your sexuality by the expression of tenderness and affection through close physical contact with the person you love and with whom you are sharing your life.

Your sexual desire can be satisfied without intercourse, as long as you believe that you can give to your partner in other ways.

Sexual function, contraception & fertility

For dialysis patients & their partners

Fertility can be affected if you have kidney failure, but this **doesn't** mean that you can't conceive or are unable to father a child. Your fertility and contraception are issues that you need to discuss with both your partner and your doctor.

Women with kidney disease or undergoing dialysis treatment may have irregular periods or no periods at all, and men may have a lowered sperm count. While some women on dialysis have become pregnant, the chances of a pregnancy reaching full term with a normal size baby are low. In addition, pregnancy may pose a risk to your own health. If you had considered pregnancy while on dialysis,

it is essential that you and your partner discuss this with your doctor.

Likewise, female partners of men undergoing dialysis treatment may need to discuss the implications of a pregnancy with their partner and his doctor.

Obviously, having a child while your partner is on dialysis creates extra demands for you both, but is of course, a personal choice.

If you do not wish to conceive, then your doctor can advise you on an appropriate form of contraception.

For transplant recipients & their partners

Following transplantation, your well-being, fertility and sexual functioning can improve and those of you who had postponed pregnancy may now wish to explore the feasibility of having a child.

If you do not wish to have any children or increase the size of your family, then it is still important that you discuss the most suitable form of contraception with your doctor.

Many transplant recipients throughout the world have conceived and given birth to healthy babies and remained well following the birth. **However, the safety of new immuno-suppressive medications is limited, so consulting your doctor about your special situation is vitally important.**

It is generally recommended that the interval between transplantation and conception be at least two years, that renal function is stable, there has been no rejection for at least twelve months, there is no high blood pressure and immunosuppressive medication is minimal. The risks of premature labour needs to be assessed in all cases.

Just as a man's fertility and sexual functioning may improve after transplantation, his partner's chance of conception also increases.

The subjects of birth control and pregnancy need to be discussed with thoughtfulness, maturity and responsibility by each couple. Your decision about the possibility of family life may be difficult. It may raise many questions about your future as a couple and your ability or preparedness to provide and care for yourself and your family. You may even find that each of you has different expectations and that the subject is a source of conflict. Your doctor, social worker or nurse may be able to help you clarify the issues and assist you and your partner in reaching a satisfactory solution. Although the decision to have or not have children is a personal one, it is a subject which can affect your health and about which your doctor's advice is important.

For Polycystic Kidney Disease (PKD) patients & their partners

When you or your partner has polycystic kidney disease, each child has a 50% chance of inheriting the disease. If you are planning to have a family, you may decide to limit its size, so that fewer family members are affected by PKD. Genetic testing during pregnancy may also be possible. Your renal physician or obstetrician can arrange referral for these tests.

Because of the hereditary nature of PKD, you should especially talk to your partner and doctor to ensure that you are fully informed of the possibility of passing on the gene to your children, and the consequences of this for them in later life.

HIV, Hepatitis B & Hepatitis C

The Human Immunodeficiency Virus (HIV), Hepatitis B and Hepatitis C can be transmitted through sexual contact via the exchange of bodily fluids or through an infected needle. In Australia today, the risk of transmitting these diseases via transfusion of whole blood or blood components is minimal, thanks to thorough screening by the Australian Red Cross Blood Transfusion Service.

It is reassuring to know that if you are a haemodialysis patient, you cannot contract these viruses from machines or blood lines, due to the infection control procedures followed in all renal units. Additionally, if you are a candidate for a kidney transplant, the prospective donor will be screened for these viruses and syphilis.

If you have contracted one or more of these viruses in the past, you may be concerned not only for yourself, but also for the health of your partner or potential partners. While sexual abstinence will stop transmission of the virus, the use of condoms at all times can be equally effective. Condoms will prevent the transmission of bodily fluids and so protect your partner from infection. For infected patients and their partners, it is very important to avoid direct contact with bodily fluids.

It is worth noting that the incidence of sexual transmission of Hepatitis C virus appears to be very low and is much rarer than with Hepatitis B or HIV. The risk of sexual transmission is high if the person is in the acute phase of the disease or is also infected with HIV. If you are concerned about transmitting or contracting these viruses, please discuss it with your doctor, nurse or social worker, who will be able to advise you.

Advice for partners

You and your partner are reading this booklet because you care about each other and are interested in your sexual life together. It is important that your role and the adjustments you have made are not overlooked or underestimated.

You now have special concerns for your partner's health. You may have assumed extra duties at home or through a return to the workforce. Your income and aspirations may be reduced, as well as your social life, free time and opportunities for sexual expression. What's more, you may sometimes feel you are being taken for granted and that you no longer have anyone to lean on. It might sometimes all seem just too hard.

It is not surprising that you may occasionally feel depressed, angry and resentful. Because the reality is, while your lifestyle has changed, your need for sexual fulfilment has not. Although you may try to minimise its importance, deep down you both know how important it is.

As long as you remember that it may not be exactly as it was before your partner became ill, if you are both open to new ideas you can successfully re-establish a sexual life together.

Before you start afresh, it is important that you dispense with any angry or hurt feelings, as these will hold you back from feeling warm and loving. You can start doing this by talking to someone you trust, such as a close friend or perhaps the social worker at the hospital.

Once you understand your feelings, you are in a better position to understand and work with your partner. Both of you may need to adjust your expectations and work towards enjoying your life together.

The way forward

Talk with your doctor

While talking is not always easy, it's important to be aware that your doctor understands the importance of a sexual relationship to your overall well-being and will be happy to help.

It is a good idea to first check whether there is a medical cause for your sexual difficulties. Treatment is available to correct anaemia, thus increasing your energy and stamina. Medication for high blood pressure can diminish the sexual interest of both men and women and affect a man's ability to have an erection. A change



in your medication may help. Of course, never stop taking medication without consulting your doctor.

For many people, differences in libido, or sex drive, can be resolved through counselling and medical treatment. Endocrinologists specialise in treating hormonal irregularities in men and women. Your doctor can arrange a referral, if appropriate.

Today, there are also several options available for treating erection problems. If you or your partner has difficulty getting or maintaining an erection, ask your doctor which treatment is likely to be suitable for you.

If you have had a transplant, your sexual functioning may have improved, but if you are anxious that sexual activity may harm your kidney or cause you to be more prone to infections, speak with your doctor. You will learn that sexual activity is perfectly safe after transplantation. As with any major surgery, it is wise to wait at least four weeks after your transplant before intercourse.

Women may have particular concerns about changes in the menstrual cycle, pregnancy and contraception. Your doctor can discuss these with you and may refer you to an obstetrician and gynaecologist, especially as it is still important that you have regular pap smears and breast examinations.

The good news is that with the right communication and advice, most couples can resume a satisfying sexual relationship.

Dealing with your emotions

Most people find that it takes some time to come to terms with the changes they face. You may be feeling angry about being unwell or you might have fears about the future. Talking to your social worker or doctor can help you sort out these feelings and there are many books on depression which may help you cope with these feelings as well.

No matter whether we feel well or we feel sick, everyone needs to set goals and have a sense of achievement to feel worthwhile. Start to look for all the positive aspects of your life and begin to plan some goals, no matter how small, for the future. If you can start to lift your spirits, you will find that every aspect of your life will improve.

By being more open and seeking close contact with others, especially your partner, you will feel better, as they reciprocate by being concerned and interested in you. The reassurance and closeness which results from the affection and closeness of your partner or friends and family will help to diminish your depression and anxiety.

Look after yourself

Personal appearance: Feeling unattractive can make you feel miserable. It's only natural that this in turn affects your partner and your sex life.

Take an interest in yourself by concentrating on your appearance. You might decide to try a new hairstyle. Well cut, clean and shiny hair will help to make you feel attractive and confident.

Bathing and showering can be relaxing as well as cleansing. If you have a peritoneal catheter and are discouraged from bathing, you may decide to use a bath seat and hand shower, so that you can sit in the shower and relax. A good deodorant will help to keep you fresh for the rest of the day - why not try a new perfume or after shave as well?

Dental care: Care of your teeth and gums is equally important. Regular, six-month dental check-ups, brushing and flossing are especially important when you have kidney disease.

Healthy diet: A well balanced diet, as prescribed by your doctor or dietician, will help you maintain a healthy weight and increase your level of energy. Your dietary restrictions may mean that you do not enjoy your food as much as you used to but it is essential to your whole well-being that you have an adequate intake of vitamins and protein. Your dietician can guide you in trying new recipes or adapting old favourites.

Regular exercise: Today, there is an ever-increasing emphasis on the importance of exercise. Feeling unwell and being inactive can affect your muscle tone. This can be improved by exercise, which just needs to be regular, rather than vigorous. Try to exercise a little every day and you will notice an improvement in your energy level and mental attitude. It will also help to give you a feeling of achievement and satisfaction.

While regular, gentle exercise is important, do not force yourself to do more than is comfortable. Your body will tell you when you are overdoing it. Walking, playing tennis or bowls or swimming are all possible. Clean, private pools and clean beaches are usually safe if you have a peritoneal catheter, but check with your doctor first, just to make sure.

Your attitudes & expectations

Having discussed any possible physical causes for sexual difficulties with your doctor, it is time to review your attitudes towards sex with your partner and your expectations of life together. Open discussion of the issues is important. You may be surprised to find your partner has adjusted to reduced sexual activity better than you think.

If sexual intercourse is not possible, it is important to explore other forms of sexual activity for the mutual satisfaction of yourself and your partner. These include caressing, cuddling and massage. Some of these activities can be as intimate and loving as intercourse.

Sex education

If you are planning to try new techniques, you might need to expand your knowledge of sex. There are many books written on sex and most good bookshops carry a comprehensive range. Women's magazines often feature articles on sex and can be a useful source of information for both men and women. Keep an open mind! Through reading, you can be introduced to new ideas and be better prepared to experiment with your partner.

Talk with your partner

Once you have reviewed your expectations and broadened your knowledge and attitudes, it is time to share these with your partner and find out exactly how he or she feels. This is not always easy, especially if you have drifted apart sexually. Choose a time when you are feeling well, when you are both relaxed and have time to talk and are unlikely to be interrupted. Perhaps you can use this booklet as a way of beginning your discussion. It would be a good idea if you both read it first.

Make up your minds not to be angry and not to blame or accuse. Take time to work out together how you can improve your relationship by achieving a mutually satisfying sexual relationship. Do not try to achieve too much too soon. Just aim to be understanding, close, loving and tender.

Change your habits

Think about how things might have changed and what you can do to minimise those changes. One thing to consider is if you have been sleeping separately, start sleeping together again. Another thing you can do to feel closer to your partner, is find time during the week to spend together doing things you both enjoy, without other distractions. It is important to make time for these leisure activities - it is too easy, with your dialysis schedule, to never manage to find time together having fun.

Simply by sharing some good times together, you can begin to regain the closeness you desire.

Do not feel afraid to give each other a cuddle and kiss just for the sake of it. Hold hands, walk arm in arm or with an arm around each other. All these little gestures

will enhance your closeness and help make the transition to sexual encounters less awkward.

Touching and being touched satisfies our innate need for physical contact. You might like to try to give each other a massage at the end of the day. You can use this as an opportunity to find out what each of you likes and does not like. Try to overcome your self-consciousness and be honest with your partner, as it is all part of building your closeness.

If you become sexually aroused, enjoy it and try to communicate what made you feel this way. Don't feel you have to proceed to intercourse every time. Just try to meet each other's needs and you have already reached a new kind of sexual satisfaction. Whether or not you are aroused all the way to an orgasm does not matter. The important thing to remember is that you are giving and receiving tender feelings, at the same time, reassuring each other that you are lovable, valuable and worthwhile.

Professional help

If you are finding that you and your partner are having difficulty maintaining a positive outlook, you might need to talk to someone. You might be getting angry because of residual feelings, or maybe you are not sure if you really want to be closer, or perhaps you are just finding the changes too difficult to achieve.

Your doctor or social worker may be able to help, or they can refer you to someone who specialises in sexual or marital counselling.

What next?

After reading this booklet, you might have decided that you do not really need to change anything and that you are perfectly happy and satisfied with your love life. It may also have helped you to explore some of your attitudes and practices. If you have found that some of the difficulties are familiar to you, a good time to start doing something about them is now. Start by giving this booklet to your partner to read and find time to discuss it. Then arrange to see your doctor together.

Both you and your partner can resolve many of these difficulties as long as you retain your understanding, honesty, warmth and love. Assistance is available from members of your healthcare team, who can either help directly or provide referral to an appropriate relationship professional.

Suggested reading

Take some time to browse in the self-help and health sections of your local bookshop.

The following books are highly recommended.

Everywoman Derek Llewellyn-Jones

Everyman Derek Llewellyn-Jones

Man, Woman And Relationships John Gray

Men Are From Mars, Women Are From Venus John Gray

Mars And Venus In The Bedroom John Gray

Resurrecting Sex: Resolving Sexual Problems And Rejuvenating Your Relationship David Schnarch

Caring For Sexuality In Health And Illness Diane Wells

Man Maintenance 2 Jill Margo

A Woman's Guide To Sex Kate Taylor

The Passionate Touch: The Ultimate Guide To Giving And Receiving Sexual Pleasure Nitya Lacroix

The Australian Guide To Women's Health And Wellness Lesley Hickin

100 Questions & Answers About Erectile Dysfunction Pamela Ellsworth and Bob Stanley