



Maintaining a Healthy Sex Life

Information for people with
chronic kidney disease

A photograph of a middle-aged man and woman smiling and embracing each other. The man is on the left, wearing a white button-down shirt, and the woman is on the right, wearing a black top and white pants. They are both looking at each other and smiling warmly. The background is a soft, out-of-focus light color.

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Foreword

It is not unusual for people with or without kidney disease to experience sexual health problems from time to time. Living with a chronic illness such as kidney disease adds to the weight of the normal stresses and challenges that are encountered during a lifetime. Whatever your relationship status, it is important for people with kidney disease and their partners to understand that chronic kidney disease (CKD), just like many other chronic illnesses, can potentially affect general health and well-being, libido, sexual desire and/or sexual function.

Advances in the medical management of CKD, dialysis and transplantation, over the last fifty years, have significantly improved the well-being and lifestyles of people with kidney disease. Fortunately, this has translated for some people, into an improvement in their sexual health and function. Nevertheless, in the context of CKD, the ideal of achieving and maintaining a happy, healthy and satisfying sex life and relationship can sometimes be elusive or problematic.

Throughout life, most people will confront events, issues, illness or change that can impact their lives and relationships, especially their intimate and sexual relationships. For much of last century, the term “sexual health” was generally understood to mean freedom from disease. The term sexual health is now recognised as being multi-dimensional and the product of the complex interplay between biological, psychological and socio-cultural factors.

Sexuality is an important part of who you are as a person. It is more than sexual intercourse. Sexuality involves how you feel about yourself as a man or woman, the giving and receiving of sensual pleasure, the desire for closeness with another person and the release of sexual tension.

Medical interventions and interpersonal and relationship counselling are available to help minimise and manage the effect of CKD on this aspect of life. Speaking with your doctor, social worker or trusted member of your health care team and having your concerns acknowledged and addressed, is the first step. It is hoped that this booklet will guide you in those discussions.

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Talking is a good start

For some people, talking about sexual issues, especially to their doctor, can be embarrassing. This booklet will provide you with some background knowledge about the effect of chronic kidney disease (CKD) on your sexual health. This will make it easier to talk with your doctor and other health professionals about the specific issues that concern you.

Members of your renal health care team will understand, treat your conversations with respect and confidentiality and offer treatment or referral to other specialists. Talking with an understanding and helpful health professional can relieve a lot of fear and distress. Appropriate treatment may reduce or even fully resolve your particular problem. However difficult, try to communicate your concerns and your doctor's recommendations with your partner, so that you can start to resolve the sexual health issues that may potentially affect your relationship and life together.

What changes should I be aware of?

Both men and women with advanced kidney disease, undergoing dialysis treatment or following kidney transplantation, may notice changes in their sexual interest and/or functioning. Changes in sexual function are caused by several factors. These changes vary in intensity and can occur at different times. Each individual is affected differently and each person's treatment is tailored to his or her particular situation and needs.

Men may experience reduced libido, difficulties in achieving or maintaining an erection or achieving an orgasm. Women may also notice a change in their libido, ability to become sexually aroused or to 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. For others, it can affect their overall quality of life, feelings of self-worth and self-esteem, create on-going interpersonal tensions and conflict and sometimes, relationship failure. Many relationships experience discrepancies in desire from time to time and this can especially be so when one partner has a chronic illness.

Discussing any changes you have noticed with your partner (and their reaction to them) is the first step in working out whether they even pose a problem. Then it's a matter of discovering how best to address those changes and to achieve a relationship that is satisfying for both of you.

Why does CKD affect sexual function?

Medical, psychological, relationship and social factors, either in isolation but more commonly, in combination, can contribute to changes in sexual desire and function for people with chronic kidney disease (CKD).

Medical causes

Hormones: Various hormones regulate and influence sexual interest and function and fertility. CKD can affect hormone levels in men and women and you may have noticed the effects of these changes. Both men and women may notice a change in their libido and sexual function. Menstrual periods may become irregular or stop altogether. Men may experience erectile difficulties, reduced sperm counts and motility. Medications may be prescribed to correct hormone imbalances (e.g. high prolactin levels) or to treat erectile dysfunction.

Anaemia: CKD 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 reduction in the number of red blood cells results in lowered levels of haemoglobin (the oxygen carrying pigment in red blood cells). Low haemoglobin (Hb) levels cause anaemia.

The main symptoms of anaemia are breathlessness, tiredness, pale skin, poor appetite, irritability and low sex drive. The anaemia associated with CKD can be treated with therapeutic forms of EPO. These treatments are effective in increasing red blood cell counts and haemoglobin levels. The successful treatment of anaemia has been shown to improve sexual function in people with CKD.

Medications: Some blood pressure medications, such as beta blockers, can diminish sexual interest and impair sexual function. Angiotensin-converting enzyme (ACE) inhibitors and angiotensin receptor blockers (ARBs) are associated with a lower incidence of impotence and represent useful alternative treatments for high blood pressure. Other medications may also affect sexual function. If your sexual function has changed, ask your doctor if any of your medications may be responsible.

Waste Products: When kidney function is very low or is being replaced by dialysis, waste products normally removed by healthy kidneys, accumulate in the blood and can cause unpleasant symptoms. High levels of these wastes or toxins (particularly before dialysis is commenced) may cause nausea, low energy, poor memory and concentration. Dietary changes and eventually dialysis will minimise the build-up of toxins and help you to feel well.

Excess Fluid: Many people undergoing dialysis treatment need to limit their fluid intake. When there is excess fluid in your body, you will feel unwell. Blood pressure will rise; your heart will have to work harder; you will be breathless and feel bloated and energy levels will be reduced. When large amounts of excess fluid need to be removed during dialysis, low blood pressure and cramps can result. If fluid restrictions are followed, these symptoms can be avoided.

Narrowing and Stiffening of Arteries: Cholesterol or fatty deposits called atheroma can block the arteries throughout the body, including those to the genital area. In addition, CKD causes phosphate and calcium imbalances, which can lead to the calcification of arteries. If the arteries to the genital organs are narrowed or blocked, blood flow will be reduced during periods of sexual arousal. When this occurs, sexual function can be affected. Medications and dietary changes are prescribed to control high cholesterol levels and mineral imbalances. They help to keep your blood vessels, heart and bones as healthy as possible.

Neuropathy: Neuropathy or nerve damage can occur in people with diabetes and CKD. If the nerves to the genital organs are affected, sexual function may be impaired.

Vitamin and Trace Metal Depletion: During dialysis, vitamins and trace metals can be removed. Some evidence has suggested that the depletion of zinc may contribute to sexual dysfunction. The use of zinc supplements in men who are deficient in zinc may contribute to improved sexual function.

Transplant Rejection: After a successful transplant, interest in sex and sexual function usually improves. However, treatment for transplant rejection and the anxiety and depression often associated with a rejection episode, can affect sexual interest or function.

Chronic Illness: Living with a chronic illness such as kidney disease and managing its treatment can be time consuming and tiring, especially if you are working full-time and have family responsibilities. It is not surprising that with the extra demands of dialysis or other treatments, you may sometimes feel tired and run down. It is difficult to feel interested in sex if you are tired or not feeling well.



Psychological causes

Adjustments: The degree to which your illness has affected your life and that of your family will vary but it is likely that you've 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 can create stress and drain your emotional resources and those of your partner.

Body Image: Your self-esteem and the way you feel about your body and yourself can affect your sex life. Maintaining a healthy weight, looking after your appearance and engaging in some regular exercise to stay fit will contribute towards your feeling and looking healthy and attractive.

A fistula or peritoneal dialysis catheter is a constant reminder of dialysis and may affect the way you think you look, your partner's reactions and maybe the way you make love. Coming to terms with the fact that these are a necessary and important part of your treatment may take time and an understanding partner. Sexual activity is safe and neither form of access should interfere with it.

Some people notice a change in their complexion and the thickness of their hair. High levels of urea can cause a bad taste in the mouth or breath that smells of ammonia. Optimal dialysis and dietary modifications can reduce these symptoms.

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. Everyone can feel down from time to time. However, because kidney disease and its treatment can affect many aspects of your life, you may find you become depressed more easily and more often.

Coming to terms with having a chronic illness, the changes in your body and your concept of yourself can contribute towards depressed feelings. Speak with your doctor or social worker if you feel depressed most of the time. Counselling to optimise your adjustment and antidepressant medications can really help improve your mood and coping skills. Exercising regularly can also improve your mood.

Anger: Feeling angry or distressed about all the changes in your life is very understandable. Expressing anger in a controlled way rather than taking it out on your partner can help to reduce the risk of depression. Some people find it very helpful to channel their anger through some form of physical or sporting activity. Importantly, your doctor and social worker can help you find strategies to deal with the issues causing distress.

Relationship and social causes

Lifestyle adjustments: The dialysis routine, dietary and fluid restrictions, restless nights and tiredness can all contribute to the need for lifestyle adjustments. These changes can place heavy strains on all your interpersonal relationships but especially affect your day-to-day relationship with your partner and the expression of intimacy.

A significant adjustment for you and your partner is that dialysis treatment may take up the time spent doing what you enjoy. With limited spare time, socialising out or at home with friends may not have the priority or appeal it used to have. Many people find it frustrating that their familiar ways of relaxing and enjoying themselves become more difficult. It is easy for conflict to arise when the usual ways of having fun are reduced and when extra pressures, such as financial and emotional stress occur.

It is easy to fall into a pattern where everything, including sex, becomes too much trouble. You might have even started sleeping in separate beds because restlessness or snoring keeps your partner awake or because you dialyse overnight in another bedroom. Satisfying the need for physical closeness and comfort is important to most people, especially when times are tough. So making a special effort to ensure those times are not lost altogether is very important for your relationship and a general feeling of well-being.

Sexual attitudes: Sexuality and sexual activities embrace far more than the act of sexual intercourse. Closeness, tenderness, warmth, caring, consideration, laughter, cuddling and touching are part of our sexuality and sensual experiences and pleasure. All these activities can be enjoyed even if intercourse isn't possible or desired. 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. Sexual desire can be satisfied without intercourse, by giving physical, emotional and sensual pleasure to your partner in other ways.



Sexual function, contraception & fertility

For dialysis patients and their partners

Fertility can be affected by kidney failure but this doesn't mean that women can't conceive or men are unable to father children.

Women undergoing dialysis treatment may have irregular periods or no periods at all and men may have a lowered sperm count and motility. 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 may wish to discuss the implications of pregnancy with their partner. Having a child while your partner is on dialysis can create extra demands for you both. Taking this into account may be useful when planning your family.

For transplant recipients and 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 to increase the size of your family, then it is still important that you discuss the most suitable method 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. **The safety of some immunosuppressant 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 immunosuppressant medication is minimal and safe during pregnancy. The risk 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 are best 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 or social worker can help you to clarify the issues and assist you and your partner to reach 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 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, talk with your partner and doctor about 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, the risk of transmitting these diseases via transfusion of whole blood or blood components is minimal, due to thorough screening by the Australian Red Cross Blood Service.

In the case of haemodialysis, infection control procedures are followed in all renal units to prevent the transmission of these viruses through machines or bloodlines. If you are a candidate for transplantation, 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 talk with your doctor.

Advice for partners

Kidney disease, its treatment and your partner's response will inevitably affect you. Understanding the possible impact of kidney disease on your partner will help you to strengthen your relationship and sexual life together and prevent any difficulties becoming entrenched. It is also important that your partner recognises and acknowledges your role and the adjustments you have made.

It is normal to have special concerns for your partner's health and future. You may have assumed extra duties at home or returned 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 don't 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. Even though your lifestyle may have changed, your need for sexual fulfilment has not. Even if your sexual relationship isn't exactly the same as it was before your partner became ill, it is possible to 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. Once you understand and acknowledge your feelings, you and your partner will be in a better position to adjust your expectations and work towards enjoying your life together. Your social worker can provide relationship counselling to help with these issues.

The way forward

Talk with your doctor

While talking isn't always easy, it's important to be aware that your doctor knows how important a sexual relationship is to your overall well-being and enjoyment of life. Your doctor will appreciate your concerns and explore appropriate solutions.

There may be a medical cause for your loss of libido or sexual difficulties. Anaemia, hormonal irregularities and medication side-effects can often be resolved so that sexual function improves.

If erectile dysfunction persists, several treatment options are available. Oral medication is commonly prescribed. If this is potentially unsafe (because of interactions with other medications) or is not effective for you, then other treatment options are available and your doctor will discuss these with you.

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. It is very important that you continue to see your GP for regular pap smears and breast examinations.

Sexual activity is safe after transplantation. The transplanted kidney cannot be damaged. However, if you or your partner is worried that having sex may be harmful in any way, speak with your doctor. As with any major surgery, it is wise to wait at least four weeks after your transplant before sexual intercourse. 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. Try talking to your social worker or doctor. Professional counselling is very effective in treating these problems. Sometimes, medications may be prescribed for anxiety or depression. These will assist you to cope more effectively with the stresses you face.

No matter whether we are well or sick, everyone needs to set goals and have a sense of achievement to feel worthwhile. Start to focus on the positive aspects of your life and begin to plan some goals for the future. If you can start to think more positively, other aspects of your life will gradually improve. A very simple and effective approach is to take one day at a time and make the most of each day.

Be more open and honest about how you feel and seek close contact with others, especially your partner. The reassurance and closeness which comes with the affection and care of your partner, friends and family will help to reduce your feelings of depression and anxiety.

Look after yourself

Personal appearance: Feeling unattractive can make you feel miserable and sexually undesirable. It's only natural that this in turn affects your partner and your sex life. Take an interest in your appearance. Try a new hairstyle or colour. 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. Try a new perfume or after-shave.

Dental care: Care of teeth and gums is equally important. Regular, six-month dental check-ups, brushing and flossing are especially important for people with kidney disease and those intending to have a transplant.

Healthy diet: A well balanced diet, as prescribed by your doctor or dietitian, will help you maintain a healthy weight and increase your level of energy. It is essential to your whole well-being that you have an adequate intake of vitamins and protein. Your dietitian can guide you in trying new recipes or adapting old favourites that comply with your dietary restrictions.

Regular exercise: Muscle strength and tone 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, mental attitude and general well-being. It will also help to give you a feeling of achievement and satisfaction.

Your attitudes & expectations

Open discussion with your partner of your attitudes towards sex and your expectations of life together 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, try exploring other forms of sexual activity that are mutually satisfying. These include caressing, cuddling and massage. Some of these activities can be as intimate and loving as intercourse.

Sex education

There are many books written on sex and most good bookshops carry a comprehensive range. Keep an open mind and have fun experimenting with new ideas and techniques.

Talk with your partner

Beginning a discussion with your partner about all these issues may not be 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 help if you both read it before you start a discussion.

Agree not to be angry and not to blame or accuse. Take time with each other to work out how you can improve your relationship by achieving something that is mutually satisfying. Don't try to achieve too much too soon. Just 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. If you have been sleeping separately most nights, try sleeping together, at least occasionally. Find time during the week or on weekends to do things you both enjoy, without other distractions. It is important to make time for having some fun together. It is too easy, especially with a dialysis schedule, to never manage to find time to relax and do some enjoyable things together. Sharing some good times and laughter together will help you to regain the closeness you desire.

Don't be afraid to give each other a cuddle and kiss just for the sake of it. Try to establish some kind of physical contact and show tenderness. These physical expressions will enhance your closeness and help make the transition to sexual encounters less awkward. Touching and being touched satisfies our basic 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. Be honest with your partner and have fun. It's 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. Giving and receiving tender feelings reassures each of you that you are loving, lovable, valuable and worthwhile.

Professional help

If you and your partner are having difficulty maintaining a positive outlook and are experiencing other relationship difficulties, it is recommended that you seek professional counselling. Your doctor or social worker can help or if you prefer, can refer you to a sexual or marital counselling specialist.

What next?

After reading this booklet, you may not need to do anything other than to celebrate your health and relationship! Alternatively, you may be reflecting on the fact that it might be time to review some of your attitudes and practices. If some of the difficulties described in this booklet sound familiar, give this booklet to your partner to read and find time to discuss it. Then arrange to see your doctor together.

It is possible that you and your partner will successfully resolve the issues that you currently face, with a combination of medical treatment and counselling. Healthy relationships contribute to your overall health so maintaining yours is a legitimate concern. Don't overlook or neglect your partner or your relationship. Treasure and nurture them.

Suggested reading

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

The following books are 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

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