



Module 11

# Sexuality and Fertility



## Module 11 – Table of Contents

Feeling Good About Yourself .....	11-4
Kidney Disease and Body Image .....	11-6
Fatigue or Lack of Desire .....	11-10
Communicating with Your Partner .....	11-13
Male Sexuality .....	11-15
Female Sexuality .....	11-20
Male Fertility .....	11-24
Female Fertility .....	11-26
Sexuality and the Child with Kidney Disease .....	11-33
Personal Plan .....	11-37
Take the Kidney Quiz! .....	11-39
Additional Resources .....	11-40

### Please Note

Use of Kidney School does not replace the need to talk with your health care team about your care and your options.

### Legal Disclaimer

The information you find on the Life Options website or printed pages, including Kidney School, is provided “as is,” and to the extent permitted by law, the Life Options Rehabilitation Program, the Medical Education Institute, Inc., and their affiliates, employees, officers, board of directors, or shareholders give no warranty of any kind, either express or implied, including without limitation any warranties of condition, quality, performance, merchantability, fitness for a particular purpose, or non-infringement in relation to information, services, or products provided through or in connection with the Life Options website or printed pages. To the extent permitted by law, the Life Options Rehabilitation Program and the Medical Education Institute, Inc. disclaim all liability for any damages or injury caused by any failure of performance, error, omission, deletion, defect, access to, alteration of, or use of record, whether as a result of breach of contract, tortious behavior, negligence, or under any other cause of action. The contents of the Life Options website and printed pages, including, but not limited to text, graphics, and icons, are trademarked materials owned or controlled by the Medical Education Institute, Inc. *No permission is granted here for you to reprint in whole or in part Life Options or Kidney School content, graphics, illustrations, photographs, or icons.* (Revised March, 2015)

a	(10.)	b	(5.)
b	(9.)	a	(4.)
c	(8.)	c	(3.)
c	(7.)	d	(2.)
d	(6.)	b	(1.)

Congratulations, you've finished the quiz! Here are the correct answers so you can see how you did:

### Module 11 – Kidney Quiz Answers





**E**d has been married for 11 years to his second wife, Maria. Lenore has been dating her boyfriend for 8 months. Robert is afraid his partner will leave him. Sarah wants to have a baby with her husband.

What do they all have in common? Kidney disease.

Sexuality and having children are central to many people's relationships and lives. So when you learn that you have kidney disease, some of the many questions you have may include: how will this affect my relationships? Will my partner stay with me? Will anyone new want me when I'm not "perfect?" Can I still have children?

These are important questions, and it is often hard for us to talk freely about them. We may have been taught never to discuss religion, politics, or sex in polite company. Some of us were raised not to talk about sex with others—even those we're closest to.

You don't have to talk to anyone about what you learn here. But we hope that when you're done,



you'll want to share your questions or concerns with your health care team and your partner.

In the first part of this module, we'll cover issues of sexuality and kidney disease, including:

## Sexual Relationships

Just as in the general population, people with kidney disease can be heterosexual, homosexual, or bisexual. Your health care team will provide the same level of care regardless of your sexual orientation. You can choose whether to talk about your sexual orientation with your health care team. Your social worker can answer questions about sexuality.

Although many people with kidney disease are married or in relationships, you may live alone because you are widowed, divorced, or because you never married. If you want to

meet other single, widowed, or divorced people, your social worker may be able to suggest groups in your area.

You bring your personality into any relationship so remember, *you are still you* even though you have kidney disease. On the other hand, you may be happy without a partner and have plenty of friends and activities to keep you busy and happy. Just don't isolate yourself. Studies have shown that having a social network helps people do better with any chronic illness, including kidney disease.



- Feeling good about yourself
- Kidney disease and body image
- Fatigue and lack of desire
- Communicating with your partner
- Sexuality and fertility
- Pregnancy in women with kidney disease
- Special information for parents of children with kidney disease

So, let's get started!

### Feeling Good About Yourself

In our culture, there are many stereotypes about sexuality. In American society, people in their late teens, 20s, and 30s are seen as “sexy” while people over 50 or 70 may not be. Even healthy people may try to “turn back the clock” as they age; taking pills or using creams and hair dyes, or even having plastic surgery to look more youthful.

We may feel as if we're not measuring up—and that's even when we're healthy! You may have heard that sex begins in the mind. It's true! Feeling good about yourself and your body is key to a healthy sexual relationship.

### Healthy Aging

Older people—even those in their 70s, 80s, and 90s—are often more accepting of their bodies than younger people. They say their quality of life is good. If they enjoyed sex when they were younger, they may still do so. They can have good relationships with their partners, whether or not they have sex.

*“I'm comfortable enough in myself not to care what other people think of me. This is me—I can't change it. What's perfect? To be good looking? Well off? That means nothing to me; I don't like perfection. And if anyone is looking for it, they're wasting their time because it doesn't exist. When I meet someone, I tell them up front about my kidney disease. I never thought of it as a dark secret. I'm not ashamed. This is me, take it or leave it. Some people may be turned off, but that's okay. I can see how they may feel about it. I admit it took me a while to feel this way about it. But I feel lucky to be alive! And I'll say it until the day I die.”*

You may believe that having a chronic disease means being less than a whole person, especially if you're feeling tired, or doing less than you used to. But if you think of yourself as less than you used to be, unattractive, or unlovable, you may stop visiting friends and family who could give you support. You may avoid social events where you could meet new people. And if you have a partner, you may start to push her or him away.

*“My wife and I went through some rough times. I had no desire to have a physical relationship for a few years. Luckily she stuck with me, through that and everything else, and now we have a good relationship again. For us, keeping the discussion open and honest helped. Also knowing that things can change over time was important.”*

### Self-talk

The words you use to talk to yourself are very powerful. The thoughts you have in your own mind that you may never say out loud are “self-talk.” These thoughts and beliefs play a big part in how you feel about yourself. Examples of negative self-talk might be, “nobody will want me now,” “I'm worthless,” or “I have nothing to look forward to.”





With practice, you can learn to turn your negative thoughts into positive self-talk. This will speed up your coping and make your relationships better. How can you do this?

If you talk with people who've had kidney disease for a while and coped well, you'll find that they look on the bright side, feel good about themselves, and take pride in what they've done. Here are some positive thoughts, or "affirmations" that have helped others who have lived 15 years or more with kidney failure:

- "I want to live."
- "I am still me."
- "I am still valuable."
- "I am in control."

Try saying these to yourself a few times each day, and whenever you catch yourself thinking something that makes you feel bad about yourself. If your own efforts are not enough, ask your doctor or social worker to refer you to someone who can work with you. "Cognitive behavior therapy" can help you change negative self-talk.

*"Because of some of the after-effects of kidney disease—like skin problems and body image problems when I was on PD, for example—I felt less attractive, less desirable, and so I took myself 'offline' that way. I found myself thinking that since I had kidney disease and was on dialysis, no one would want me anymore. I had to work through a mourning process—the loss of my health, feeling betrayed by my*

## Protecting Against Abuse

Although no one likes to think about it, someday you could become a victim of physical, emotional, or sexual abuse. Don't let yourself become a victim just because you have kidney disease. To protect and empower yourself, learn as much as you can about how to avoid places where you might be abused, how to know signs of abuse, how to defend yourself, and, finally, know your legal rights and how to stand up for them.

Report abuse to the police, seek physical and/or psychological exams, and help the police prosecute anyone who abuses you. You could be protecting yourself and others who might be victims. To learn more, see the resources at the end of this module.

*body, accepting my frailty, which all of us share—and move to self acceptance. I have gotten to a place where I feel that I deserve love and acceptance from the opposite sex, and now I comport myself as if that is true."*

## Staying Connected

If you worry that you might lose your partner's love, you may think it's better to end the relationship than wait for your partner to end it. But, like other challenges, if you work together as a couple, you can adjust to kidney disease and have a loving relationship. Like many other couples, some people with kidney disease do get divorced. Others say that kidney disease brought them closer as they faced it together.

A counselor can often teach you better ways to talk with each other. If you and your partner are having trouble talking about your relationship, talk with your social worker about finding someone to help you.



### Ladies: Makeup Can Even Out Skin Tone

Well-applied makeup can help to even out your skin tone; hide blemishes, wrinkles, and acne; and make you feel more attractive. Department store cosmetic counters may offer free makeovers and advice about products. Ask the salesperson about skin-tone correcting foundation and other tips to help you look your best.

You don't have to spend a lot of money, though. Studies have shown that low-cost drugstore brands often have the same ingredients and quality as the pricey ones.

The truth is, no one is perfect! With or without kidney disease, very few of us look in the mirror and are fully happy with what we see. We all need to make peace with ourselves, and our faces and bodies.

Feeling good about yourself—and being willing to be intimate with a partner—is not just a matter of how you look. It has to do with accepting who you are and your value in the world. You need to believe that you are a good, worthwhile, interesting person who deserves to be happy.

*“My PD catheter is just another proudly-worn battle scar that makes me unique.”*

### Does Your Skin Tear Easily?

Some people on dialysis find that their skin becomes very thin and fragile. It may tear at the smallest impact, causing red or purple sores that are slow to heal. This problem, called *porphyria* (por-fear'-ee-uh) or *pseudoporphyria*, can make you feel self-conscious! The good news is a dermatologist (skin doctor) can treat this problem and help your skin get better.

*When I meet someone new, I always lay all my cards on the table. It is much easier to proceed from there. It's true that many run when they learn of my impairments, but that only saves me from any greater trauma later on and they just weren't my type anyway. Maybe it takes a little courage to overcome fear of rejection.”*

### Kidney Disease and Body Image

There are some aspects of kidney disease that may affect how you feel about your body (called “body image”). These include:

- Skin changes
- Ammonia breath
- Hair changes
- Weight loss or gain
- Surgical scars

You can do something about many of these changes.

#### Skin changes

A build up of waste products that your kidneys no longer remove can cause changes in your skin color. If you are white, your skin may look gray or have a yellowish tinge. If you're African-American, your skin color may darken. The more dialysis you get, the healthier your skin color will be. Getting a kidney transplant—or doing longer or more frequent hemodialysis—may return your skin color to normal.

Other skin changes are common in people on dialysis, as well. Dry, itchy skin can make you less willing to be close to your partner. Some causes of dry skin, and some solutions, are in the table on the next page.





*“I’m 26 and on hemo. My skin is super-sensitive and any bump rips my skin...my hands look horrible. I have scars all over them from very small bumps and scratches! It’s awful. No sooner does one heal—which takes forever—than I get another! This is not dry skin. I use lotion all the time and my skin is not dry...”*

### Ammonia breath

As your kidneys fail, you may notice an ammonia taste in your mouth. This comes from a build-up of waste products your kidneys can no longer filter. Your breath may have an ammonia smell, too. To freshen your breath, brush your teeth, gums, and tongue a few times a day, use mouthwash, and suck on regular or sugar-free candy. If you are on dialysis and have ammonia breath or an ammonia taste, you may not be getting enough treatment to stay healthy (see Module 10—*Getting Adequate Dialysis*).



### Hair changes

Like skin, hair can be affected by kidney disease and dialysis. When people start dialysis, they may have thinning hair. Hair is made of protein, and in the months before dialysis, many people eat less protein. In about 3 months, your hair will start to grow back.

## Dry, Itchy Skin: Causes and Solutions

Cause of Dry, Itchy Skin	Possible Solution
High blood phosphorus levels	More dialysis removes more phosphorus. Think about doing daily or nocturnal hemodialysis (HD). Take phosphate binders as directed. Using moisturizing creams (e.g., Eucerin®) or ointments (e.g., Aquaphor®, Vaseline®), which have less water than lotions, can help.
Not enough dialysis	Think about doing daily or nocturnal HD. If you do standard in-center HD treatments, stay for the full treatment time, make up time lost to machine alarms and other causes, and/or ask for more dialysis. If you do PD, be sure you are getting enough treatment.
Alcohol-based skin products	Check the ingredients and look for alcohol-free products.
Allergy to medication, detergent, or even the dialyzer, lines, or bags	Pay attention to when you itch. Is it all the time? Just on dialysis? This can help you narrow down the cause.
Allergy to bleach on dialysis chair	Bring along a towel to sit on.



### Hair Where You Don't Want It

Blood pressure and transplant drugs can make hair on your face and body grow more. You can remove the hair with hair removers, wax, or electrolysis or bleach the hair with a 50% peroxide solution. There are even drugs to help slow hair growth. Don't stop taking your blood pressure or transplant drugs because of the side effects. Talk with your doctor or nurse to see what can help you.

Of course, people do lose some hair as they age, but brittle or thinning hair can be caused by chemical hair treatments, too. Poor nutrition, zinc deficiency, drug side effects, thyroid problems, and other hormone imbalances are other things that can affect your hair. Tell your doctor if you notice thinning hair so he or she can assess and treat it. Ask your doctor if over-the-counter hair growth drugs are safe for you to take.

### Weight loss or gain

If you worry about weighing too much or too little, talk with a renal dietitian. He or she can suggest things to eat that will help you gain or lose weight:

### Limb Loss and Body Image

Diabetes is the leading cause of kidney failure, and also the leading cause of limb loss. Amputation can affect your body image as well as your mobility. If you and your partner are coping with limb loss, you'll need to give yourselves time to grieve the loss and adapt to it.

It helps to talk with someone else who has gone through the same thing. The Amputee Coalition of America can help you find answers and resources. Their contact information is in the resources section at the end of this module.



- If you are on standard in-center HD it may be easy for you to gain fluid weight but not so easy to gain *real* weight.
- PD dialysate has sugar in it. You may need to limit other carbs to avoid putting on weight.
- If you have a transplant, you may gain weight or your face may become rounder from the steroids you have to take. These problems may fade when your doctor reduces your drug dosage.

Good nutrition and exercise can help you live well and feel good about yourself.

*“My husband is a very attractive man, raised in a family that is fanatical about looks. Let's just say that my polycystic kidney disease (PKD) has given me that 9 months pregnant look...oh, to have my waistline back. I have always had a weight problem, but I had a figure at least! So what can you do about it? You can thank God daily that you are still drawing breath and be who you can be and do what you can do. I find that when I am able to help someone else, my own troubles fade.”* –Deb, on home hemodialysis







*“I had just, after years of working on it, lost [weight] and was for the first time in years feeling great about my figure when I started CAPD. Now, a year later, I am 20 pounds overweight, plus the big belly. No wonder I don’t feel attractive to my husband. He is more than understanding. He is more than willing. He doesn’t seem to have a problem with it, but I sure do.”*

## **Surgical scars**

As we get older, surgeries and accidents have a way of marking us. You can view your scars as signs of the battles you have fought and won. Or, you can be embarrassed about them and hide them from others. The scars are the same either way—and the choice is yours. No one wins the battle with kidney disease without scars from vascular accesses, PD catheters, or a kidney transplant. No matter what your body looks like on the outside, you are still the same on the inside.

*“Bob and I have gotten to the level of kidding about the PD catheter and transfer set. I tell him he looks like a character in a sci-fi movie—like he can plug himself into any system. When I first saw the tube, I really liked it because it’s keeping my husband alive and hopefully living a good life. It’s his lifeline, and I am sooo grateful it’s there. We both like his tube!”*

## **Sex and the vascular access**

If you worry that having sex will hurt your fistula, graft, or catheter, talk to your doctor or nurse. Ask how you can protect your access during sex. In general, you need to avoid putting direct pressure on a fistula or graft. Keep a catheter clean and dry and avoid tugging or pulling on it.

If you do standard in-center HD three times a week, you may be too worn out on a treatment day to feel like being intimate. Ask your doctor about daily or nocturnal HD. Patients who do these treatments say they have more energy—and much better sexual function, too. In fact, when patients were surveyed, those on standard three times a week HD rated their sex lives as 1.6 on a scale of 1 to 10 (with 10 high). Patients doing daily home HD rated their sex lives as 4.4. And, those doing nocturnal home HD rated their sex lives a 9.2.

Here’s what one person said about doing daily HD: *“One thing I’m really thankful for is the return of my libido. I’m not joking here. When it is gone you don’t really miss it, but when it is there, you wouldn’t want to lose it for the world.”*

Nocturnal HD creates a new set of challenges. If you get treatments in a center, you are away from your partner three nights a week, which is something to get used to. At home, you may not want to have sex while the machine is running. This may mean that you need to be flexible with your timing (e.g., before you start the machine at night or after you stop in the morning) or where you choose to be with your partner.

## **Sex and PD**

If you use PD, you may not feel different before and after an exchange. But give yourself time to get used to having fluid in your belly. If the fluid bothers you, your PD nurse can tell you if it’s okay to have sex between a drain and fill, with or without a cycler.

Tape your catheter well or use a PD belt to keep it out of the way. If you want to have sex while on a cycler, be sure to place the line so it won’t get crimped.



*“Sam is still as sexy to me as he ever was, even with that little tube coming out of his belly. We have an active and satisfying sex life. To us, it includes holding hands, caressing, flirty looks, smooches, having intercourse—verbally and physically—and whatever else becomes a part of ‘making love’. Even Sam’s clearing the table or my taking out the trash—the idea is that doing for the other is an act of love. Sexuality is bigger than the bedroom mambo.*

*“Yes, I miss the Sam who was stronger and didn’t have the little pot belly—and he misses my svelter self. But that doesn’t make him any less attractive to me. He is not just a body, he is my soulmate and partner. That is what makes him so wonderful and loving and lovable—and sexy. The mechanics of CCPD require moving the tubes around a bit to fit our positions and body parts if he is on the machine when we become aroused, but they are hardly a deterrent! We talked about this briefly when he had his catheter put in, and while on CAPD it was only a small distraction.”* –Mary Lou, wife of Sam

### Too Tired to Tango?

If fatigue or joint pain is a problem for your sexual relationship, you may want to rethink your position on sex—literally.

Couples may believe the missionary position is the “right” way to have sex. But there is no right way. You may use less energy (and have just as much fun) if you try lying on your sides facing each other, “spooning,” having your partner on top, or even sitting in a sturdy chair with your partner facing you. You don’t have to use the *Kama Sutra*, but a little experimenting can help you to have a more fulfilling sex life.

### Sex and a kidney transplant

Talk with your transplant surgeon about how long you should wait to have sex after you get home, and if there are any sexual activities you should postpone. In general, the rule of thumb is, if it hurts, don’t do it.

### Fatigue or Lack of Desire

So far in this module we’ve covered how helpful it is to feel good about yourself, and some ways that kidney disease can affect your body image. But what if you’re just so tired that you don’t want sex? We’ll cover causes and solutions for fatigue and lack of desire in this section.

### Anemia

One common reason for feeling worn out with kidney disease is *anemia*—a shortage of red blood cells. Kidney disease can make your body less able to form red blood cells, which carry oxygen to your muscles. Anemia can reduce your interest in things you enjoy. Symptoms of anemia include:

- Fatigue/loss of energy
- Feeling cold all the time
- Pale skin, gums, and fingernail beds
- Shortness of breath/chest pain
- Trouble concentrating
- Lack of interest in sex
- Erectile problems

*“I’ve been on dialysis now for almost 4 years, and I found that my libido did decline when I was having problems with kidney disease, but not dialysis per se. When my anemia got really bad about 2 years ago, I began to worry that*



**Normal red blood cell count**



**Anemic red blood cell count**

*I would forget what sex was like! Now that my blood is strong and I'm doing better, well, let's say there's more of a 'rev' in my engine again."*

The good news is, anemia can be treated—and you can feel better and have more energy. Treating anemia early may also help prevent heart damage. Let your treatment team know how your fatigue is a problem in your life. To learn more about anemia, visit Module 6—*Anemia and Kidney Disease*.

## Chewing Ice? You May Have Anemia

Another common symptom of anemia in people with kidney disease is called *pica*—or having the desire to chew ice, clay, or even laundry starch. The reason for this link is unclear, but if you notice this, ask your doctor about anemia treatment.

### Other health problems

Other health problems can also make you tired or reduce your interest in sex. These include:

- Diabetes
- *Neuropathy* (nerve damage)
- Poor blood flow
- Hormone imbalances, like low testosterone levels

- Zinc deficiency
- High blood pressure
- Blood pressure drugs
- Depression

If you have—or think you might have—one of these problems, talk to your care team about getting help. Your relationship is worth it.

### Lifestyle behaviors

Besides health problems, some lifestyle behaviors that can affect your sex life include smoking, drinking a lot, and using street drugs like marijuana and cocaine. Reducing or avoiding these behaviors can improve your health as well as your sex life.

When you're tired all the time, it's tempting to just sit around and save your strength. But this leads to weak, flabby muscles and even *more* fatigue.

### Jump-starting Desire

Regaining your interest in sex is easier if you *think* about sex. Spend some time each day focusing on all of your senses by noticing colors, textures, and smells around you. Get a massage with lotion or oil.

Exercise can help get your blood flowing and increase a healthy interest in sex. Aerobic and weight lifting exercise are both helpful. (Get your doctor's okay before starting an exercise program.)

Couples who want a happier sexual relationship should talk about it and look for ways to improve it. Some people have found that romantic music, soft lighting, pleasant aromas, books or movies with romantic or sexual content, or even sex toys can bring fun and excitement into a loving relationship.



## Talking About Sex with a Partner

Even couples who know each other very well may feel uneasy talking about sex, or asking for things that would help them to enjoy it more. Pick a quiet time and place where you can have privacy. Use “I” statements to talk about what you feel without blaming.

If there are certain ways that you would prefer to be touched, it may work better to show rather than tell. Guide your partner’s hand, and let him or her know how you would prefer to be touched.

Even though it sounds backwards, being active doesn’t “use up” your energy. Instead, it helps you have *more*. Walking is one of the best forms of exercise and more fun if you do it with a friend. Talk with your doctor about joining a fitness club or other ways of safely staying active.

Raising your energy level through exercise will help you do more things you enjoy, including sex. To learn more about exercise read Module 12—*Staying Active with Kidney Disease*. Sleep problems, which can cause fatigue, are in that module, too.

## Using “I” Statements

Problem	Common Statement	“I” Statement
Feeling unattractive	“You think I’m ugly.”	“I feel like you don’t find me attractive now.”
Needing household help	“You expect me to do everything myself.”	“I feel overwhelmed and need help.”
Money concerns	“All you ever think about is money.”	“I feel worried about how we’re going to pay our bills.”

*“My libido was affected when my lupus flared up the first time 11 years ago. My body ached all over, I was exhausted and was consumed by my illness, physically and emotionally. Since then, I have gone through periods of remission and then I feel better again, and my energy comes back. Kidney failure was one more ‘challenge’ for me. It was a doozy!”*

*“How you feel about yourself matters! If you don’t like what you see in the mirror, it is hard to feel ‘sexy’. That’s when the real challenge began for me, when I could watch my body change before my very eyes. I’d gain weight, then lose weight. I lost my muscle tone. I didn’t feel attractive even though my husband was telling me I was. That called for a good therapist! Someone outside myself and my family to remind me that it really is what’s on the inside that counts; that the core of my being was still very much the same as before my disease.*

*“Exercise helps my libido too. Getting out and doing physical things like walking, riding a bike, and working out. If I sit still too long, everything starts to slow down, including my sex life.”*

## Not enough dialysis

Not enough dialysis is another source of fatigue that can reduce interest in sex among people with kidney disease.

Standard in-center HD treatments clear wastes from your body three times a week. You may feel tired and “washed out” after a treatment. Soon after each treatment, wastes start to build up again. If you are able to do daily or nocturnal HD, these more frequent treatments reduce “dialysis hangover”. People who do more frequent HD say they sleep better, have better quality of life, and they have better sexual function.



PD treatments can become less adequate over time as your kidney function decreases. Your doctor should check the adequacy of your PD every 3 months or so. To learn more, read Module 10—*Getting Adequate Dialysis*.

## No desire

Lack of desire for sex is a common problem among many people in the U.S.—with or without kidney disease. Fatigue is one reason for it: you may just be too tired to think about sex. But if fatigue is not the cause for your lack of interest, think about your answers to these questions:

- Do I feel safe, respected, and loved by my partner?
- Do I feel guilty about how my illness has changed our lives?
- Do I like myself and my body enough to enjoy sex?
- Do I trust my partner to treat me kindly and gently?
- Do I feel calm, happy, and secure?
- Do I feel like I can talk openly with my partner?
- Have I had help coping with a past sexual trauma?
- Do I get enough alone time to recharge my batteries?
- Do I *ever* feel interested in sex? (If so, when?)
- Do I feel satisfied by sex with my partner?
- Other: \_\_\_\_\_

Sometimes people lose interest in sex because they set it aside for a while to deal with more pressing issues. But the longer you and your partner go without sexual contact, the harder it can be to start back up again. You may both be worried about being rejected. Or you may even just feel a little silly.

Sharing your bodies can make you both feel vulnerable. It's normal to want to protect yourself.

If your last encounter did not go so well, it may loom larger and larger in your minds as time passes. Talking to your partner or finding a therapist you can trust can help you resolve the past and head into the future.

Poor sexual relations can also be a reason for loss of desire. If your sexual needs are not being met, or you do not feel love and trust for and from your partner, you may not want to try again.

Depression and anxiety, or past rape or abuse are all problems that can be helped by your renal social worker or a counselor. With or without kidney failure, feeling safe, respected, and valued is vital in any relationship.

## Communicating with Your Partner

Companionship, good communication, and sex are the “glue” that helps keep partners together in a relationship. It's easy when you have kidney disease to get so wrapped up in what's happening to you, your treatment, and your changed life that you ignore those around you.





You may believe your partner has it much easier than you do. But he or she is living with kidney disease and changed hopes, dreams, and plans, too. Always putting your own needs first can harm your relationship.

On the other hand, sometimes people don't want to say what they're thinking or feeling because they are afraid they'll hurt their partner's feelings. Keeping your feelings inside won't help—and it can also hurt your relationship.

When you are angry or frustrated, try not to take it out on your partner. You might be surprised when you talk openly about your illness that your partner feels just as bad about it as you do.

### Sharing information

If you feel less attractive or less interested in sex, share the reasons with your partner. Most people (including your partner) are not mind readers. Unless you share your feelings, you can't expect



your partner to understand them. You may assume that if you *feel* less attractive, your partner *finds* you less attractive. This may not be the case—but the only way to find out is to talk about it.

You may even be surprised to find that if you are less interested in sex, your partner may think *you* don't find *him* or *her* attractive! Snuggling, hugging, and holding hands are ways that you can help reassure your partner that you still care.

Sometimes partners have different levels of interest in sex, also called *libido*. If your libido is much higher or lower than your partner's—or even if one of you prefers sex in the morning and one of you prefers it at night—it can cause problems in your relationship. Again, this is something you'll need to talk about.

### Improving intimacy

You can improve intimacy in your relationship. Which of the ideas below would you be willing to try? Check all that apply:

- I will talk about issues that mean a lot to me and ask my partner to do the same.
- I will share my feelings.
- I will let my partner know if something bothers me and ask my partner to do the same.
- I will listen to my partner's point of view and be willing to compromise.
- I will make time for intimacy.
- I will let my partner know what I want.
- Although it's hard, I will admit when I make a mistake.
- I will respond to my partner's needs and feelings.
- I will limit television time to allow time to talk.
- Other: \_\_\_\_\_





By choosing to be more proactive, you're taking a first step toward a higher level of intimacy in your relationship.

Now let's learn a little bit more about male and female sexuality, starting with male.

## Male Sexuality

To better understand male sexuality, it helps to know a little bit about how healthy men's bodies work.

When a man is aroused, blood flows into the spongy corpus cavernosa chambers of the penis. As more blood flows in, the chambers fill up. A valve closes at the base of the penis, shutting off the blood vessels that carry blood out. This creates and maintains an erection.

If the penis doesn't work like it once did, there can be many reasons for it. First, as men age, they will often have fewer and less firm erections than

when they were younger. Many couples find that any reduced quantity is more than made up for by an increase in the quality of their time together.

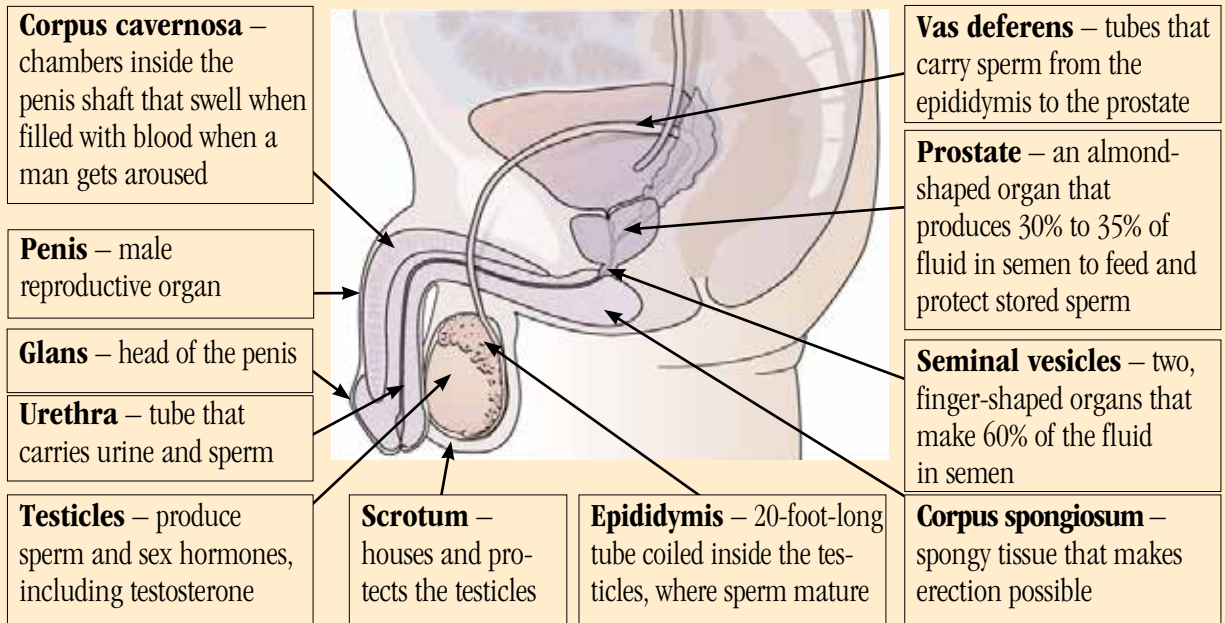
Medical words used for absent, soft, or short-lasting erections are *impotence*, or *erectile dysfunction* (ED). ED is more common in chronic illnesses like diabetes and kidney disease and in men as they age.

Kidney disease *may* or *may not* have an effect on sexual function. Some men with kidney disease

### ED Is More Common Than You Think

Researchers estimate that 10 to 15 million American men have ED, including 35% to 50% of men with diabetes. There are 525,000 doctor visits for impotence annually—and countless more men don't seek treatment that could help them because they are embarrassed to talk about it.

## Review of Internal and External Male Anatomy





have no problems. Other men on dialysis or with transplants have reported:

- Less interest in sex
- Trouble getting an erection
- Erections that are less firm than usual
- Trouble keeping an erection long enough for sex
- Less frequent sex
- Less satisfaction with sex

*“I’m 33 and on PD. We have one child but want another soon. I am sexually functioning, though, to be honest, my interest has plummeted. I used to think about sex every minute or so—now it is more like every hour! I’ve been on dialysis 10 months and things have finally improved. Like all men I dread impotence, especially while I’m still quite young. I was told HD was much more likely to cause it than PD, but over a long period of time.”*

*“After 2 years of HD, 27 years with a transplant, 1 year of CAPD, and now HD again—because I wasn’t getting enough dialysis, plus a lot of BP medicine—a firm erection has become a problem.”*

Why can ED be related to kidney disease? There are several reasons:

### Men: Give Your Testosterone a Lift

Did you know that weight lifting is a non-medical way to raise testosterone levels and increase stamina? You’re never too old to start weight lifting. Even people in their 80s and 90s can gain muscle strength from lifting weights. If you’re interested in starting a weight lifting program, talk to your doctor.

- 1 **Less testosterone.** Like aging, kidney failure can reduce sex hormone levels. If a man’s hormones are out of balance, it can cause lack of libido and ED. Hormone levels can be checked with a blood test—and a testosterone skin patch or injections can help treat the problem.
- 2 **Not enough dialysis.** “Adequate” dialysis may be enough to keep you alive, but not enough to make you feel your best. If you do standard in-center HD three times a week, ask your doctor about doing daily or nocturnal HD.
- 3 **Anemia** is another reason why ED is common in kidney disease. Men with kidney disease say that treatment with *erythropoietin* (EPO)—a hormone that tells the body to make more red blood cells—helps their libido and reduces ED.
- 4 **Diabetes**, the most common cause of kidney disease, causes blood flow problems throughout the body, including the penis. Good blood sugar control can help a man stay as sexually healthy as possible.
- 5 **High blood pressure**, another common cause of kidney disease, can damage blood vessels and reduce blood flow to the penis, making it hard to get an erection. Controlling blood pressure can help keep blood vessels healthy and an erection firmer. Also, some blood pressure drugs can cause a problem.
- 6 **Increased levels of the hormone prolactin** is a treatable problem which can reduce libido and cause ED.
- 7 **Depression** can rob you of energy and lower interest in usual activities, including sex. Anti-depressants can also affect sexual function.

*“I was having problems with not being interested in sex. I went to an endocrinologist and he tested my testosterone levels. The normal*







*range for the test is 300 to 1,200; mine was 125. I now give myself a 200 mg shot of testosterone enanthate every other week. This has made a big difference in my interest in sex. Testosterone is also an anabolic steroid. It helped me gain almost 50 lbs of muscle that I lost with my kidney failure.”*

## Medications

Besides kidney disease, more than 200 drugs may have sexual side effects in men—like reduced libido, ED, or trouble reaching orgasm. Which of the medications below are you taking? Check all that apply:

- Antianxiety drugs or sedatives** (like Ativan<sup>®</sup>, Tranxene<sup>®</sup>, Valium<sup>®</sup>)
- Antidepressants** (like Prozac<sup>®</sup>, Paxil<sup>®</sup>, Zoloft<sup>®</sup>)
- Antihistamines** (like Benadryl<sup>®</sup>, Antivert<sup>®</sup>, Phenergan<sup>®</sup>, Vistaril<sup>®</sup>, Dramamine<sup>®</sup>)
- Antipsychotic drugs** (like Haldol<sup>®</sup>, Mellaril<sup>®</sup>, Thorazine<sup>®</sup>, Risperdal<sup>®</sup>)
- Blood pressure drugs** (like Tenormin<sup>®</sup>, Indural<sup>®</sup>, Lopressor<sup>®</sup>, Apresoline<sup>®</sup>, Catapres<sup>®</sup>, Vasotec<sup>®</sup>, generic drugs ending in “olol”)
- Cholesterol-lowering drugs** (like Zocor<sup>®</sup>, Pravachol<sup>®</sup>, Lipitor<sup>®</sup>, Lipid<sup>®</sup>)
- Heart drugs** (like Digoxin<sup>®</sup>)
- Diuretics**, to remove extra fluid (like Lasix<sup>®</sup>, Zaroxolyn<sup>®</sup>, Diuril<sup>®</sup>)
- Finasteride**, for hair loss
- Muscle relaxants** (like Flexeril<sup>®</sup>)
- Prostate drugs** (like Proscar<sup>®</sup>)
- Stomach drugs** (like Reglan<sup>®</sup>, Tagamet<sup>®</sup>)
- Anabolic steroids** (like Durabolin<sup>®</sup>, Deca-Durabolin<sup>®</sup>)
- Tranquilizers** (like Thorazine<sup>®</sup>, Haldol<sup>®</sup>, Prolixin<sup>®</sup>, Compazine<sup>®</sup>)



*“My sex drive had been dropping for a few years, but since there was no loss of performance I wasn’t really worried. I just didn’t watch women go by on the street. A scantily dressed female at a store would just go by me without me even seeing her. After I started dialysis my desire came back, but there is a slight loss of performance. At least I think so. Been so long I can’t remember! Twenty-three years of marriage does that, you know.”*

Ask the doctor if changing a drug, dosage, or timing could help reduce sexual problems.

## Nerve damage and blood flow

Nerve damage or reduced blood flow to the penis can cause ED that is not related to kidney disease.

### Smoking Can Add to ED

Cigarette smoking narrows all of the blood vessels in the body—including the blood vessels to the penis. Without enough blood flow, erections become less firm and less frequent. Smoking also makes kidney disease progress more quickly. Quitting smoking can improve overall health—and your sex life!



This kind of injury can be caused by surgery or accidents, such as:

- Prostate surgery
- Bladder surgery
- Previous transplant
- Surgery for blood flow to the legs
- Spinal cord disease or injury
- Injury to the penis

Blood flow to the penis can sometimes be helped with surgery or drugs. Nerve damage is harder to treat. Nerves severed by prostate surgery may grow back in time (in 1 year or more). Some doctors offer nerve-sparing surgery for prostate cancer. Recently, surgeons have also begun to transplant nerves to the penis—a promising approach.

Men who are having sexual problems can ask for a referral to a *urologist*—a doctor who specializes in the genitourinary system. The urologist may:

- Take a medical and sexual history
- Do a physical exam
- Do a psychological assessment
- Order lab tests to measure blood sugar and hormones
- Assess erections
- Test blood flow to your penis
- Test the nerves going to and from your penis

If the doctor cannot find a physical reason for ED, stress and other emotions may be a factor.

*“When I was on PD, my self-esteem was really low and I hated the tube sticking out of my belly. I never wanted sex and I thought that no woman would ever want me. I could get an erection, but my heart just wasn’t in it. I was not as attracted to women as I had once been. It was like I felt that since I had very little chance of being with them, they were not as attractive to me anymore. Once I started HD that all changed. After a while I got my self-esteem back, and started to feel better about myself. My sex drive increased tenfold. It’s like my body decided it needed to catch up on those 3 years it missed out on; I feel like an 18 year old again! I think it’s mostly a matter of how you feel about yourself. I started to feel good about myself and since then my sex drive has gone up.”*

### **ED: Physical or Psychological**

Some men believe ED is “all in their heads.” Actually, most ED has a physical cause. Only about 10% to 20% of impotence is due to psychological causes.

Healthy men have 5 to 7 erections each night while they sleep. If erections occur while sleeping but not with a partner, ED may be psychological. If erections don’t occur in sleep, the cause is likely physical.

### **Low libido**

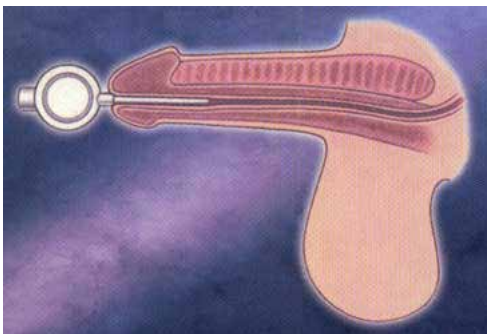
Low testosterone levels can reduce desire. This problem can be treated. Ask your doctor about testosterone patches or weight lifting to help increase testosterone levels without drugs.



## Rare, soft, or short-lasting erections

There are many treatments that can help if your erections won't permit intercourse. If the problem is an erection that goes limp, here are some solutions:

- **Oral drugs:** Viagra® (sildenafil), Cialis® (tadalafil), and Levitra® (vardenafil HCL) increase blood flow to the penis. They are not for men with severe coronary artery disease who need nitroglycerine. If you have a transplant, you may need a different dose. Ask a pharmacist about drug interactions. Other oral drugs are now being tested or may be on the market.
- **Sex therapy:** A qualified sex therapist can help couples work on issues of self-esteem, communication, stress reduction, and realistic expectations.
- **Prostaglandins:** These products work by causing smooth muscles in the penis to relax so the corpus cavernosa can fill with blood. Alprostadil is a pellet called Muse® that you insert into the urethra (see picture below) or a drug you inject (Caverject® or Edex®) into the penis, using a tiny needle (see picture, top right). Do not use this drug if you have sex with a pregnant woman, since prostaglandins can trigger labor.



- **Surgery:** Surgery can sometimes increase blood flow to the penis. Penile implants are made in either rigid or flexible forms.



- **Vacuum suction:** Devices like ErecAid® or Post-T-Vac® force blood into the penis, then keep it there using an elastic band at the base.



As you can see, there are many ways to help men with ED to have sex. But before we leave this section, there is one more thing that is good to know.



A common belief that can keep men from enjoying their sexuality is the idea that all sexual activity must lead to intercourse—or their partners will be disappointed. But there are many other ways to enjoy sexuality and to satisfy a partner, like:

- Conversation
- Hugging
- Kissing
- Snuggling
- Massage
- Masturbation
- Oral sex
- Focusing on “non-sexual” areas, like your partner’s ears, neck, ribs, knees, etc.

Your most important sex organ is between your ears: your brain. Showing your partner that you care, being loving and tender, and sharing your lives together—the good and the bad—can help you have a more satisfying sex life, despite kidney disease.

Now, let’s review female sexuality.

### Female Sexuality

To better understand female sexuality, it helps to know a little bit about how healthy women’s bodies work.

When a woman becomes aroused, her vagina lubricates and expands. The labia and clitoris fill with blood—like a male erection. If arousal goes on, the clitoris almost disappears under its hood, and the labia minora puff up to triple their normal size and turn dark red. The skin of a woman’s throat and chest may flush.

If she is stimulated enough, for long enough, orgasm can occur: the pelvic muscles, uterus, and bottom third of the vagina contract. Her heart rate, breathing, and blood pressure increase. After orgasm, blood leaves the genitals, the flush fades, and some women perspire.

It is easier for most women to reach orgasm in their 30s and 40s, but 5% to 10% of women do not have orgasms. In fact, this is the main reason why women seek sex therapy. Lack of desire and pain during intercourse are other common reasons for seeking help.

For a woman, being able to have an orgasm during intercourse has a lot to do with feeling comfortable with her body and safe with her partner. A woman who can reach orgasm alone is much more likely to be able to have one with a partner.

Many people believe intercourse can cause a woman to have an orgasm. But for most women, intercourse alone does not stimulate the clitoris enough to make orgasm happen. If a woman or her partner touches the clitoris during intercourse, orgasm is much more likely.

### Medications

Earlier in this module, we talked about things that can cause lack of sexual desire in people with kidney disease. Besides body image and relationship issues, there are some other factors for women, too.

Many medications can have sexual side effects in women, like reduced desire, changes in the menstrual cycle, or trouble reaching orgasm. If you are a woman, which of the medications below are you taking? Check all that apply:



- ❑ **Amphetamines** (like Dexadrine<sup>®</sup>, Ritalin<sup>®</sup>, Ephedrine<sup>®</sup>)
- ❑ **Antianxiety medications** (like Xanax<sup>®</sup>, Valium<sup>®</sup>)
- ❑ **Antidepressants** (like Prozac<sup>®</sup>, Paxil<sup>®</sup>, Zoloft<sup>®</sup>, Elavil<sup>®</sup>)
- ❑ **Antipsychotic medications** (like Prolixin<sup>®</sup>, Haldol<sup>®</sup>, Thorazine<sup>®</sup>, Stelazine<sup>®</sup>, Mellaril<sup>®</sup>)
- ❑ **Antihistamines** (like Benadryl<sup>®</sup>, Zyrtec<sup>®</sup>, Claritin<sup>®</sup>, Clarinex<sup>®</sup>, Allegra<sup>®</sup>)
- ❑ **Birth control pills**
- ❑ **Blood pressure medications** (like Inderal<sup>®</sup>, Lopressor<sup>®</sup>, Tenormin<sup>®</sup>, Corgard<sup>®</sup>)
- ❑ **Cholesterol lowering medications** (like Lipid<sup>®</sup>)
- ❑ **Heart medications** (like Digoxin<sup>®</sup>)
- ❑ **Lithium**
- ❑ **Sleeping pills**
- ❑ **Steroids** (like prednisone, prednisolone)

Ask the doctor if changing a drug, dosage, or timing could help reduce sexual problems.

## Menopause

Another factor that can reduce the desire for sex in women with kidney disease is something that will one day affect all women—menopause.

Aging changes a woman’s hormone levels. Starting 5 years or so before menopause, women may have perimenopause: irregular periods, breast tenderness, night sweats, hot flashes, sleep problems, and mood swings. Women with kidney disease may have perimenopause at a younger age than other women.

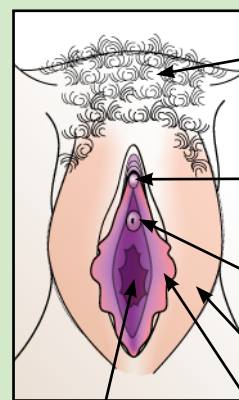
Menopause—when the ovaries stop making estrogen and periods stop—normally happens between the ages of 45 and 55. The result can be reduced sexual interest, less lubrication, menstrual changes, and reduced fertility. Many lubricant products are on the market that can help with vaginal dryness. Some can even be discretely inserted before intercourse. Any drugstore will have choices for you. Personal lubricants are often kept near the condoms.

## Pain

Pain during intercourse, or *dyspareunia*, can reduce sexual desire as well. If vaginal dryness is not the reason, it’s a good idea to talk to a gynecologist. The pain can often be treated.

Shingles, a painful reactivation of the chicken pox virus that affects the nerves, may be the cause

## Review of External Female Anatomy



**Mons pubis** – fatty tissue over the pubic bone

**Clitoris** – small, bulb-like, nerve-filled tissue solely for sexual arousal

**Urethra** – place where urine exits the body

**Labia majora** – hairy outer lips

**Vagina** – canal from the uterus to the outside of the body

**Labia minora** – hairless inner lips that also form the hood over the clitoris



of some vaginal pain. If this is the problem, treatment with prescription Acyclovir® cream or other shingles drugs may help.

A rare condition called *vaginismus* can cause the muscles around the vagina to contract, also causing pain and making it hard to have intercourse. A doctor can help find the cause and suggest treatments that have a high success rate.

### Health exams

Follow the recommended schedule for pelvic exams, Pap smears, breast exams, and mammograms to screen for cancer and other gynecologic problems.

### Hormone Replacement Therapy: Yes or No?

Some doctors recommend hormone replacement therapy (HRT). For years women have been told that HRT helps protect them from heart disease, ovarian cancer, and osteoporosis.

But a large study found that women who have a uterus and are on estrogen/progestin therapy have a higher risk of heart attack, stroke, invasive breast cancer, and blood clots.

For women who have had a hysterectomy and are on estrogen-only therapy, HRT may also cause a higher risk of ovarian cancer. Each woman needs to talk to her gynecologist about the risks and benefits of HRT.

If a woman does not want to take HRT, other options may include:

- Changing the diet
- Stopping smoking to improve blood flow
- Exercising more

The American Cancer Society says this includes:

- **Pelvic exam** – each year for women aged 40 or older
- **Pap smear** – each year for women who are sexually active or starting at age 21, or every 2 years with the new liquid-based PAP test; every three years if three Pap smears in a row have been negative
- **Breast exam** – every three years for women aged 20 to 39, yearly for women aged 40 or older
- **Mammogram** (low dose breast X-ray) – each year for women aged 40 or older
- **MRI** – women who know that they are at high risk for breast cancer (20% lifetime risk) should get an MRI each year plus a mammogram. Women at somewhat increased risk should ask their doctor about getting an MRI each year. Having a breast cancer gene, a personal history of breast cancer, or close relatives with the disease raises your risk.

If you have sexual problems, a gynecologist is also a first source of help. An exam will turn up any physical problems, and blood tests can check hormone levels. A gynecologist may ask about:

- Menstrual history
- Sexual activity and history
- Past surgeries
- Safe sex practices
- Pregnancies
- Frequency of or pain during intercourse
- Ability to have orgasms
- Any symptoms

Depression can also rob you of your energy and lower your interest in things you enjoy, like sex.



The gynecologist will look for things that can affect sexual function, like:

- Signs of a hormone imbalance
- Gynecologic conditions (bladder infection, incontinence, endometriosis, vaginal infection)
- Past surgeries (breast cancer, hysterectomy, abdominal surgeries)
- Drugs with sexual side effects

He or she may also ask lifestyle questions, because some activities can add to sexual problems. It's not known if smoking causes sexual problems in women, but smoking can make it harder for men to have normal erections. Alcohol and street drugs can cause sexual problems, too.

## Communication

Sexuality is complex, and your body and mind must work together. If you're not "in the mood," be careful of your partner's feelings. Don't assume that he or she can read your mind about how you feel or what you do or don't like. Communicate.

Even when you don't want to or can't have sex, there are many things you or your partner can do to stay close. In today's stressful world, it is



important to relax. Choose which of these tips might help you and your partner feel closer, even without sex:

- I will schedule a date with my partner.
- I will make our environment more pleasant (e.g., dim the lights, play soft music, and use scented candles).
- I will remember what attracted me to my partner in the first place and think back to how we used to spend hours talking together.
- I will put off some obligations or tasks until later.
- I will give my partner a neck, shoulder, back, foot, or hand massage.
- I will ask for a neck, shoulder, back, foot, or hand massage.
- I will offer to play a favorite game or watch a television movie together.
- I will make an effort to touch my partner's arm or hand or offer hugs and kisses more often.

## Coordinating Different Specialists

As someone with kidney disease, you are most likely seeing a nephrologist, who specializes in your kidneys. You may also have an internist or general practice doctor, and other specialists. If possible, try to be sure that each of your doctors knows how to consult with the others so you get the best care.

If your gynecologist or another doctor writes you a prescription, protect yourself! Check with your nephrologist or a pharmacist before you fill it. Some commonly-used drugs are not safe for people with kidney problems or need to be taken at a different dose or frequency.



Whether or not you have sex, take some time to relax and focus on things that feel good as ways to get in touch with your sensuality. Showing your partner that you care, being loving and tender, and sharing your lives together—the good and the bad—can help you have a more satisfying sex life, despite kidney disease.

### Male Fertility

Men on dialysis or with kidney transplants have fathered healthy children. But kidney disease can reduce the number and quality of your sperm. This can make it harder to fertilize the egg. Doctors define “infertility” as a couple not getting pregnant after more than a year of trying. If you and your partner want to have a baby of your own, it may be wise to involve your doctor up front.

The fewer years on dialysis, the more plentiful and active your sperm may be, so sooner may be better than later—but this may be hard to think about if kidney failure is recent and the future seems to be in question. Only you and your partner can decide what’s right for you.

If you and your partner are having trouble getting pregnant, it is always easier to check out the man first. A sperm sample can be analyzed for how many sperm are present, whether they are fully developed, and if they are moving well.

### Millions and Millions

An adult man produces millions of sperm every day. The average amount of semen ejaculated is about 1 teaspoon—which usually contains 100 to 600 million sperm!

*“I am on PD, four exchanges a day for 1.5 years. My wife and I had a 9 lb. baby boy 2 weeks ago after trying for 2 years.”*

*“My wife and I have been trying to start a family for about 3 years with no luck. During this time I’ve noticed a decline in my sex drive. I saw one urologist who was reluctant to do anything because of the dialysis, other than the basic tests that found that I had a low serum testosterone and low sperm count. He seemed to think there was little to nothing that could be done. So then it was time for another opinion from a urologist my nephrologist suggested. I got a different story...the low sperm count, in his opinion, was a direct result of the lower testosterone.”*

It only takes one sperm to fertilize an egg. But to improve the chances that fertilization will happen, most men make about 100 million sperm each time they ejaculate. If you have fewer sperm than normal, or they are not active, it can take longer to achieve a pregnancy.

With a sperm count in the lower ranges, you and your partner may be able to raise your chances of having a baby by yourselves. How? Here are some options:

- 1 Time intercourse to ovulation** (release of an egg). Some women can feel when they ovulate: they get cramping. Or, a woman can take her temperature each morning before she gets up and watch for a slight increase. Ovulation test kits from drugstores, are another way to find out when a woman ovulates. The most fertile time is from two days before to two days after ovulation.
- 2 Position the woman on her back during and after sex.** Propping a pillow beneath a woman’s hips will tilt her pelvis so sperm stay







close to the uterus. From there, it is a shorter swim to the egg. Staying in that position for 10 to 15 minutes after intercourse will give the sperm the best chance of reaching the egg.

- 3 Have sex every other day during the fertile time.** This allows you to build up a higher sperm count.

Many factors can affect sperm count, sperm movement, and fertility. Tell your doctor if any of these apply to you:

- I've worked with lead or some chemicals in solvents and herbicides.
- I'm taking stomach drugs (like Tagamet®).
- I'm taking steroids (like prednisone).
- I'm taking drugs for a urinary tract infection.
- My mother took DES when she was pregnant with me.
- I have a *varicocele* (varicose vein above the testicle).
- I had mumps after puberty.

Low sperm counts may also be caused by certain behaviors. Since sperm are made all the time stopping these behaviors may improve your sperm count:

- Smoking marijuana
- Smoking cigarettes
- Using hot tubs or taking hot baths
- Wearing close fitting underwear (briefs) or tight fitting shorts (such as biking shorts)

If your sperm count is very low or the sperm are all inactive, you and your partner will likely need medical help to conceive. Your doctor can help list your options. You and your partner will need to talk about what you want, and what you can afford, to do.

## Can a Kidney Transplant Improve Male Fertility

It can. In most cases, sex hormone levels and sperm counts return to normal shortly after a kidney transplant. However, some men with transplants still report problems with sexuality and fertility.

## Birth control

If you are not ready to have a child or have been advised not to have children, you will need to use birth control. The only 100% fail-safe way to prevent pregnancy is not to have sex.

For men, condoms and vasectomy are two birth control options. Properly used condoms are one of the best methods of birth control. So, what's "properly used?" Once your penis is erect, *any* drop of fluid contains sperm. So a condom must be used *before* any genital contact occurs, and

## Avoiding Sexually Transmitted Diseases

According to the Centers for Disease Control and Prevention, 65 million people in the U.S. have an incurable sexually transmitted disease (STD). Each year, 19 million new cases of STDs are diagnosed. The most common STDs are genital warts—also called *human papillomavirus* (HPV), *trichomoniasis*, *chlamydia*, and *herpes*. Using a condom can reduce your risk of getting an STD. Having multiple sexual partners may increase your risk. Always practice safe sex if you or your partner have sex with multiple partners. Be sure to tell your doctor right away if you have any questions about or symptoms of STDs.



### What About Withdrawal?

There is an old joke about “What do you call couples who use withdrawal for birth control?” Parents! Pulling out before ejaculation still allows some sperm to enter a woman’s body, so it is not a good way to prevent pregnancy—or STDs.

stay on until *after* ejaculation. And, latex condoms are also the best way to prevent HIV and other STDs.

Use a water-based lubricant (like K-Y® or Liquid Silk) with latex condoms, not an oil-based one (like Vaseline®). Because latex is oil-based itself, oil-based lubricants can dissolve it. Polyurethane condoms are thinner and stronger than latex and can be used by someone with a latex allergy. You may need to use more lubricant, but either water- or oil-based products are okay. Don’t use Nonoxynol-9 (N-9) with a condom if you or your partner has HIV. Allergy to N-9 can cause sores, making it more likely to transmit HIV.

### Reversing a Vasectomy

There are two ways to reverse a vasectomy:

- If the epididymis is scarred from a vasectomy the surgeon can connect it to a new section of the vas deferens in a procedure called a *vasoepididymostomy*.
- If the epididymis isn’t scarred, the doctor can reconnect the two ends in a procedure called a *vasovasostomy*.

In some cases, a second try at reversing a vasectomy has worked. It can take from three months to as long as a year to know if the surgery will work, so it’s best to have it as early as you can once you know that you want to try.

### Vasectomy

Surgical sterilization, or vasectomy, is 99.5% to 99.9% effective at preventing pregnancy. To do a vasectomy, the doctor numbs the scrotum and vas deferens. He or she makes a tiny cut or puncture in the scrotum to locate the vas deferens and sew it shut, tie it off, or remove a small section to prevent sperm from reaching the urethra. Insurance usually covers it.

Think about what might happen before you have a vasectomy. If something happened to your children, might you want another child some day? What if you don’t stay with your partner? While vasectomy can be reversed, the surgery is costly (\$5,000–12,000) and is not covered by many insurance plans. If it has been more than 15 years since your vasectomy, it is less likely to work. You may need a testicular biopsy to see if you still have enough sperm to make the surgery worth trying. Reversal surgery may not help you to father children.

### Female Fertility

To better understand female fertility, it helps to know a little bit about how a healthy woman’s body works. At birth, her ovaries have 400,000 to 700,000 eggs, but only about 400 of them will ever be released. Each month, from puberty to menopause, hormones cause one egg to ripen and burst free. This is called *ovulation*. Once free, the egg travels into one of the fallopian tubes.

### A baby? Maybe

Some women of childbearing age who have kidney disease or kidney failure want to know if they can have a baby. Can they? Maybe. Pregnancy is rare and high risk, but it may be possible with





extra medical care. Women with kidney disease, transplants, and even dialysis have carried healthy babies to term.

As kidney function drops, you may start to have irregular periods. Toxins building up in your blood can affect hormones. Although 42% of dialysis patients of childbearing age have periods, half of them are irregular. This makes it harder to get pregnant.

Heavy periods can make anemia worse. Treating anemia and getting a lot of dialysis or having a working transplant improves your chances of having regular periods during the childbearing years.

*“I know that women aren’t advised to get pregnant while on dialysis, and some say that dialysis patients become infertile. I could do dialysis forever if I knew I’d be able to have kids. A big reason for my transplant wish has to do with kids. If it’s not gonna last for me, at least I might have the chance to have a baby.”*

Many women with kidney disease don’t know that:

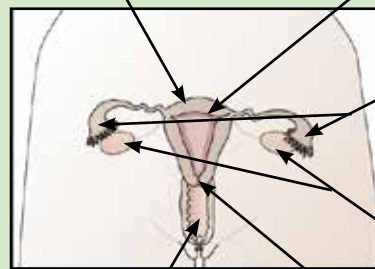
- Women on HD may need to reduce heparin (a blood thinner) on the first few days of their periods.
- Women on PD may see a small amount of blood in their PD bags around ovulation time or near their periods.
- Women with transplants may have irregular periods for the first few months after transplant.

Of course, just having a period is not enough to make a pregnancy possible. Ovulation, fertilization, implantation, and then normal growth must also occur. Each of these steps is less likely with kidney disease.

## Review of Internal Female Anatomy

**Uterus (womb)** – place where a baby can grow

**Endometrium** – lining of the uterus that sheds monthly if the woman is not pregnant



**Fallopian tubes** – passageway from the ovaries to the uterus

**Ovaries** – produce eggs

**Vagina** – the birth canal

**Cervix** – narrow end of the uterus that opens into the vagina

## Getting pregnant with kidney disease

Some couples decide that what they really want is the chance to be parents, and it’s okay if the child is not biologically theirs. Others decide that if they cannot have their own child, they would rather stay childless. This is a very personal decision. There are no right or wrong answers.

## Do Your Homework

There are a number of studies about pregnancy outcomes in women with kidney disease, dialysis, and transplant. Arming yourself with the facts can help you make an informed decision.

You can visit the free Medline site offered by the National Library of Medicine at [www.pubmed.gov](http://www.pubmed.gov), and search for articles to read and share with your doctor.



Women who know they have kidney disease and want to have a baby need to find a nephrologist to explain the risks and support them through a pregnancy. Not every nephrologist will be willing to do this—it may take many tries to find one who will.

If a man with kidney disease and a very low sperm count (less than 20 million) wants to become a father, there are a number of options (see page 11-29). However, many health insurance plans do not cover fertility treatments.

### Pregnancy and risks

If a pregnancy does occur, it is high risk. During a normal pregnancy, kidney function rises by as much as 150% by the end of the first trimester. The extra function helps to support a pregnancy. The kidneys even grow larger by a centimeter or so.

In a woman with chronic kidney disease (CKD), pregnancy may speed up the rate of kidney failure because it puts more stress on the kidneys. More protein is lost in the urine during pregnancy, which may harm the kidneys. One study found

that 16% of pregnant patients with CKD lost some kidney function. The cause of the CKD (i.e., diabetes) did not make a difference—unless the cause was lupus.

In a woman on dialysis, pregnancy has about a 50% chance of resulting in a living infant, and 80% are premature. Preterm labor and stillbirths are increased. Getting *much* more dialysis—20 or more hours per week—is vital. Higher levels of water soluble vitamins are needed, since some will wash away during the treatments. Higher doses of EPO are also needed to make sure you have enough red blood cells to bring oxygen to the fetus. Very careful control of blood pressure is needed, as high blood pressure is a danger to you and to a fetus. Steps will also need to be taken to watch for and prevent preterm labor.

### Infertility treatment options

If you and your partner decide that the risks are worth taking, but you have trouble getting pregnant, there are a number of ways to help a woman with kidney disease try to have a baby.

Many health insurance plans do not cover fertility treatments. Different centers charge different rates; treatments can be very costly; and success rates vary depending on the treatment needed, the quality of the sperm and egg, and the skill of the staff. There are very few experiences with the following treatments in women on dialysis.

Success statistics are given in two ways: *pregnancy rate* or *live-birth rate*. Pregnancy rate means that the embryo (the fertilized egg created in a lab dish outside of the body) has successfully implanted and can be seen on an ultrasound.

### Lupus and Pregnancy

Pregnancy with lupus is possible, though it may not be easy. About half of the time, pregnancy is quite normal and results in a healthy baby. And, about half of women with lupus will have a flare during pregnancy, which can raise the risk of kidney damage. About one in four women with lupus will deliver prematurely. When a flare during a pregnancy causes kidney damage, doctors may suggest an early birth if the pregnancy is at least 34 weeks. If it is earlier than that, you may have a difficult choice to make between your kidney function and the fetus you carry.





A live-birth rate means one or more babies were born as a result of the treatment. Rates will vary from center to center, so be sure to ask your doctor.

**Intrauterine insemination (IUI)** – Semen is collected and placed near your cervix or uterus during your most fertile time (ovulation). The pregnancy rate is higher if semen is put into your uterus. IUI costs from \$300 to \$800 per session. Using IUI, you and your partner can have your own biological child.

**Mixed IUI** – An anonymous donor's sperm can be mixed with your partner's and placed near your cervix. Using donor sperm raises the cost of IUI. You may or may not have your partner's biological child. IUI and mixed IUI work best if you are under age 41.

**Conventional in vitro fertilization (IVF)** – Your egg is mixed with your partner's sperm in a lab dish. The fertilized eggs are then returned to you. The cost per IVF may be \$8,000 or more. With IVF you have your own biological child, but there is a risk of multiple births.

**Intracytoplasmic sperm injection (ICSI)** – A variation of IVF that is sometimes used if your partner has a very low sperm count, low sperm motility, or sperm that are not well formed. As in IVF, eggs are taken from you. Sperm are removed from your partner's testicle or epididymis in an outpatient procedure. One sperm is injected into each egg, and one or more fertilized eggs are put into you. The cost may be \$1,500 to \$2,000 plus IVF. As with IVF, you have your own biological child, but if more than one egg is returned, there is a risk of multiple births.

## Boys, Boys, Boys...

Although boys are born in 51% of all births in the general population, in artificial insemination, 60% of the children born are boys.



**Frozen embryo transfer (FET)** – Extra embryos collected during the IVF process can be frozen so that you can try again. Or, in some cases, couples who have been successful may donate their unused frozen embryos. FET is not very invasive and has been done since the '80s.

**Adoption** is another way that infertile couples can have a child. The cost depends on the type of adoption—public adoption agency, private adoption through an attorney, doctor, and/or an agency, or an international adoption agency. Public agencies may require more information and background checks of potential parents. They may limit adoptions to people under a set age. Adoptions through private or international agencies may be less restrictive. Couples where one member has kidney failure *have* successfully adopted children.



### Medications

If you have kidney disease and think you might be pregnant, talk with your doctors *right away*—and don't take *any* drug without your doctor's okay. Some drugs can harm a growing fetus. Tell your doctor if you are taking any of these drugs:

- ❑ ACE inhibitors (like Altace® or Capoten®) can cause fetal death
- ❑ Angiotensin receptor blockers (ARBs)
- ❑ Some beta blockers (like Tenormin®) can cause slow fetal growth
- ❑ Migraine medications (like Ergotamine®) can cause miscarriage
- ❑ Tetracycline can cause discolored teeth in the baby
- ❑ Aspirin or nonsteroidal anti-inflammatories (NSAIDs, like Advil®, Aleve®, Celebrex®, Motrin®, Naprosyn®, Nuprin®, Orudis®, Toradol®, Vioxx®) can cause bleeding in the mother or fetus and interfere with labor
- ❑ Acne drugs (like Accutane®) can cause birth defects and miscarriage
- ❑ Sleep medications (like Phenobarbital®) can cause birth defects, bleeding, or breathing problems in the new infant
- ❑ MAOIs for depression (like Nardil®, Marplan®, Parnate®) may make the baby slow to breathe, cause sleep apnea and feeding difficulties, and/or lead to poor muscle tone
- ❑ Lithium may make the baby slow to breathe and have sucking problems
- ❑ Benzodiazapines (like Valium® and several other psychotropic medications) have been linked to birth defects in the first trimester

Many other drugs can be harmful, and the greatest danger is in the first three months when a fetus is developing—and you may not know you are pregnant.

Your behaviors can harm a growing fetus:

- Even small amounts of alcohol can cause infant growth problems, and alcohol abuse can cause birth defects, lower IQ, and behavioral problems in children.
- Moms who smoke during pregnancy are likely to have lower weight babies with breathing problems, and there is a link between smoking and sudden infant death syndrome (SIDS).
- Moms who use cocaine, especially crack, are more likely to have babies with severe birth defects.
- Moms who use heroin, morphine, codeine, or opium are likely to have addicted babies.





### Extra pregnancy precautions

If you become pregnant, extra medical care is needed to ensure the safety of you and the fetus. The type of care will depend on your kidney disease treatment. We'll go over each type. It is very important to have *both* a high-risk obstetrician and a nephrologist or transplant team caring for you.

*You need to know your kidney lab test values and blood pressure.* Check your blood pressure often. It is wise to buy a blood pressure cuff and learn how to check it at home. Your doctor may change your blood pressure drugs to others that protect your kidneys while not harming a fetus. Tracking your blood pressure and lab test results in a notebook will help you to know what is going on with your health. Lab tests should probably be done more often than once a month.

You will also need to be aware of and report any symptoms of possible kidney problems. These include:

- **Fluid build-up** – swelling in the face, hands, or feet; shortness of breath; puffiness around the eyes
- **Changes in urination** – if you make urine, tell the doctor if you have more or less urine than usual, a change in urine color, bubbly or foamy urine, pain or pressure when urinating

- **Anemia** – feeling cold all the time; pale skin, gums, or fingernail beds; shortness of breath; a desire to chew ice or clay
- **Changes in taste for food** – a metallic or bad taste in the mouth, ammonia taste or breath, losing the taste for protein (such as meat, chicken, or fish)

### Pregnancy with kidney disease

If you get pregnant, your kidney function should be tested often because the advancing pregnancy can cause a drop in your kidney function.

### Pregnancy with transplant

The first child was born to a woman with a kidney transplant from her twin in 1958. Today, reports from the National Transplantation Pregnancy Registry (NTPR) find that the chance of having a live birth was 71% to 76%, though preterm birth is more likely. The chance of losing the kidney within two years of a pregnancy was 4% to 13%. If you become pregnant, your doctor may prescribe:

- A change in dose or type of transplant drug
- An increase in the EPO dosage

### National Transplantation Pregnancy Registry (NTPR)

The NTPR is an ongoing study founded to look at pregnancy outcomes of female transplant recipients and those fathered by male transplant recipients.

Transplant coordinators, physicians, and transplant recipients are asked to submit a 1-page questionnaire on the NTPR website. We'll provide contact information in the resources section at the end of this module.



A pregnancy with a transplant is high risk, due to the need to balance your health, your transplant, and the health of the fetus. High blood pressure is common. You will likely need to see the doctor more often during a pregnancy than someone who has not had a transplant.

A study of 30 patients reported to the NTPR found that babies born to women with kidney transplants who took mycophenolate mofetil (CellCept®) had more birth defects. No birth defects have been found in patients who took sirolimus (Rapamune®). If you take CellCept and want to have a baby, talk with your transplant doctor. Talk with your transplant doctor and your OB/GYN about whether it is safe to breastfeed while taking transplant drugs.



Doctors from the American Society for Transplantation say that it's safest to try to get pregnant when:

- The kidney is working well (creatinine is less than 1.5 mg/dL, with less than 500 mg of protein in the urine in 24 hours)
- Transplant drug doses are stable (and the drugs are taken as prescribed)

### Pregnancy with HD

If you are on HD, your nephrologist will change your treatments to help you keep the pregnancy. Some of these changes may include:

- Daily or every-other-day dialysis (20+ hours/wk.)
- Lower levels of bicarbonate in the dialysate
- Less heparin and the use of saline to flush the dialyzer instead, to reduce the risk of bleeding
- A higher EPO dose to treat anemia
- Higher protein diet (more than 1.5 g/kg per day)
- The obstetrician may prescribe medication if premature labor starts

### Pregnancy with PD

If you are on PD, your nephrologist will change your PD dose to help you keep the pregnancy. Some of the changes may include:

- Smaller, more frequent exchanges or larger volume exchanges
- A higher protein diet
- Checks for catheter problems, leakage, or peritonitis
- Use of a cycler later in pregnancy to allow frequent smaller exchanges, or adding hemodialysis to PD to get better adequacy







- Betamethasone from week 28 on to ensure good fetal lung development
- Indomethacin, if premature labor starts
- Possible bed rest

If you need a c-section, you may be able to resume PD with more frequent small volume exchanges 24 hours after delivery. Over time, the volumes slowly increase and the number of exchanges can be reduced to the pre-pregnancy prescription.

## Breastfeeding

Breastfeeding is a big question for women on dialysis who have babies. Only one scientific study has been published on this topic, in 1986, and it found that high levels of sodium and kidney wastes in the bloodstream made the milk of the three women studied unsafe for infants.

Many drugs can appear in breast milk at levels that can be harmful to infants. It is suggested that you not breastfeed if you take cyclosporine or azothioprine. Consult with a nephrologist, obstetrician, and/or pharmacist before you decide whether to breastfeed.

## Birth control

If you are not ready to have a child or have been advised not to have children, you will need to use birth control. The only 100% fail-safe way to prevent pregnancy is not to have sex.

Women with kidney disease who are of childbearing age should use birth control to avoid an unplanned (or unwanted) pregnancy. Some options for family planning are included in a table in the Personal Plan. Talk with a gynecologist about the best options for you.

As you can see, sexuality and fertility are important issues that require communication. The good news is, there is much you can do to improve your relationships.

## Making the decision

Deciding when and if to have a baby is a big life issue for nearly everyone. It is even more complex when kidney disease is added into the picture. Only you and your partner can decide what is best for you, and how much risk you are willing to take.

If you decide you want to have children in your life, but do not want to have a baby, some people on dialysis and with transplants have been able to adopt. Surrogacy, where another woman carries a child that genetically belongs to a couple, may be another option.

Your renal social worker can help you explore your choices and help you find resources and people to talk to.

## Sexuality and the Child with Kidney Disease

When you have a child with a chronic illness, your first instinct may be to protect him or her. But treating your child as if he or she were healthy will provide him or her with a sense of responsibility, positive self-esteem, and independence that will serve your child well through life and in future relationships.



One way to urge your child to be independent is to *expect* him or her to go to school and play with other children. This will help your child become a part of a community of peers. Don't let your child off the hook for chores and family duties. Let him or her find a way to do what you require.

*“From the time I was 2 years old I (and my parents) knew that I had ‘a rare form of nephritis with no known cure’. The absolutely best thing a doctor ever told my parents was that if they wanted me to have any kind of a decent life, to treat me just as they would treat a child without a chronic illness. My parents succeeded at following that advice most of the time, and I think it made a big difference in my life.”*



Between the ages of 5 and 12, many children begin to have crushes—and your child may, too. Talk to him about sexuality. Children with kidney disease are just as likely to have sex as healthy children when the time comes.

### The View in Retrospect...

*“When I first started my ‘ESRD Life,’ I was 13 years old and so embarrassed about the ‘tube’ (back then you had an external graft) in my arm while on dialysis and its scars after it was pulled post-transplant. At that time a friend of the family told me I should be proud of those scars!*

*“I could not fathom that concept at all. People stared and asked questions I was embarrassed to answer because of my access. Why should I be proud of that? I felt that those scars just showed that I wasn't as good as everyone else. I wore long-sleeved shirts, even on the 90 degree scorches we get most summers. I wouldn't swim. I was miserable.*

*“But after a while I realized that I was letting others' ignorance of my medical condition dictate my comfort and limit my living life to the fullest. I began (slowly, I admit) to wear short-sleeved shirts and shorts, and even began to wear a bathing suit and swim again. I also tried to answer people's questions, since I felt that it would be better for the whole ESRD community the more people understood about what we go through.*

*“I am so glad I figured out that I had every right to wear what I felt like wearing and doing what I was able to do. If I hadn't I'd really be in a fix now, as I've had six more arm accesses and two leg accesses over the years, and would have to stay covered head to toe if I let other folks' opinions bother me!”*





If you feel awkward talking about sex with your child, welcome to parenthood! Many people feel the same way, but it is vital for you to share your values and knowledge with your kids. There are books and videos you can use together, and your child's health care team can help, too.

## Parenting through puberty

As you know from having been there yourself, puberty is a time of major physical and emotional change. Girls tend to develop about 2 years earlier than boys. They start to grow breasts as early as 8 and can have periods as early as 10, though most girls begin having periods at 12 or 13.

Expect a daughter with kidney disease to develop about 2 years later than a healthy child. More than half of girls with kidney disease do not have periods until they are 15. Girls on dialysis may have their first period sooner than those with transplants. Reassure her that this is very normal. If your daughter has kidney disease, her doctor may want her to avoid over-the-counter pain pills like Motrin<sup>®</sup>, Advil<sup>®</sup>, or Aleve<sup>®</sup> for cramps, because these drugs can make kidney disease progress more quickly.

If she is on dialysis, encourage her to tell her care team when she gets her period each month, because fluid retention can affect her weight. The amount of heparin she receives during HD may need adjusting to keep her from having heavier periods. If she's on PD, she may find that she notices blood in her drain bag around the time she ovulates or has her period.

Healthy boys can produce sperm when they are 11, although full sexual development occurs later. Boys with kidney disease have a 2- to 3-year delay

in genital growth. Both boys and girls with kidney disease start their growth spurt about 2 years later and have a shorter growing time, so they don't grow as tall as their healthy classmates. As a result, they are likely to be short teenagers and adults. Hormone treatments can help a child with kidney disease to be taller.

Pre-teens and teens are very conscious of their appearance. At this stage, they compare their bodies with their peers and with societal role models—often cheerleaders, athletes, models, and movie stars.

Because they grow later and are shorter, children with kidney disease often feel less mature than their peers. Adults and other children often make this worse by viewing and treating them as if they're younger. This can be very upsetting for a pre-teen or teenager with kidney disease who wants to be seen as mature and independent.

## Faking It

Although children with kidney disease have times they feel okay and times when they feel sick, some chronically ill children pretend they are sick when they're not to stay home from school. You and your child's health care team will need to assess when your child is sick and when he or she is not.

Even if your child tries to get out of school, having friends and taking part in school and extracurricular activities, including gym class—if possible—are important to physical, intellectual, social, and vocational growth.



### Self-esteem

Self-esteem comes from meeting life's challenges—something that kids with chronic diseases may well have more experience with than healthy children. Give your child chances to be challenged, and remind him or her of challenges he or she has faced well in school, sports, health, or another area. This can help any child build positive self-esteem.

Children on dialysis or with transplants want to do what their peers do. This isn't always possible because of treatment or diet limits. They may be able to hide a dialysis access and surgical scars, but it's harder to hide a round belly or rounder cheeks from PD, unwanted hair, and acne from transplant drugs.

Teens with transplants may even think about stopping their anti-rejection drugs to avoid side effects—and some lose their transplanted kidney. Helping your child stick to a renal diet and drugs in the teen years can be a challenge. If you have problems, ask your child's health care team for help—they are used to dealing with the issues faced by teens with kidney problems. As your child gets older, he or she will need to learn to take on responsibility for his or her own health. The care team will help your child to make the transition.

### Communication

Keep the lines of communication open with your child, or if you can't talk to him, help him or her find someone who can. Children's kidney camps or teen support groups can help.

Consider asking for a team conference with the school nurse or principal and your child's care team. This can help everyone understand kidney disease and how children react, so your



child's school time is as pleasant as it can be. Some parents and children use kidney failure as a chance to inform teachers and other students through school projects.

Be aware of your child's behavior since it can be a sign of how he or she is coping with growing up with kidney disease. Like healthy children, children with CKD may develop behavioral problems. Some may be happy-go-lucky, while others become withdrawn, moody, and depressed.

Use consistent and responsible discipline. You are closer to your child and may see changes sooner than anyone else. Report concerns about changes in your child's behavior to his or her nephrologist and/or social worker, and seek their help when you need it.

It's time to wrap up this module on sexuality and fertility. But before we do, we want to give you a Personal Plan to help you get a start on some of the most important ideas in this module. We encourage you to put it where it will remind you of the goals toward which you're working.





## Personal Plan for \_\_\_\_\_

### ***Sexuality and Fertility***

Sexuality and fertility are important aspects of life that can be affected by kidney failure. Feeling sexual has a lot to do with feeling good about myself and my body. To help my body image, I will ask my health care team about:

- What I can do to help me gain/lose weight
- Exercises to improve my muscle tone and strength
- How to keep my skin looking healthy
- How to keep my hair looking as thick and healthy as possible
- How to keep my breath smelling fresh
- How to make my scars less visible
- Whether people need to know that I'm on dialysis or have a transplant

People who've had kidney disease for a while and coped well look on the bright side, feel good about themselves, and take pride in what they've achieved. These positive thoughts have helped others with kidney failure and may help me, too:

- "I want to live."
- "I am still me."
- "I am still valuable."
- "I am in control."

No one wins the battle with kidney disease without scars from vascular accesses, PD catheters, or a kidney transplant. No matter what my body looks like on the outside, I am still the same on the inside. Physical conditions which may be treated can make me tired and reduce my interest in sex. These include:

- Anemia
- Diabetes

- Neuropathy (nerve damage)
- Poor blood flow
- Hormone imbalances, like low testosterone levels (in men and women)
- Zinc deficiency
- High blood pressure
- Depression
- Pain during intercourse

Other factors that may reduce my interest in sex:

---

---

To improve intimacy in my relationship I will:

---

---

Even when I don't want to or can't have sex, to stay close with my partner, I will:

---

---

As a woman, if I think I may be pregnant, I will tell my doctor right away and not take any drug without my doctor's okay. These are the drugs I am taking which may harm a fetus:

---

---

I am interested in these types of birth control (see table on next page):

---

---



## Module 11 – Sexuality and Fertility

Method	Success Rate with Perfect Use and Notes
Progestin-only pills	99.5% effective. Can make some high blood pressure worse. Does not protect against STDs.
Implanon® (implant)	99% effective. Works for three years, but less effective for women with a BMI over 35. Blood clots may be more likely with this device, and this risk is higher in smokers. An increase in blood pressure may also occur. Does not protect against STDs.
Depo Provera® (shots)	99.7% effective. Can make some high blood pressure worse. Does not protect against STDs.
Combination pills estrogen/progestin	99.9% effective. Can raise blood pressure and cause blood clots, especially in women with diabetes, high blood pressure, vascular disease or heart disease, and in those who smoke. Does not protect against STDs.
Birth control patch estrogen/progestin	The patch has not been tested in women with kidney disease. Does not protect against STDs. The risk of blood clots is higher than with the pill.
NuvaRing® (flexible ring containing estrogen and progestin)	98% effective. Should <i>not</i> be used by women with diabetes, high blood pressure, or kidney disease. Does not protect against STDs.
Intrauterine device (IUD) – Progesterone T® or Copper T380A®	98.5% to 99.4% effective (depends on type). Should not be used by women on PD, with transplants, or with diabetes, due to an increased risk of infection. Does not protect against STDs.
Cervical cap (latex or silicone barrier device that covers the cervix)	94% effective. Does not protect against STDs.
Diaphragm	Must be fitted by a health care professional. Does not protect against STDs.
Sponge	80% to 90% effective (higher in women who have never borne children, and lower in women who have). Does not protect against STDs.
Female condom	95% effective. Limited STD protection.
Male condom	97% effective. Protects against most STDs.
Natural family planning (periodic abstinence)	90% to 99% effective. Does not protect against STDs.
Spermicide	94% effective. Does not protect against STDs.





## Take the Kidney Quiz!

You'll see how much you're learning if you take our quick kidney quiz. It's just 10 questions. How about it? *(Answers are on page 11-2.)*

- 1. Feeling good about \_\_\_\_\_ is key to a healthy sexual relationship:**
  - a) Your job
  - b) Yourself
  - c) Your car
  - d) Your genitals
- 2. The danger of feeling unlovable or dependent is that:**
  - a) You may overcompensate in other areas
  - b) You may spend too much money
  - c) You may have high self-esteem
  - d) You may push your partner away
- 3. "Nobody will ever want me" is an example of:**
  - a) The truth with kidney disease
  - b) Worthless psychobabble
  - c) Negative self-talk
  - d) A song lyric
- 4. Which of the following would *not* harm your "body image?"**
  - a) Shiny, lustrous hair
  - b) Ammonia breath
  - c) Dry, itchy skin
  - d) Surgical scars
- 5. To improve how you feel about your body, you can:**
  - a) Avoid looking in the mirror
  - b) View your scars as signs of battles you have fought and won
  - c) Eat comfort foods
  - d) Stay away from other people
- 6. Anemia can interfere with your sex life by:**
  - a) Making it hard to sleep at night
  - b) Giving you bad breath
  - c) Making your hair fall out
  - d) Causing overwhelming fatigue
- 7. Which of the following can be a good solution for feeling tired?**
  - a) Sleeping at least 14 hours a day
  - b) Taking caffeine pills
  - c) Getting regular exercise
  - d) Eating more blue foods
- 8. If you feel anxious or depressed and are having sexual problems, you should:**
  - a) Put on a "happy face" and stop dwelling on these things
  - b) Ignore it and hope it will get better
  - c) Talk to a social worker or counselor
  - d) Postpone having sex for a while
- 9. One way to improve your relationship with your partner is to:**
  - a) Hide your feelings
  - b) Share your feelings
  - c) Buy costly gifts
  - d) Assume all is well
- 10. You can improve intimacy in your relationship by:**
  - a) Talking with your partner
  - b) Ignoring your partner
  - c) Watching TV with your partner
  - d) Listening to your partner snoring



### Additional Resources

In addition to the free Life Options materials you can find at [www.lifeoptions.org](http://www.lifeoptions.org), the resources below may help you learn more about the topics in this module of Kidney School.

PLEASE NOTE: Life Options does not endorse these materials. Rather, we believe you are the best person to choose what will meet your needs from these or other resources you find. Please check with your local library, bookstore, or the internet to find these items.

#### Books and other materials:

- 1 ***Help, I Need Dialysis!*** by Dori Schatell, MS, and Dr. John Agar  
(Medical Education Institute, 2012, [http://www.lifeoptions.org/help\\_book](http://www.lifeoptions.org/help_book), ISBN-13: 978-1937886004)  
Easy to read, fully referenced book covers the lifestyle impact of each type of dialysis—including the effects on sexuality and fertility.
- 2 ***Dialysis: An Unanticipated Journey***, by David L. Axtmann  
(Tucky Paws Pub, January 2001, ISBN-13: 978-0970705815)  
The author was 26 years old, married, the father of two young children and going to college when he was told his kidneys were failing. Axtmann shares those days of doubt and fear and explains how he coped with low blood pressure, sleep problems, lack of energy, and even changes in his sexual needs and desires. He also explains his reason for choosing dialysis over a transplant.
- 3 ***The Ultimate Guide to Sex and Disability: For All of Us Who Live with Disabilities, Chronic Pain, and Illness***, by Miriam Kaufman, MD; Cory Silverberg; and Fran Odette (Cleis Press, November 2007, ISBN-13: 978-1573443043)  
This guide is the first “complete sex guide for people who live with disabilities, pain, illness, or chronic conditions.” It is written by a medical doctor, a sex educator, and a disability activist, and provides readers with encouragement, support, and all the information they need to create a sex life that works for them. Topics covered include building a positive sexual self-image, positions to minimize stress and maximize pleasure, dealing with fatigue or pain during sex, and finding partners and talking with partners about sex and disability.
- 4 ***Enabling Romance: A Guide to Love, Sex and Relationships for People with Disabilities (and the People who Care About Them)***, by Ken Kroll  
(No Limits Communications, November 2001, ISBN-13: 978-0971284203)  
This book covers topics including sexual stereotypes, building self-esteem, creative sexual variations, and reproduction and contraception for people with disabilities.







5 The following brochures are available from the National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC):

- *Erectile Dysfunction*
- *Growth Failure in Children with Kidney Disease*
- *School and Family Problems of Children with Kidney Failure*
- *Sexual and Urologic Problems of Diabetes*
- *Urinary Incontinence in Children*
- *Urinary Incontinence in Men*
- *Urinary Incontinence in Women*
- *What I Need to Know About Erection Problems (Easy-to-Read)*
- *What I Need to Know About Prostate Problems (Easy-to-Read)*

If you would like more information, please call the NKUDIC at (800) 891-5390 or visit their website at <http://kidney.niddk.nih.gov/kudiseases/a-z.asp>.

## Websites

### **Amputee Coalition of America**

- 1 Resources and support for limb loss at [www.amputee-coalition.org](http://www.amputee-coalition.org)

### **Abuse resources**

- 1 MedlinePlus article: [www.nlm.nih.gov/medlineplus/domesticviolence.html](http://www.nlm.nih.gov/medlineplus/domesticviolence.html)
- 2 National Domestic Abuse Hotline at [www.thehotline.org](http://www.thehotline.org), or 1-800-799-SAFE
- 3 U.S. Department of Justice's Office of Justice Program's Office on Violence Against Women has resources including reporting to the police, myths and facts about sexual assault, and more at [www.usdoj.gov](http://www.usdoj.gov)
- 4 U.S. Department of Justice's State Sexual Assault Hotlines at <http://www.ovw.usdoj.gov/statedomestic.htm>

### **Dating service for people with disabilities**

- 1 Google "disabilities dating" to find sites that can help you meet others.

### **Gay and lesbian resources**

- 1 Parents, Families and Friends of Lesbians and Gays (PFLAG) at [www.pflag.org](http://www.pflag.org)



### ***Infertility and options***

- 1 Adoption at [www.adoption.org](http://www.adoption.org)
- 2 American Society for Reproductive Medicine at [www.asrm.org](http://www.asrm.org)
- 3 Centers for Disease Control and Prevention’s Reproductive Health Resource on Assisted Reproductive Technology at [www.cdc.gov/ART/](http://www.cdc.gov/ART/)
- 4 National Foster Parent Association, Inc. at [www.nfpainc.org](http://www.nfpainc.org)
- 5 Resolve: The National Infertility Association at [www.resolve.org](http://www.resolve.org)

### ***Learning about medication side effects***

- 1 American Society of Health-System Pharmacists’ MedMaster at [www.safemedication.com](http://www.safemedication.com) (search by drug name)
- 2 RxList at [www.rxlist.com](http://www.rxlist.com) (search by drug name)

### ***Physicians specializing in sexual concerns***

- 1 American College of Obstetricians and Gynecologists (women): See “Find an Ob-Gyn” at [www.acog.org](http://www.acog.org)
- 2 American Society for Reproductive Medicine: See “For Patients” then “Find a Doctor” at [www.asrm.org](http://www.asrm.org)
- 3 American Urology Association (men): See “Find a Urologist” at [www.urologyhealth.org](http://www.urologyhealth.org)

### ***Pregnancy and kidney disease***

- 1 National Transplantation Pregnancy Registry at [www.jefferson.edu/ntpr/](http://www.jefferson.edu/ntpr/), call toll-free (877) 955-6877, or e-mail [NTPR.Registry@jefferson.edu](mailto:NTPR.Registry@jefferson.edu).

### ***Sexual counseling***

- 1 American Association for Marriage and Family Therapy at [www.aamft.org](http://www.aamft.org)
- 2 American Association of Sexuality Educators, Counselors, and Therapists at [www.aasect.org](http://www.aasect.org)
- 3 American Academy of Clinical Sexologists at [www.esextherapy.com](http://www.esextherapy.com)

### ***Sexually transmitted diseases (STDs) and STD prevention***

- 1 Centers for Disease Control and Prevention’s Division of STD Prevention at [www.cdc.gov/std/](http://www.cdc.gov/std/)

