

Sexual Health After Transplant: **What Every Patient Should Know**



International
Transplant Nurses
Society

Please note—

The information in this brochure is intended for adult transplant patients and their partners. The content is mature in nature and is meant for responsible adults dealing with chronic disease and sexuality. ITNS provides this brochure as a forum for advice only. In no way should it replace the expertise of your medical doctors and nurses. Always share all pertinent questions, including those regarding your sexual health, with your health care team.

Patients with chronic illness often struggle with the many ways their quality of life is altered by their disease and treatments. For some people, sexual functioning is one of the first aspects of “normal” life that is disrupted by the physical symptoms and anxiety about their illness. When a patient first learns that they may have a transplant, their thoughts are on survival and recovery. After transplant, as they regain their health and endurance, a new question becomes important: How normal will my sexual and intimate life be?

This booklet explains how transplant patients can maintain their sexual health during and after treatments or surgery.

What is Sexuality?

Sexuality is an important part of our everyday life and also a part of who we are as man, woman and partner. Sexuality is one way to fulfill our needs for closeness, touch, playfulness, caring and pleasure. Feelings about our sexuality provide zest for our life, impact our self-esteem and body image, and affect our relationships with others. (American Cancer Society, *Sexuality and Cancer*, 2007). As important as this is for each of us, many patients and their health care providers do not discuss the impact of the disease, treatment or surgery on their sexual health.

What is a normal sex life? It can be:

- whatever gives the patient and partner pleasure
- touching and other signs of affection that do not necessarily end in intercourse
- an active interest in sex throughout your life, regardless of age
- positioning that takes into account a patient’s physical condition
- temporary loss of interest in sex when a patient isn’t feeling well due to a treatment or preoccupation with concerns for their health.

Phases of the Sexual Response Cycle

According to *Masters and Johnson* (1966), the sexual response of both men and women is a cycle with four phases.

Desire

This is an interest in sex. You may simply think about sex, feel attracted to someone or feel frustrated because of a lack of sex. Sexual desire is a normal part of life from the teenage years throughout adulthood.

Excitement

This is a phase where you feel aroused. Touching and stroking feel much more intense when a person is excited. Excitement can result from sounds, scents and tastes. Physical excitement means increased heartbeat, blood pressure and breathing as well as blood being sent to the genital area.

Orgasm

This is the sexual climax. In both men and women the nervous system creates intense pleasure in the genitals.

Resolution

This occurs within a few minutes after orgasm. It is the return of the body to its unexcited state.

To complete the cycle, the phases must happen in this order. The cycle however can be stopped at any phase.



“Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment, or the smallest act of caring, all of which have the potential to turn a life around.”

—Leo Buscaglia

Returning to Sexual Activity After Transplant Surgery

Doctors usually recommend waiting 4-6 weeks after surgery to begin sexual intercourse. This period gives you a chance to regain your strength and stamina. It also gives you and your partner time to share your concerns and feelings and permits the resumption of your relationship in a slow and relaxed manner.

When you feel ready to try sexual touching with your partner, start with plenty of time and privacy to create a relaxed environment. Plan for time when you aren't too tired and when any pain is well-controlled. Although you may feel a little shy, let your partner know that you would like to have some time to be physically close. You could even make a date for this purpose. You might say, "I feel ready for sex again, but I'd like to take things slowly. Would you be in the mood tonight to try a little touching? I can't promise that it will go perfectly, but we can have fun trying."

What Causes Sexual Dysfunction for Transplant Patients

- Medication side effects
- Self-esteem issues including altered body image as well as altered roles and relationships
- Physical issues including fatigue, fragility, erectile dysfunction, uncontrolled blood sugar, vaginal dryness, yeast infections, etc.
- Loss of intimacy
- Depression and fear
- Lack of interest

While the issues above may be physical or emotional, they can all lead to a lack of interest in sex. After

surgery is complete or treatment has begun, there may still be little interest in sex. Loss of interest in sex may be due to very real issues including concerns for survival, worry or depression, nausea and vomiting, pain, relationship conflicts or any emotion or thought that keeps you from feeling sexually excited. This may include anxiety that your partner may not like the changes in your body.

Other causes for disruptions in your sexuality may be the underlying disease, medications and physical changes in your body. These can include weight gain or loss, acne, unwanted hair growth or hair loss. For some patients, surgical scars may cause them to feel unattractive, thus decreasing their interest in sex.

Remember to communicate your fears, hopes and dreams to your partner and listen to their concerns as well. To nurture your love life, you must keep emotional connection and commitment alive.

For a woman, uncontrolled blood sugars can play havoc with her reproductive, as well as her overall health. High blood sugars can promote yeast infections and vaginal irritation. Low estrogen levels can also cause lubrication problems.

In men, erectile dysfunction is common and it increases with age. Many medications affect sexual functioning so it is important to talk with your health care team to obtain a good understanding of your medications and their side effects.

The process of dealing with chronic illness and recovery can affect many patients emotionally. Other emotional or psychological factors that can impact sexuality include a sense of losing control of bodily functions, anger, anxiety, disappointment, fear, isolation and sadness.



How Medication Affects Sexuality

As mentioned earlier, some of the medications you are taking may affect sexual functioning. Check with your physician or health care provider to find out if your medications could impact your sexual functioning or desire. Specific medications that can affect sexuality include:

- antihypertensives
- antidepressants
- anticonvulsants
- lipid-lowering agents
- nicotine
- alcohol
- marijuana

Symptom Management: Living Life to the Fullest with Organ Transplant

The following overview describes some of the common symptoms transplant patients can feel. This section will help you recognize the symptoms early so you can find solutions to help manage them. It is always important to have a conversation with your doctor or health care team when these symptoms occur.

Fatigue

Feelings of fatigue are common for people living with a chronic illness. No matter what your level of fatigue, don't ignore it as it can strongly affect your quality of life. Symptoms are sometimes vague and include: low energy level, an increased need to rest after normal activities, overall weakness with heaviness in your arms and legs, difficulty completing daily activities and difficulty concentrating or thinking clearly.

Tips for managing fatigue include:

1. Prioritize your activities to conserve energy.
2. Schedule important activities earlier in the day. This may be a good time to try returning to sexual activity as well.
3. Exercise daily if possible.
4. Try to eat a balanced diet. A dietician can counsel you on a good eating plan.
5. Maintain a normal sleep routine. Too much or too little sleep can cause fatigue. Limit daytime naps and limit caffeine to morning or early afternoon.
6. If you are having difficulty sleeping try relaxation techniques before bedtime. If sleeping difficulty continues, discuss it with your doctor.



Pain

It is common to have pain after surgery, but this should decrease over time. Your health care team will ask you to rate your pain on a scale of 0-10 and can apply interventions to help manage pain. Pain can impact your self-esteem and desire for sexual activity. While pain medications may influence your ability to enjoy sex, you may need them to reduce your discomfort and actually help you feel more interested in sex.

Tips for managing pain include:

1. Take your pain medication one-half to one hour prior to sexual activity.
2. Take enough pain medication to be physically comfortable, but not so much that you get sleepy and can't enjoy sexual activity.
3. Try relaxation techniques before and after intercourse to help you keep your muscles relaxed. Deep breathing can aid in relaxation.
4. Experiment to find the most comfortable position. Use pillows to help provide support.
5. Use water-soluble lubricants for comfort with intercourse.

Many couples don't talk much about sex, but after surgery your sexual routine may need to change for a while. For example, you may want to try a new lovemaking position after surgery so you don't put pressure on your surgical incision. There is no one position that works for everyone, you and your partner need to find something that works for both of you. Use large and small pillows for support. Your sense of humor can lighten the situation.

"The best and most beautiful things in the world cannot be seen or even touched. They must be felt with the heart."
—Helen Keller

Decreased Desire

It is not uncommon to have decreased interest in sexual activities when you are not feeling well physically, are fatigued and dealing with uncomfortable symptoms such as pain, nausea, and so on. Also, emotional concerns can combine with physical symptoms to reduce a person's desire for intimacy. **Tips for managing a decreased sexual desire include:**

1. Give yourself time to recover physically from the surgery.
2. Do activities to increase your physical stamina. This can include getting up, getting dressed and taking a walk.
3. Find ways to enhance your appearance to help you feel more desirable as a man or woman.
4. Talk to your partner openly to let him/her know what you're feeling.
5. Plan a date to have time together to just enjoy each other's company.

Don't let fatigue slow your sex life. Instead, keep a journal to chart your energy ebbs and flows, then identify which times may work best for you.

6. Talk about special times you have had together in the past, and plan for a special time away in the future.

Changes in Body Image

Transplant patients may have an altered body image due to illness and some of its side effects such as weight gain or loss or hair thinning. When this body image change is sudden and dramatic, the person may feel uncomfortable.

For some patients, this is accompanied by feelings of shame, embarrassment, inferiority and anger. When the change is visible to others, these feelings can be reinforced by reactions of others when they see the change.

When someone is anxious about their body image, reassurance does not usually help because it only gives a short-term release from anxiety. Instead, talk to your partner about your fears and concerns. Some

patients may feel comfortable talking to a counselor. Partners also may have fears about changes in their loved one's body and may also need to talk through their fears with a professional.

For some patients, surgical scars may be upsetting and they will not let their partner see them naked or undressed. If your scars have made you more sensitive about your body, find someone on your health care team to talk to about this. Some people find it helpful to look in the mirror and process what they have been through. As you feel stronger and healthier, you start adjusting to your new body image. **Tips for managing altered body image include:**

1. Take time to physically recover from surgery.
2. Gradually become more active to enhance your stamina.
3. Take time daily to pay attention to your appearance. For example, wear clothing that makes you feel attractive and comfortable.
4. Do something special for yourself each day to enhance your joy of life.



"I love you, not for what you are, but for what I am when I am with you." —Roy Croft

5. Attend a support group to discuss your concerns with others.
6. Read a book that discusses how to manage your concerns.
7. Talk to your health care team to let them know how you are feeling.

Fertility and Pregnancy

Fertility in women can return quickly after transplant. Some antirejection medications may prevent menstruation, but ovulation still occurs so birth control is necessary. The birth control pill carries some risks so discuss this option with your health care team. Female transplant recipients should wait at least one year post-transplant and demonstrate stable transplanted organ function before becoming pregnant. Female patients should discuss this with their physician and obstetrics specialist to determine immunosuppressive medication changes and doses. Some medications can have a negative impact on the developing fetus and the transplant

and obstetrics specialists will guide you on this. Read the International Transplant Nurses Society (ITNS) Fact Sheet on *Pregnancy after Transplant* to learn more. **Tips for fertility and pregnancy issues include:**

1. Discuss birth control methods with your health care team.
2. Practice safe sex to prevent sexually transmitted infections such as Hepatitis B, Hepatitis C, HIV and genital herpes.
3. Ask to meet with a fertility specialist prior to getting pregnant so you have the information you need for both you and the baby.

Vaginal Dryness and Infection

Female transplant patients may have problems with both vaginal dryness and vaginal infections. In the case of vaginal dryness, medications and certain diseases can cause a variety of vaginal problems that lead to vaginal dryness or narrowing, ulcers, and infection. These changes can lead to pain during intercourse. To help,

several non-hormonal creams and gels are available over the counter and can be applied prior to intercourse such as K-Y® Jelly and Senselle® or several times per week (Replens®). **Tips for managing vaginal dryness include:**

1. Plan ahead by having vaginal lubricants available to help with lubrication during intercourse.
2. Discuss what is happening with your partner and include him/her in the process.
3. Discuss your concerns with your health care team.

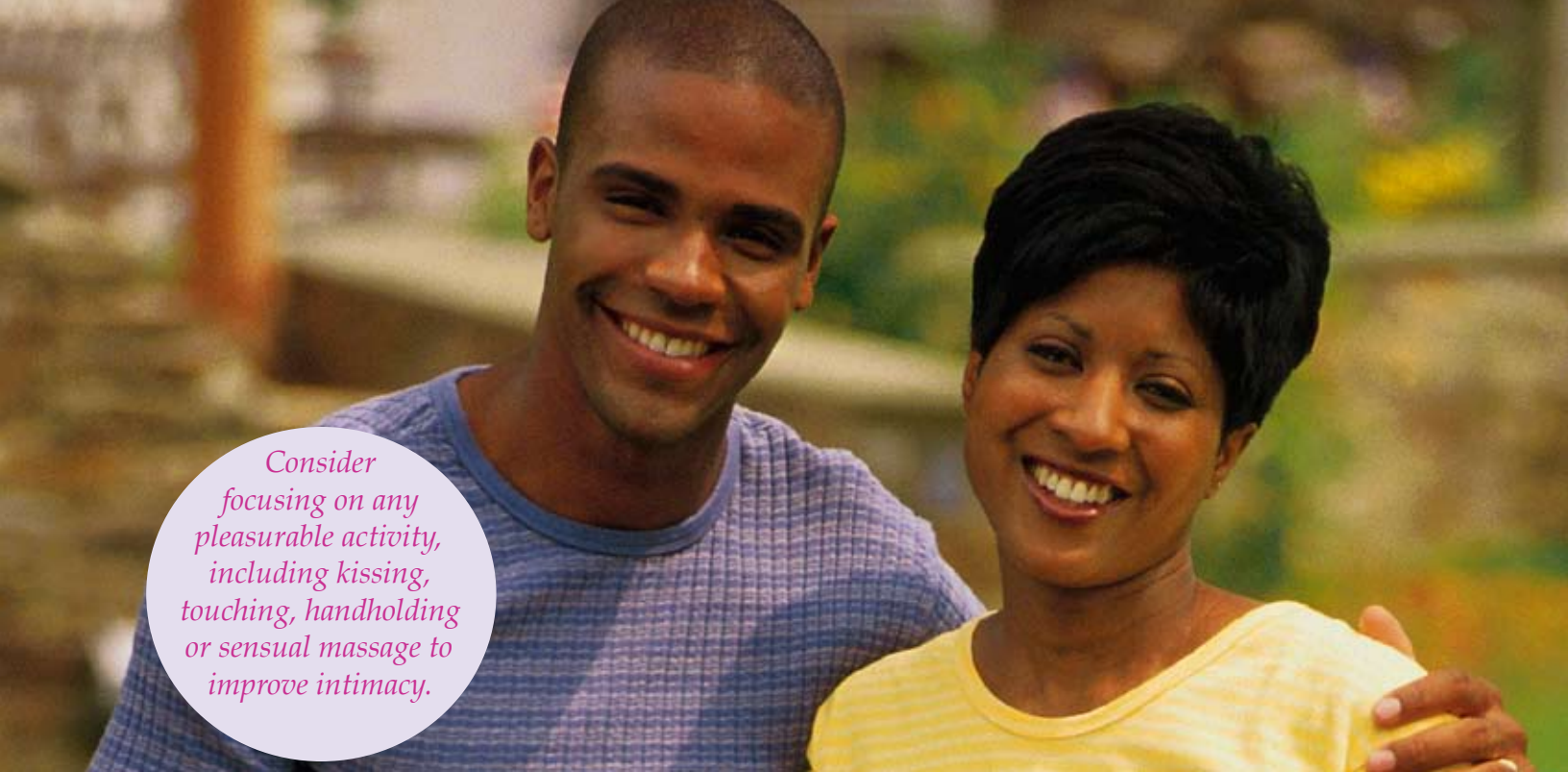
Some women find they are prone to getting vaginal infections. This can occur when there is a change in the normal vaginal acidity that routinely keeps the good and bad organisms in balance. If you notice a discharge or vaginal itchiness, contact your transplant team so this can be resolved. Your partner may also need to be treated. **Tips for managing vaginal infections include:**

1. Discuss your medications and their



“Being deeply loved by someone gives you strength while loving someone deeply gives you courage.”

—Lao-Tsu



Consider focusing on any pleasurable activity, including kissing, touching, handholding or sensual massage to improve intimacy.

sexual side effects with your health care team. You may be more prone to vaginal infections based on the medications you will be on after transplant.

2. If you are noticing symptoms, contact a member of your health care team right away for treatment options.
3. Identify if your partner may need treatment.
4. Talk to your team to see if you need to have your partner wear a condom while you are being treated.

Erection Issues for Men

Erectile dysfunction may be an issue for some men due to emotional issues, prior chronic disease or medications. Talk to your health care team if you are having issues with erectile dysfunction. For some, it may be difficult to get or keep an erection. Many times fatigue or stress can play a role. If men have problems maintaining an erection there are many options to help including medication, pumps and injections. Talk to your physician about meeting with a urologist for a consultation.

Tips for managing erectile dysfunction include:

1. Discuss your feelings and concerns with your partner.
2. Discuss new ways to show love and be close.
3. Talk to your physician about medical options you can try.
4. Learn more about techniques to improve erectile dysfunction.

Communication: The key to a caring relationship after transplant

Communication is the key to a caring relationship and the beginning step before initiating sexual relationships. Many times, chronic illness can impact the sense of closeness between a couple.

So how do you communicate in a caring way to your partner? Respect for your partner communicates acceptance of their ideas, feelings and experiences. Showing respect communicates “I value you as a person.” It says “You are important to me.”

How do you show respect in your relationship? It’s the little things you do like:

- Looking at your partner when you talk to them
- Offering them your undivided attention
- Maintaining eye contact
- Smiling at them when appropriate
- Connecting with them by touch, such as a hug or pat on the back.

Another way to show caring in a relationship is to give your partner reassurance. Take the time to reinforce your partner’s good qualities. Compliment them on their abilities and talents. Take the time to reinforce all of the good qualities that attracted you to each other.

- Tell your partner what you appreciate about them

“Love is just a feeling of togetherness and openness in your heart.” —Ken Keyes

- Remind them that you do care about them
- Concentrate on the positives when you talk to each other
- Focus on the unique gifts your partner brings to your relationship.

Improving Daily Communication as a Couple

Create an open-minded loving attitude toward your partner. Believe that your partner has your best interest in mind. So give each other the benefit of the doubt.

Because life is very busy, it is important to keep in touch. You can nurture your relationship by keeping your partner informed of what is going on with you on a daily basis. You can create a message center, or calendar to keep each other informed.

Watch out for generalizations in your conversations with each other. Avoid statements like, "You never listen." This automatically puts up a wall between the two of you.

Many minor disagreements and communication breakdowns happen because one person is feeling unloved. The more you can start a conversation with "I appreciate you and love you," the less often you will end up misunderstanding each other.

Trust is an expectation, often unspoken, that someone will be there for you. Trust can be broken, physically, emotionally and spiritually. What can you do to foster trust in your relationship? Talking with each other in a caring way can facilitate trust. Telling the truth with each other is the place to start. Then look at these five ingredients for developing trust in a relationship:

1. Say what you are going to do.

Communicating to your partner eliminates the guesswork.

2. Do what you say.

Be sure that your actions match your words.

3. Live in the present.

Keep in the present and don't keep track of your partner's previous faults.

4. Look at yourself first.

Before pointing a finger at your partner, consider your own behavior. What is your behavior saying to your partner?

5. Time, time and more time

Time plays a major role in the development and strengthening of trust.

So how do you create a caring relationship with your partner?

Communication is the key. Other qualities that will help make your relationship successful are:

- | | |
|--------------------------|--------------|
| • Love | • Tolerance |
| • Support | • Commitment |
| • Sense of Humor | • Respect |
| • Realistic expectations | • Caring |
| • Enjoy one another | • Nurturing |

The last ingredient for a caring relationship is having fun together. Plan time in your day and your relationship for fun together. Go for a walk together, go to a movie, get away for the weekend, read a book together, visit an historic site, go out with friends to a play and dinner. It doesn't matter what you do, just that you plan something to look forward to as a couple.

Tips for Renewing Intimacy in your Relationship

Having a sense of satisfaction with your sexual life is a highly personal and important sentiment, greatly influenced by your past experiences, current expectations and future aspirations. Living with a chronic illness may have impacted your intimacy with your partner, and you are wondering "What do I do now to regain what is missing?"

Intimacy means that we can be who we are in a relationship, and allow the other person to do the same. "Being who we are" requires that we can talk openly about things that are important to us.

Romance, on the other hand, is a state of mind. It is about the little things or small gestures that you do daily to let your partner know you love him/her. It is the things you do to make each other feel special. Romance is the expression of the love you feel. It is not the same as love, but it is the language of love.

A part of renewing intimacy can be about the romance you bring to your relationship.

Ideas for renewing intimacy/sexuality

As you and your partner decide to renew the intimacy in your relationship, explore these new ideas.

Just touch – touching and being touched increases feelings of closeness or connections. Try cuddling on the couch, massaging, and kissing. Begin doing these activities without the goal of intercourse.

Change your schedule – many times we get in a routine and think we need to be sexually active at the same time of the day or week. Look for a time of day when you have more energy, less pain, less demands on your time.

"Kind hearts are the garden, kind thoughts are the roots, kind words are the flowers, and kind deeds are the fruit."

—Hungarian Proverb



Maybe you need to get away from your normal routine to connect as partners.

Alternative positions – Experiment with different positions that are more comfortable, and take less energy such as side-lying.

Vibrators – the use of vibrators can add pleasure during lovemaking and does not require a lot of exertion. At times it may be more comfortable to experiment with a vibrator individually before using it as a couple. This may help you learn what works/feels best for you.

Lubricants - if lack of natural lubrication is a problem there are many safe and effective over-the-counter lubricants that can help prevent pain associated with vaginal dryness. Ask your doctor or pharmacist to recommend one.

Providing emotional support for your partner who is chronically ill or recovering from a transplant can be the first step in connecting as a couple.

Ideas for the well partner

Your partner needs your support. There are four important things the well partner can do to provide emotional support:

1. Spend time together

Plan time together and give your partner attention.

2. Ask what your partner wants and needs

Ask them what they truthfully need and what they want or don't want from you.

3. Listen to what your loved one says

Listen without judging or coming up with answers or solutions.

4. Reassure your loved one of your continued love

Let your partner know you love them today, tomorrow and always.

Renewing intimacy in a relationship is about more than sexual intercourse. Find ways to connect on an emotional level, and then plan on ways to connect on a sexual level. Plan ways to make your sexual encounter a positive one for both of you. Think back to when you started dating, and all the things you did to prepare for your date. Do you pay as much attention now to preparing for a rewarding sex life, as you did when you were dating?

Start slow, and enjoy just being together. Do something fun that you enjoy. Create pleasant moments, and hopefully this can move you into a place of renewing intimacy in your relationship.

Regaining Your Sexual Health

Returning to a fulfilling and satisfying sexual relationship is possible. It may take time and attention to little details to make it happen for you. Open communication with your partner is

one of the keys to make it work. Start slowly by planning a date and plan for the details of that special time together. Start by holding hands and enjoying each other's company. For most patients, the following strategies may be helpful for enhancing your body image and self esteem:

- Continue to view yourself as feminine or masculine.
- Exercise to feel stronger and more energetic.
- Maintain a healthy diet.
- Get adequate sleep and rest.
- Spend time enhancing your appearance each day.
- Do something you enjoy each day.
- Maintain a healthy mental attitude.
- Find something to be grateful for each day.
- Plan time for closeness with your partner.
- Provide for your spiritual needs.
- Maintain a sense of humor.

Continue learning as much as you can about the usual effects of your surgery and medications on your sexual health. No matter what type of treatment you have, the ability to feel pleasure from touch almost always remains so keep an open mind about ways in which to feel sexual pleasure. Remember to strive for good communication with your partner and continue to find ways to boost your self-esteem and body image.

Important Information to Discuss with your Physician or Nurses prior to your Organ Transplant

Talk to your doctor or nurses to discuss possible changes that might affect you sexually after a transplant. The changes can depend on the type of transplant you have, your age and other health issues.

Some Questions for Women

1. What sexual problems, i.e. vaginal dryness, might I have after transplant?
2. Will I have hot flashes?
3. When is it okay to have sex?
4. What about getting pregnant?
5. Should I be using birth control, and if so, what is the right birth control for me?

Some Questions for Men

1. What sexual problems, i.e. maintaining an erection, might I have after transplant?
2. When is it okay to have sex?
3. Do I need to wear a condom?
4. Will I be able to have children?

Definitions:

Body Image

noun

1. The subjective concept of one's physical appearance based on self-observation and reactions of others.

Intimacy

in·ti·macy (in'tə mə sē)

noun

1. The state or fact of being intimate; intimate association; familiarity
2. An intimate act

Libido

li·bido (li bē'dō)

noun

1. the sexual urge or instinct

Self Esteem

es·teem (ə stēm')

transitive verb

1. To have great regard for; value highly; respect
2. To hold to be; consider; regard. We *esteem* it an honor to be invited
3. Favorable opinion; high regard; respect. To be held in high *esteem*

Sexuality

sexu·al·ity (sek'shō al'ə tē)

Noun

1. The state or quality of being sexual
 - interest in or concern with sex
 - sexual drive or activity

Sexual Dysfunction

Refers to a difficulty experienced by an individual or a couple during any stage of a normal sexual activity, including desire, arousal or orgasm.

Sexual Response Cycle

The Sexual Response Cycle consists of four phases. The one most known is **orgasm** or·gasm (ôr' gāz' əm)

Noun

1. The peak of sexual excitement, characterized by strong feelings of pleasure and by a series of involuntary contractions of the muscles of the genitals, usually accompanied by the ejaculation of semen by the male. Also called climax.



Related Links for More Information

ITNS is not responsible or liable for any information received from these websites. These sites are provided as a network resource. Information from the Internet in regard to your transplant should always be discussed with your transplant team.

Web sites

American Association of Sex Educators, Counselors, and Therapists (AASECT)

<http://www.aasect.org>

American Psychiatric Association

<http://www.psych.org>

Kinsey Institute for Research in Sex, Gender, and Reproduction

<http://www.kinseyinstitute.org/>

Information and Education Council of the United States (SIECUS)

<http://www.siecus.org>

Psyche Central

<http://psychcentral.com/sex/>

References

Kaufman, M. et al (2007). *The Ultimate Guide to Sex and Disability: for all of us who live with disabilities, chronic pain, and illness*. Cleis Press.

Laken, V. & K. Laken (2002). *Making Love Again: Hope for Couples Facing Loss of Sexual Intimacy*. North Star Publishers.

Lerner, H. G. (1997). *The Dance of Intimacy*. HarperCollins Publishers.

Louden, J. (2005). *The Woman's Comfort Book: A Self-Nurturing Guide for Restoring Balance in Life*. HarperCollins Publishers.

Louden, J. (2005). *The Couple's Comfort Book: A creative guide for renewing passion and commitment*. HarperCollins Publishers.





Author:

Barbara J. Schroeder, MS, RN, APRN-BC

Reviewers:

Bernadette Dodd, RN, MN

Patricia G. Folk, RN, BSN, CCTC

Michelle James, MS, RN, CNS, CCTN

The International Transplant Nurses Society was founded in 1992 as the first professional nursing organization to focus on the professional growth and development of the transplant clinician. ITNS is committed to the promotion of excellence in transplant clinical nursing through the provision of educational and professional growth opportunities, interdisciplinary networking and collaborative activities, and transplant nursing research. This educational brochure is designed to enhance patient education as provided by individual transplant centers. Patients should follow their transplant team's specific guidelines for sexual activity and health after transplant.

Made Possible from a charitable grant from Pfizer

www.itns.org



International
Transplant Nurses
Society