

# Sexual Functioning and Satisfaction after Traumatic Brain Injury: An Educational Manual



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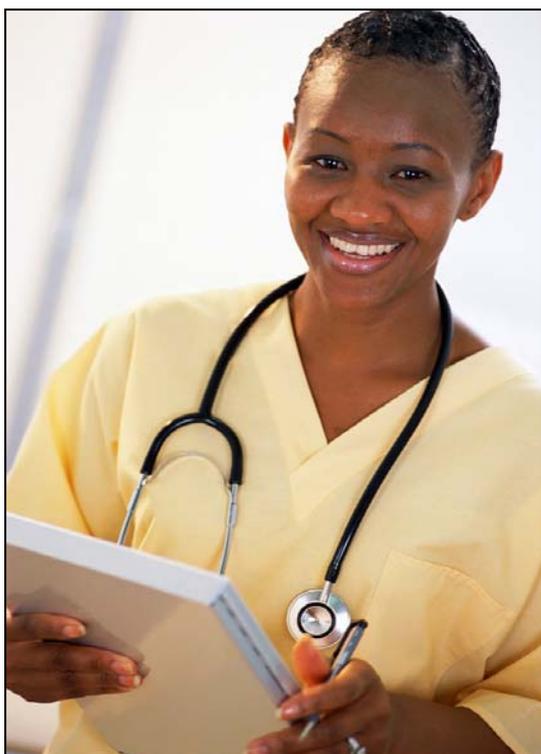
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# Introduction

Sexuality is a very important part of who we are and how we see ourselves. It is a part of what makes us feel attractive, confident, and close to others. These are all important for forming new relationships. Sexual functioning means any intimate activity that you do to get pleasure. When sexual functioning changes, it can make a person feel unattractive, less confident, and less close to other people.

If you are reading this brochure, you have likely either had a traumatic brain injury (TBI) or someone close to you has. You may have some questions or concerns about how TBI affects sexual functioning. The purpose of this booklet is to provide you with information on changes in sexual functioning that can occur after TBI. It is hoped this information will help you better understand and cope with any changes in sexual functioning that you may experience. Even if you have not yet returned to sexual activity, you may have questions about how TBI affects sexuality.



The first thing to know is that you should try not to feel embarrassed about sexual changes. You should feel comfortable talking about them with your doctor, a nurse, or any other rehabilitation professional (for example, physical therapist or psychologist). Sexuality is a normal part of physical functioning, and problems with sexuality should be dealt with just like any other medical problem.

This booklet is divided into several sections. You can choose to read the entire thing or skip to sections that interest you. Keep the booklet to refer to at a later time when your questions may be different.

# Chapter 1: Types of Sexual Changes After TBI

## Human Sexual Response Cycle

There are different stages the body goes through during sexual activity. After TBI, problems can occur during one or more of these stages. Knowing about these stages may help you understand problems that can happen.

- ◆ **Desire:** Usually a person will experience a desire for sexual activity before it happens. Other words used to describe desire are “sex drive” or “sexual need.” Different people feel desire in different ways. Some of the ways may be thoughts, daydreams, or fantasies. Desire can be the result of viewing sexual books or movies. It can also be the result of seeing someone that you are attracted to.
- ◆ **Arousal/Excitement:** This is the stage in which you may feel sexually excited. During the arousal stage, your body prepares for sexual activity. Physical changes occur, including increased heart rate, changes in breathing, increased muscle tension, and increased blood flow to the penis or vagina. In men, the penis becomes erect. In women, lubrication or moisture happens in the area of the vagina. Nipples may also harden.
- ◆ **Plateau:** During this stage, sexual activity is occurring and the physical changes that started during the arousal phase become more intense, resulting in a high build-up of tension.
- ◆ **Orgasm/Climax:** This is the stage in which feelings of sexual tension are released. There is typically a feeling of intense pleasure that is experienced differently by different people. Men may ejaculate during this stage. Some people report feeling sexually satisfied during this stage.
- ◆ **Resolution:** This is a “quiet” phase that follows orgasm or climax. The body returns to its normal state. Men are unable to experience erection or orgasm again until this stage over. Some women can quickly move from the resolution stage to another excitement and orgasm stage.

## Effects of TBI on the Human Sexual Response Cycle

Changes in sexual functioning are common after TBI. Some of the changes that can occur include:

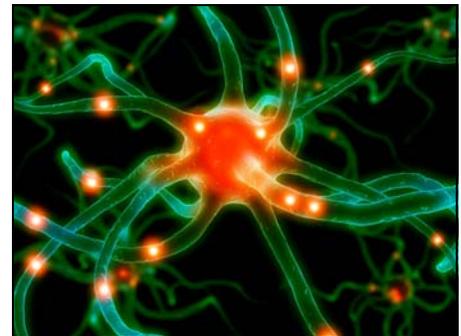
- ◆ **Decreased desire:** After TBI, many people report being less interested in sex. They simply do not feel the desire, or think or day-dream about sexual activity as they once did. There may be a decrease in starting sexual activities, and partners may feel unwanted.
- ◆ **Increased desire:** In some cases, a person may feel increased sexual desire after TBI. This can be either a little more or a lot more. In rare cases, a person may seem like they are unable to control themselves. They may make inappropriate sexual advances towards others or request sex so often that a partner becomes uncomfortable.
- ◆ **Decreased arousal/sexual excitement:** Despite having the desire for sexual activity, some people with TBI may have difficulty becoming aroused or excited. This means that while the mind is interested, the body doesn't cooperate. Men may have difficulty getting or keeping an erection. Women may not have enough moisture in the vagina, making sexual activity difficult or painful.
- ◆ **Difficulty or inability to reach orgasm/climax:** After a TBI, some people have difficulty reaching orgasm or climax, even when they are able to participate in sexual activity. This can lead to frustration and lack of satisfaction, which can lead to less willingness to have sex.



# Chapter 2: Why do Changes in Sexuality and Sexual Functioning Occur after TBI?

There are many reasons a person can experience sexual changes after TBI. Some are directly related to damage to the brain. Others are related to physical changes, to thinking problems, or changes in relationships. Possible causes of changes in sexual functioning after TBI include:

- ◆ **Damage to parts of the brain involved in sexual functioning:** The two parts of the brain most affected by TBI are the frontal and temporal lobes. Both are important for sexual functioning. Damage to these parts of the brain can cause a lack of interest in sex, or more interest than normal. Damage to other parts of the brain that are connected to the frontal and temporal lobes can also cause problems with sexual functioning.
- ◆ **Changes in brain chemicals:** Different parts of the brain communicate with each other through chemicals called neurotransmitters. Many of these help control sexual functioning. After TBI, there can be too much or too little of these chemicals.
- ◆ **Hormonal changes:** The brain controls hormones, which are the chemicals responsible for the menstrual cycle (monthly periods) in women and for the making of sperm in men. Hormones are important for the sexual organs, such as the testes and ovaries, to work correctly. After TBI, changes in the brain can cause the body to make too little of certain hormones. Monthly periods and the ability to become pregnant can be affected in women. Sperm production can be affected in men. When the sexual hormones are not working properly, sex drive, arousal, and the ability to obtain orgasm can also be affected.
- ◆ **Medication Side Effects:** People with TBI take medications for many reasons. Some reasons are to prevent seizures, treat depression, and help with sleep. Many medications have side effects on sexual functioning including decreased drive, decreased arousal, and inability to obtain an erection.



- ◆ **Fatigue/Tiredness:** People with TBI often become tired more easily than before. This tiredness can be physical and/or mental. They may not have the same physical strength as before injury, and this applies to sex as well as to other physical activity. Most sexual activity requires physical stamina,



and this may be reduced after injury. Mental tiredness may happen when the person with injury has to spend more energy to focus on any one thing for awhile. This mental tiredness can affect the ability to pay attention during sexual activity. Partners may sometimes misunderstand and feel that the person with injury is pretending to be tired in order to avoid sex. It is important to understand that tiredness is a real problem.

- ◆ **Problems with movement:** Problems with movement are possible after TBI and many of these changes can affect sexual functioning. Spasticity, weakness, slower or more jerky movements, and balance problems can make it more difficult to move during sexual activity. Movement problems can make the person with TBI feel awkward and self-conscious, which can lead to a decreased desire for sex.
- ◆ **Changes in thinking abilities:** After TBI, there is usually some change in thinking abilities. Possible changes include difficulty with attention, memory, planning ahead, reasoning, and imagining. These changes can affect sexual functioning. For example, someone with poor attention may not be able to focus during sexual activity. Their partner may think that they are bored or not interested. Memory difficulties can lead to missed dates and poor memory of recent sexual activity. Changes in thinking may make it difficult to imagine, which may make it hard to become aroused or excited. Trouble planning ahead may make it difficult to take the steps necessary to make a date.
- ◆ **Changes in emotions/mood:** People with TBI often feel sad. For some people, this sadness becomes depression and makes it hard to get things done or to have good relationships. Loss of interest in sex is one symptom of depression, although not everyone who is depressed loses interest in sex. On the other hand, some people with TBI seem overly happy and as if nothing bothers them. These individuals may not be able to recognize that anything is different and have trouble understanding their partner's concerns or needs. Sometimes, they may seem more interested in sex than they did before injury, and may not understand if their partner does not want the same thing. Some people are more irritable after injury, and this may affect their sexual desire. It may also result in them being less able to tolerate not having their sexual needs met.

- ◆ **Changes in social communication abilities:** Social communication is the way that we express our thoughts and feelings to others. It includes both speaking and listening. After TBI, a person may have trouble coming up with words, may get off topic, or be slower to understand things. Much of what we communicate is through words; however, we also communicate non-verbally, by using gestures, eye contact, and body language. Sexual interactions involve both verbal and non-verbal language. A person with TBI may have difficulty reading non-verbal messages. For example, they may not notice that others look bored or are looking at the clock. On the other hand, they may also not realize when someone is making sexual advances toward them, which can put them in a vulnerable position. Some people with TBI have difficulty understanding another's point of view or putting themselves in someone else's shoes. They may also not show emotion on their faces, although they feel the emotion inside. This may make it difficult to know how they are feeling and may make them seem uncaring. A person with TBI may also have difficulty understanding humor or subtle remarks that are often part of sexual foreplay.
- ◆ **Loss of Self-Esteem:** After TBI, a person may not feel as confident as they once did. They may feel self-conscious regarding physical changes, such as scars or a change in walking ability. They may also feel self-conscious about changes in thinking abilities. They may not feel attractive to other people. This may cause them to keep to themselves and not reach out to others.



- ◆ **Decreased Social Contacts:** Some people do not have a partner after TBI. A decrease in the number of social relationships is common after TBI. In some cases, the person with injury cannot return to work or school, and may become isolated. In other cases, the person may choose not to socialize with the friends they had before injury, because they don't want to use alcohol or drugs. Some old friends stay away because they don't understand the injury and how the person has changed. In all of these instances, the number of social relationships can decrease, and the opportunity for sexual activity is less. This decrease can be a frustration and an added sadness for the person with injury.
- ◆ **Headaches:** Headaches occur frequently in persons with TBI. They can be mild or intense. When these occur, they can affect sexual desire.
- ◆ **Inability to control bowel or bladder:** Some people have trouble knowing when they have to urinate or have a bowel movement after injury. Others may know when they need to use the bathroom, but may not be able to hold it long enough to get there. This can lead to bowel and bladder accidents, which can be embarrassing. The person with injury may avoid having sex, because he or she is afraid of having an accident.
- ◆ **Other medical problems:** A person with TBI can have other medical problems. Many medical problems lead to sexual difficulties. Examples of these problems include diabetes, heart disease, circulation disorders, neurological disorders, hormonal imbalances, menopause, and organ dysfunction, such as kidney disease or liver failure.
- ◆ **Use of Alcohol and Drugs:** Alcohol and many other non-prescription drugs (e.g., barbiturates or "downers") can cause decreased interest in sex. Alcohol or drugs may seem to make you feel more relaxed about sex at first, but they can decrease sexual performance.



# Chapter 3: Suggestions for Improving Sexual Functioning and Satisfaction

- ◆ **Get a Comprehensive Medical Examination:** This can help determine the cause of sexual problems and help your doctors to recommend the right treatment. You should get a thorough physical exam. Be sure to tell your doctor about any sexual difficulties or other health problems that you are having. You may also want to get a blood test to check for problems with hormone levels. Your doctor can review your medications to determine if any of them may have side effects on sexual functioning. If your doctor forgets to bring this up, you can ask him or her if the medications that you are taking can affect your sexual functioning. If you are a man, you may need to see a urologist. Women should receive a gynecological examination. It is common following brain injury to temporarily stop having menstrual cycles (periods). If menstrual cycles have not returned after approximately 6 – 12 months following injury, your healthcare provider can help you determine the next steps to take.
- ◆ **Arranging a non-distracting environment:** Setting the right mood for sexual activity can help with attention problems. Dim lights and a quiet environment can help make you less distracted. This may mean not having sex with the television or with loud music on. It may also mean more planning, so that sex is not rushed during a limited time frame.
- ◆ **Minimizing fatigue/tiredness:** To minimize physical and mental tiredness, sexual activity should take place at the time of day when the person with injury is less tired. This may mean having sex more in the mornings or afternoons rather than at night. Keep in mind that this time of day may be different for each person. Having the partner perform more of the physical work, and having shorter episodes of sexual activity, can also help reduce tiredness.

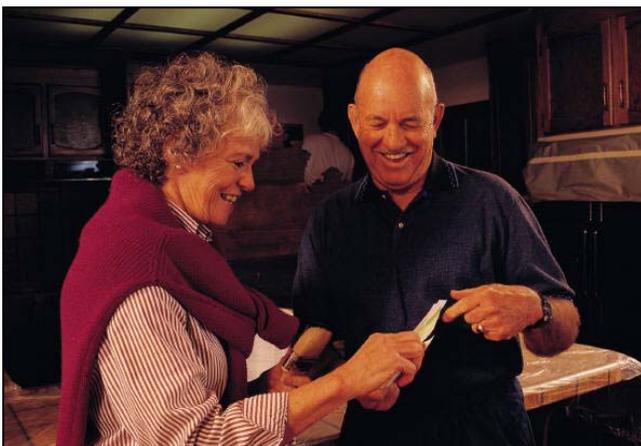


- ◆ **Compensating for memory problems:** If you are embarrassed by not being able to recall dates with your partner, use a calendar to write them down. You can make a romantic game of reminding each other of dates by leaving notes for each other or sending e-mails. Sometimes, the person with injury may have difficulty remembering that they had sexual activity, and may seem to be making too many demands on their partner. Rather than becoming angry, reminding the person about some of the romantic details may help. Maintaining a sense of humor can strengthen the relationship. Some people find that setting a date to reserve time for romantic encounters is helpful.



- ◆ **Compensating for decreased ability to fantasize or imagine sex:** Watching movies with sexual content, viewing erotic pictures on the computer, reading books with sexual content, or looking at sexually-themed magazines may help to develop fantasies and/or may help the person with injury to become aroused prior to sexual activity.
- ◆ **Compensating for erectile dysfunction:** There are some devices that can help men who have difficulty getting or keeping an erection. A vacuum pump is a device that pulls blood flow into the penis, and a ring is then placed around the base of the penis to keep the erection. A drug (Alprostadil) is also available that can be injected into the penis 20 minutes before sexual activity. The person with TBI or their partner must give this injection. Oral medications that help men to get or keep erections have become very popular in recent years; however, it is very important to discuss use of these medications with your doctor and to find out how they interact with other medications that you may be taking.
- ◆ **Compensating for female sexual difficulties:** Unfortunately, there is less known about female sexual problems. For women who have difficulty becoming aroused, the use of vaginal lubricants and/or erotic reading material or movies can be helpful. Pain during penetration of the vagina is sometimes caused by involuntary contractions of the muscles. Treatments for this include insertion of devices into the vagina, with size gradually being increased. You should ask a physician or other medical professional about this treatment. For many women, certain positions used during sex do not provide enough stimulation to have an orgasm. Exploring your body on your own, or asking for a partner's assistance in determining what feels good to you, may improve your chances of obtaining pleasure.

- ◆ **Increasing opportunities for social interaction:** The following are examples of how you may increase your social networks:
  - ◇ **Smile and Greet** – Smiling is contagious. When you smile at and greet others, you become inviting and it will be easier for others to talk to you.
  - ◇ **Focus on the other person** - Asking others how they are doing is a great way to initiate a conversation with others. We all feel good when others are interested in how we are doing.
  - ◇ **Don't wait for others to call** – Take the first step and call an old friend that you haven't spoken with in awhile or since your injury. Your friends may be meaning to call you but may feel uncomfortable because they don't understand TBI and the changes that may have occurred.
  - ◇ **Participation in recreational activities** – It may be easier to meet individuals with similar interests. Return to an old hobby or engage in new activities you have always wanted to try. This can help you to meet others with similar interests. If you are not sure where to find activities of interest in your area, there are a variety of web pages that can help you learn about activities and connect with people of similar interests.
  - ◇ **Invite others over** – Some individuals may not have reliable transportation or may not be physically able to leave their home. In such cases, invite friends and family over to your house and have them bring someone that you don't know. This will allow you the opportunity to meet the friends of the individuals in your social network. You never know, you may be one phone call away from a new best friend or partner.



- ◇ **Join a club or organization** – Participating in a club or organization will allow you to socialize with a group of people on a regular basis. Try to find an organization or group that has regular socials or get-togethers. Finding and participating in a group that is active will also help increase your chances of being active. Remember, the more you interact with others, the more chances you have to expand your social network.

- ◇ **Volunteer** – Volunteering is a wonderful way for individuals to meet new people and help others at the same time. Contact area schools, churches, community centers, hospitals, or volunteer centers to learn ways that you can help your community.
- ◇ **Stay positive** - Being negative about yourself will not help you meet new people. Most people want to meet and be around individuals who are positive. It may be difficult at first to meet new people but with practice you will build up your confidence to interact with others.



- ◇ **Say yes!** - If someone invites you to a party, wedding, or any other social event, accept the offer if you can attend. This will give you an opportunity to meet others in a friendly and positive environment.
- ◇ **Be patient.** Forming new relationships can take time, even for people who do not have a brain injury. Do not become discouraged if you do not have a partner immediately. Enjoy the socializing that may eventually lead to a more intimate relationship.

- ◆ **General counseling:** Counseling can help with depression, anxiety, and low self-esteem that often follow TBI. If you or those you love think that you are depressed or anxious, you should discuss it with your doctor or another medical professional. He or she may be able to recommend a therapist. Since relationships often change after injury, couples counseling may also be required to address negative feelings in the relationship that could also be affecting sexual functioning.
- ◆ **Treatment to Improve Social Communication Skills:** A speech therapist or neuropsychologist can help you to improve problems with social communication that have been caused by injury. For example, they can help you learn how to start conversations with people, how to take turns, how to ask appropriate questions of others, and how to make good eye contact. Improvements in these skills can lead to a better ability to form new relationships and to maintain existing ones.

- ◆ **Sex therapy:** There are licensed sex therapists with expertise in helping people overcome sexual problems and develop healthy, fulfilling sex lives. These therapists use a combination of general counseling and guided homework activities to improve sexual functioning. There is nothing perverted or dirty about sex therapy, it is simply a way for a professional who knows a lot about human sexuality and sexual functioning to help you discover how to make your sex life more fulfilling. Sex therapists will also help with emotional problems, like depression, and relationship problems that can affect sexual functioning. Partners are usually included in sex therapy sessions.
  
- ◆ **Alternative Sexual Behaviors**
  - ◇ **Change of positioning during sexual activity:** Many people are comfortable with using the same positions every time that they have sex. For many people, this position involves one person being on top of another. After TBI, this may not be possible. Your sexual functioning may improve if you are willing to try different positions to make sex more comfortable and satisfying. It is most important to have an honest discussion with your partner. Facing this issue together, with a positive attitude, rather than with embarrassment or shame, can make the difference in whether both of you feel sexually fulfilled. For example, the most comfortable position may be side by side. Another possible position is standing upright with one person leaning against a wall. Finding a comfortable position sometimes requires using a cushion or pillow. This can cushion some of the movements that may result in pain and can reduce the pressure on particularly sensitive body parts. A pillow or cushion can be placed under the lower back, under the knees, under a side, or anywhere needed to improve comfort. You may have to try a few different positions before finding one that is comfortable. Communicating openly with your partner about this can improve sexual satisfaction for both of you.

- ◇ **Masturbation or self-pleasuring:** Sometimes, it is difficult for a person with injury to find partners with whom to be intimate. If this goes on for a long period of time, sexual frustration can occur. Feeling sexually satisfied is an important part of a person's overall quality of life. If you cannot find a sexual partner, or if you prefer not to have one, masturbating or providing sexual pleasure to yourself may be an option. This is not right for everyone, and you should only do what you feel comfortable with. Accepting masturbation as an alternative form of sexual activity, however, may result in sexual fulfillment that you may not otherwise find. Self-stimulation can also be used as a way to figure out what feels sexually pleasing to you, as this could differ now from what felt pleasing to you before your injury. Knowing your body better could help you to better communicate needs to a partner. The use of vibratory devices may assist you with self-stimulation. It is important to remember to respect the feelings of others, and to follow any rules or regulations at your home or facility regarding privacy. Always do your self-pleasuring in private, behind closed doors that are locked whenever possible. Remember that having other people unwillingly witness what you are doing can have unwanted consequences, like eviction from a facility or legal charges.
- ◇ **Gratification through erotic media:** Some people obtain sexual satisfaction from just reading books with sexual content, or viewing movies or pictures with sexual content. This is a valid way of obtaining sexual gratification, as long as you are not breaking any laws or harming anyone.
- ◇ **Cyber-relationships:** In today's world of technological advances, many people are forming relationships over the internet. There are chat rooms for singles and internet dating services. Sexuality is often a component of these relationships. People with physical limitations often feel less inhibited on the internet, and may feel sexually gratified after sharing descriptions of sexual activity with someone else. It is important to be cautious so that you are not taken advantage of. Do not share personal identifying information with people that you meet over the internet. If you have started a relationship on the internet and wish to meet in person, always meet in a public place the first several times, until you feel that you know the person well enough and feel safe. Never meet someone face-to-face for the first time without taking another adult with you. People sometimes give false information on the Internet. For example, they may be a teenager pretending to be an adult. This could lead to you being arrested, so be careful when forming relationships on the internet.



# Chapter 4: Safe Sex Practices

## Birth Control

When choosing a type of birth control, it is important to think about how well it works, how safe it is, its costs, side effects, comfort, and how easy it is to use correctly. Changes in physical and thinking abilities after TBI may make it hard to use some birth control methods. For example, problems with movement may make it hard to insert a sponge or put on a condom. Problems with memory may lead to you forgetting to take birth control pills or to using a condom.

There are many forms of birth control available. Discuss the various options with your health care provider, who will help you decide what the best option is for you. It will be important to take into account your medical history and any potential side effects, as well as your ability to correctly use the method that you chose.



Some people prevent pregnancy through practicing certain behaviors, like only having sex during certain times of the menstrual cycle (e.g., “rhythm method”) or having the man withdraw or “pull out” his penis from the vagina prior to ejaculation. These methods cannot guarantee that you will not become pregnant. The only certain way of avoiding pregnancy is to abstain from sex completely. It is also important to remember that women can become pregnant when breastfeeding or at any time after having a baby.

- ◆ **Medications to prevent pregnancy:** Many women take hormone medications to prevent pregnancy. Oral medications tend to be very effective (99%), but rely on consistency, a good memory, and knowing what to do if you forget to take a pill. Injections and patches may be better options for individuals with memory problems.
  - ◇ **Birth Control Pills** – The “pill” either prevents the ovary from releasing the egg or changes the cervix and lining of the uterus so they are un-receptive to sperm. There are many kinds of birth control pills with different potential side effects and schedules.
  - ◇ **Hormone Injection** - Hormone injections protect against pregnancy for up to 12 weeks.
  - ◇ **Hormone Patch** - Patches are applied directly to the skin and release the same hormones as the birth control pill. They usually need to be changed on a weekly basis.

- ◆ **Implantable Devices:** These devices are implanted by a health care provider into the woman's body and stay in for long periods of time, months to years in some cases. Some devices are implanted in a woman's arm, and release a continual flow of hormones for up to three years. Others are implanted into the fallopian tubes, which prevents pregnancy for about 3 months. Yet others are inserted into the vagina and left in place for 3 weeks. Implantable devices are very effective (98-99%) and may be good options for individuals with brain injury with physical deficits and/or memory problems.
- ◆ **Insertable Options:** Insertable options involve placing a medication or device into woman's body by the woman herself, or her partner. These tend to be used on a one time basis, and can be less effective than other options (75-97%).
  - ◇ **Spermicides** - Spermicides are foams or gels made up of chemicals that destroy sperm. They are most effective when used with a condom.
  - ◇ **Sponge** - The sponge is placed in the vagina and contains spermicide to destroy and trap sperm, preventing it from entering the cervix.
  - ◇ **Diaphragm/Cervical Cap** - These devices are made of flexible material and are placed in the vagina prior to intercourse and must remain in place for several hours afterwards. They prevent sperm from entering the uterus and should be used in combination with a spermicide.
- ◆ **Condoms:** Condoms are considered a barrier device. There are male and female condoms and both work by preventing sperm from entering the vagina. Condoms are 97% effective in preventing pregnancy. Female and male condoms are the only forms of birth control, other than abstinence, that helps prevent the spread of sexually transmitted diseases, including the AIDS virus.
- ◆ **Other Options**
  - ◇ **Plan B® Emergency Contraception** - In recent years, emergency contraceptives have been developed and are available over the counter. These prevent pregnancy by stopping the release of the egg and prevents the egg from being fertilized and must be used within 72 hours of intercourse. This should not be considered a regular form of birth control.
  - ◇ **Sterilization** - The most common sterilization procedure for women involves cutting the fallopian tubes - this is called a tubal ligation. For men, sterilization involves a procedure called a vasectomy which closes or blocks the tubes that carry sperm. Sterilization lasts for life and is meant to be permanent. It is appropriate if you never want to have a biological child in the future.

## Prevention of Sexually Transmitted Diseases and AIDS

Sexually transmitted diseases (STDs) are caused by infections that are passed from person to person during sex or intimate contact. Most are serious and can cause long term health problems. Some can even affect your chances of having children. If identified early, many are easy to treat with antibiotics. Both partners usually need to be treated and remain abstinent until the treatment is complete.

Most people are surprised to find out that STDs are very common. In fact, more than half of us will have an STD at some point in our lives. The other surprising fact is that many people who have an STD are not even aware they have it because they have no symptoms. If you don't know you have an STD, it can't be treated. Without treatment, STDs do not go away.

The best intervention for an STD is prevention. The only surefire way to prevent an STD is abstinence. The next best way is to follow safe sex practices. Ask your partner prior to having sex if they have a history of an STD infection. Ask them if they have used IV drugs. Having a monogamous sexual relationship with an uninfected partner is another way to avoid contracting an STD. Another effective prevention strategy is to use condoms. Condoms made from latex, though not 100% effective can provide a barrier for oral, vaginal or anal sexual activity. To most effectively prevent an STD, condoms must always be used, even when using another form of birth control.

If you have engaged in any risky sexual behavior, one of the best things you can do for yourself is to get tested - and treated if you test positive. Remember, STDs are very common so your primary care provider will be glad to both test and treat you. Try not to let embarrassment interfere with the need to get checked out. Better safe than sorry is a good rule to follow.



- ◆ **Some of the more common STDs you may have heard about include:**
  - ◇ Chlamydia
  - ◇ Gonorrhea
  - ◇ Syphilis
  - ◇ Herpes
  - ◇ Human papillomavirus (HPV)
  - ◇ Cytomegalovirus (CMV)
  - ◇ Autoimmune Deficiency Syndrome (AIDS)
- ◆ **There are some common signs and symptoms of STDs that both males and females can watch for including:**
  - ◇ Burning or pain when going to the bathroom
  - ◇ Bumps, sores, or blisters near your genital region
  - ◇ Itching in your genital region
  - ◇ An increased need to urinate
  - ◇ A sore throat
  - ◇ Fever and aches and pains that are similar to having the flu
- ◆ **If you suspect that you may have been exposed to an STD:**
  - ◇ Get tested
  - ◇ Get treated
  - ◇ Inform your sexual partner or partners
  - ◇ Have no sex until both you and your partner have been evaluated and treated
  - ◇ Once you have been treated and are ready to resume sex, use condoms every time
  - ◇ If medications are prescribed, take them all, do not stop early just because you feel better
  - ◇ Do not share your medications with others
  - ◇ Schedule a follow up visit to be sure you have been properly treated

## Rights in Sexuality and Relationships\*

Persons with brain injury have the same rights as other people to engage in sexual activities and be sexually fulfilled. Some people with brain injury are more vulnerable to harm by others, as a result of physical limitations or decreased thinking abilities. It is important to know your rights, so that you can enjoy yourself, but also prevent yourself from becoming a victim.

- ◆ People have the right to have their sexual needs and preferences accepted and treated with respect.
- ◆ People have the right to privacy and confidentiality in all aspects of their lives including their personal relationships.
- ◆ People have the right to a sexual relationship with another person if both are over the age of consent.
- ◆ People have the right to stop having sex with someone at any time.
- ◆ People have a right to get information that they can understand about:
  - ◇ Social relationships and communication skills
  - ◇ Sexual matters, such as contraception, masturbation, sexual hygiene, pregnancy and prevention of sexually transmitted infections.
  - ◇ Social and legal responsibilities regarding sexual relationships
  - ◇ Ways of avoiding sexual exploitation and abuse
- ◆ People have a right to marry or live with the partner of their choice and have children.
- ◆ You have the right to say no to things that other people do that make us feel uncomfortable or upset, physically and sexually.
- ◆ If you feel that your rights are violated, you have the right to file a complaint.

\*(copied with permission from Simpson, G. (2003) You and Me: An Education Program About Sex and Sexuality After Traumatic Brain Injury. Brain Injury Rehabilitation Unit, South Western Sydney Area Health Service).

# Chapter 5: Resources

We hope that you have found the information in this booklet helpful. You may find it useful to refer to it in the future, for any questions that come up about sexuality. We also want you to know about other resources that may be helpful. Following is a list of educational materials, websites, videos, and podcasts that contain helpful information about sexuality and TBI. Some of these are about sexual functioning in general, but give information that may be helpful to anyone, including persons with TBI.

## Sexuality and TBI

### Book

- ◆ Sexual Difficulties After Traumatic Brain Injury and Ways to Deal With It by Ronit Aloni and Schlomo Katz, Charles C. Thomas Publisher, 2003, 207 pages.

### Articles

- ◆ *Sexual Dysfunction after Brain Injury: Assessment and Treatment Options* by M. Elizabeth Sandel in Brain Injury Professional, Volume 3, Issue 1, 2006, pages 28-29.
- ◆ *Relationship Issues in Traumatic Brain Injury* by Lisa Merritt in Brain Injury Source, Volume 3, Issue 1, Winter 1999.
- ◆ *Sexuality and Disability . . . An Oxymoron?* by Nora J. Baladerian in Premier Outlook, Volume 2, Issue 2, Fall 2001. Available at [http://www.premier-outlook.com/pdfs/article\\_archive/fall\\_2001/PERC&REALITYFALL2001.pdf](http://www.premier-outlook.com/pdfs/article_archive/fall_2001/PERC&REALITYFALL2001.pdf)

### Pamphlet

- ◆ Sexuality After a Person has a Brain Injury by David Strauss Ph.D., L.A. Publishing, 2006, 8 pages. Available at <http://www.lapublishing.com/sexuality-brain-injury/>

### Educational booklet

- ◆ *You and Me: A Guide to Sex and Sexuality After Traumatic Brain Injury (2<sup>nd</sup> edition)* by: Grahame Simpson, South Western Sydney Area Health Service, 2003, 40 pages. Available from: Brain Injury Rehabilitation Unit, Liverpool Health Service, Locked Bag 7103, Liverpool BC 1871, NSW Australia, Phone: 61 2 9828 5495, web: <http://www.sswahs.nsw.gov.au/liverpool/biru/>; e-mail: [grahame.simpson@swsahs.nsw.gov.au](mailto:grahame.simpson@swsahs.nsw.gov.au)
- ◆ *Head Injury Rehabilitation: Sexuality After TBI* by: William F. Blackerby, HDI Publishers, The HDI Professional Series on TBI, 1994. Available from: [www.hdipub.com/books](http://www.hdipub.com/books)

## Educational Program/Workbook

- ◆ *You and Me: An Education Program About Sex and Sexuality After Traumatic Brain Injury (2<sup>nd</sup> edition)* by: Grahame Simpson, South Western Sydney Area Health Service, 2003, 260 pages. Available from: Brain Injury Rehabilitation Unit, Liverpool Health Service, Locked Bag 7103, Liverpool BC 1871, NSW Australia, Phone: 61 2 9828 5495, web: <http://www.sswahs.nsw.gov.au/liverpool/biru/>  
e-mail: [grhame.simpson@swsahs.nsw.gov.au](mailto:grhame.simpson@swsahs.nsw.gov.au)

## Podcast

- ◆ *Sexuality after Traumatic Brain Injury* hosted by Gerry Brooks, Northeast Center for Special Care, March 2009. <http://www.northeastcenter.com/podcast-traumatic-brain-injury-029.htm>

## PowerPoint presentations

- ◆ *Intimacy after Traumatic Brain Injury: What We Know and What We Are Guessing* by Angelle Sander, Baylor College of Medicine. <http://www.tbicommunity.org/resources/index.htm>
- ◆ *Maintaining Intimacy after Brain Injury: Identifying Solutions to Difficulties in Intimacy* by Rolf Gainer, Brookhaven Hospital. <http://www.traumaticbraininjury.net/Maintaining%20Intimacy%20After%20Traumatic%20Brain%20Injury%20March2004.pdf>

## Websites

- ◆ *Sexuality Is A Family Matter* by Carolyn Rocchio in Family News And Views: A Monthly Publication of the Brain Injury Association, 1993. <http://www.bianj.org/Websites/bianj/Images/Sexuality%20is%20a%20family%20matter.pdf>
- ◆ *TBI Consumer Report #5: Coping with Sexual Problems after TBI* by Mount Sinai School of Medicine. [http://www.mssm.edu/static\\_files/MSSM/Files/Research/Centers/Traumatic%20Brain%20Injury%20Central/CR5.pdf](http://www.mssm.edu/static_files/MSSM/Files/Research/Centers/Traumatic%20Brain%20Injury%20Central/CR5.pdf)
- ◆ *You are still a Sexual Person After Your Brain Injury* by The Ohio State University Medical Center, May 2004. <http://medicalcenter.osu.edu/PatientEd/Materials/PDFDocs/discord/braininjury/sexual-person-braininjury.pdf>
- ◆ *Brain Injury: Sexuality* by Sylvia Diaz-Duraski, RIC LIFE center website, reviewed Nov 2008. <http://lifecenter.ric.org/index.php?tray=content&tid=top163&cid=2508>

- ◆ *Sexual Problems after Brain Injury* by Michael Oddy and Ian Fussey, Brain Injury Rehabilitation Trust. [http://www.birt.co.uk/images/BIRT06\\_Sexualproblems.pdf](http://www.birt.co.uk/images/BIRT06_Sexualproblems.pdf)
- ◆ *Traumatic Brain Injury and Sexual Issues* by Better Health Channel. [http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Traumatic\\_brain\\_injury\\_and\\_sexual\\_issues](http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Traumatic_brain_injury_and_sexual_issues)
- ◆ *Sexuality after an Acquired Brain Injury* by Headway Ireland, 2007. [http://www.headway.ie/download/pdf/sexuality\\_factsheet\\_final.pdf](http://www.headway.ie/download/pdf/sexuality_factsheet_final.pdf)
- ◆ *Brain Trauma and Sexuality* by Stanly Ducharme. [http://www.stanleyducharme.com/resources/combin\\_injury.htm](http://www.stanleyducharme.com/resources/combin_injury.htm)
- ◆ *Sexual Dysfunction Following Injury: Time for Enlightenment and Understanding: Suggestions* by Center for Neuro Skills. <http://www.neuroskills.com/tbi/sex-suggestion.shtml>

## **Socialization**

### **Article**

- ◆ *What I Really Want is a Girlfriend: Meaningful Social Interaction after Traumatic Brain Injury* by Mark Yivisaker and Timothy Feeney in Brain Injury Source, Volume 5, Issue 3, Summer 2001, pages 13-17.

### **Pamphlet**

- ◆ *Overcoming Loneliness and Building Lasting Relationships after a Brain Injury* by Jeffrey Kreutzer et al, Brain Injury Association of America, 2006. [http://www.biausa.org/\\_literature\\_43278/overcoming\\_loneliness](http://www.biausa.org/_literature_43278/overcoming_loneliness)
- ◆ *Recovering Relationships after a Brain Injury: The Essential Guide for Survivors and Family Members* by National Resource Center for Brain Injury, 2005. <http://www.neuro.pmr.vcu.edu/catalog/cat08/cat08.asp#relationships>

### **Website**

- ◆ *What Happens to Relationships after Brain Injury? Recovering Relationships after a Brain Injury* by National Resource Center for Brain Injury, 2005. <http://www.neuro.pmr.vcu.edu/catalog/article%20reprints/RRsamplechapters.pdf>
- ◆ *How Positive Relationships help Recovery. Recovering Relationships after a Brain Injury* by National Resource Center for Brain Injury, 2005. <http://www.neuro.pmr.vcu.edu/catalog/article%20reprints/RRPositive.pdf>
- ◆ *How and Where Do I Meet New Friends or People to Date? Recovering Relationships after a Brain Injury* by National Resource Center for Brain Injury, 2005. <http://www.neuro.pmr.vcu.edu/catalog/article%20reprints/RRdating.pdf>

## **Substance Abuse**

### **Article**

- ◆ *Sexuality and Substance Abuse in Traumatic Brain Injury Independence* by Richard L Delmonico in Brain Injury Source, Volume 5, Issue 3, Summer 2001, pages 24-26.

### **Website**

- ◆ *Substance Abuse and Brain Injuries - HIV/AIDS and Brain Injury* by Ohio Valley Center for Brain Injury Prevention and Rehabilitation, 2000. <http://www.brainline.org/content/2008/11/substance-abuse-and-brain-injuries-hiv-aids-and-brain-injury.html>

## **Gay and Lesbian**

### **Article**

- ◆ *Traumatic Brain Injury in Gay and Lesbian Persons: Practical and Theoretical Considerations* by Michael O'Dell and Richard Riggs in Brain Injury Source, Volume 5, Issue 3, Summer 2001, pages 22-23, 42.

## **Women**

### **Article**

- ◆ *Women and Sexuality Post TBI* by Tina Trudel in Brain Injury Professional, Volume 3, Issue 1, 2006, pages 18-20.

## **Teens**

### **Websites**

- ◆ *Adolescents with Brain Injury Issues of Sexuality* by Leslie Kahn, Brain Injury Association of Washington. <http://www.braininjurywa.org/resources/doc/Adolescents%20with%20Brain%20Injury%20Issues%20of%20Sexuality.pdf>
- ◆ *All About Acquired Brain Injury: Sexuality and ABI* by Brain and Spine Foundation of United Kingdom. [http://www.aboutbraininjury.org.uk/sexuality\\_and\\_ABI.aspx](http://www.aboutbraininjury.org.uk/sexuality_and_ABI.aspx)
- ◆ *All About Acquired Brain Injury: Things to Think about before having Sex* by Brain and Spine Foundation of United Kingdom. [http://www.aboutbraininjury.org.uk/things\\_to\\_think\\_about\\_before\\_having\\_sex.aspx](http://www.aboutbraininjury.org.uk/things_to_think_about_before_having_sex.aspx)
- ◆ *All About Acquired Brain Injury: Sexual Health and STIs* by Brain and Spine Foundation of United Kingdom. [http://www.aboutbraininjury.org.uk/having\\_sex\\_contraception\\_and\\_STIs.aspx](http://www.aboutbraininjury.org.uk/having_sex_contraception_and_STIs.aspx)

## **Sexuality and Disability**

### **Pamphlet**

- ◆ *Sex Resource Guide for People with Disabilities* by Susan Nussbaum, Access Living of Metropolitan Chicago, 2005, 40 pages.

### **Books**

- ◆ *Ultimate Guide to Sex and Disability* by Miriam Kaufman, Cory Silverburg, and Fran, Odette Cleis Press; 2nd edition, 2007, 360 pages.
- ◆ *Enabling Romance: A Guide to Love, Sex and Relationships for People with Disabilities (and the People who Care About Them)* by Ken Kroll and Erica Levy Klein, No Limits Communications, 2001, 218 pages.
- ◆ *Disability and the Art of Kissing* by Gary Karp, Life On Wheels Press, 2008, 112 pages.

## **General Resources**

### **Parenting with a Disability**

- ◆ Through the Looking Glass, website: <http://www.Lookingglass.org>  
Toll Free: (800) 644-2666
- ◆ Parents with Disabilities Online  
Website: <http://www.disabledparents.net/>

### **Sexual Health, Birth Control, and Sexually Transmitted Diseases (STDs)**

- ◆ <http://www.Plannedparenthood.com>

### **Domestic Violence**

- ◆ Domestic Violence Helpline: Phone 877-863-6338
- ◆ Between Friends: Phone 800-603-4357

### **Adaptable Sexual Aides**

- ◆ Website: <http://www.Mypleasure.com/education/disability/index.asp>
- ◆ Website: <http://www.Comeasyouare.com>

### **National Association of Sexuality Educators, Counselors and Therapists**

- ◆ You can locate a certified sex therapist in your geographic area on the following website: <http://www.aasect.org/>

## **Sexual Functioning and Satisfaction after Traumatic Brain Injury: An Educational Manual**

To obtain an electronic copy of this manual, please visit the following website:  
<http://www.tbicommunity.org/resources/index.htm>

Texas Traumatic Brain Injury Model System of TIRR Memorial Hermann  
Brain Injury Research Center  
2323 Shepherd, Suite 907  
Houston, Texas 77019  
Phone: 713.630.0515  
Email: [asander@bcm.edu](mailto:asander@bcm.edu)