

Tip Sheet # 15



Love, Affection, and Sexuality Issues

Stroke can cause changes in how stroke survivors feel about themselves and others. Whether you are a spouse caregiver, adult child caregiver, or other type of caregiver, love, affection, and sexuality issues may be of concern. A stroke survivor may not feel as attractive, or may not be able to show love or affection like they used to. For some stroke survivors, brain damage from the stroke might cause them to display sexual behaviors in public. Having sex after a stroke can also be different, and many stroke survivors and their partners have questions.

What is the problem with love, affection, and sexuality issues?

There are a number of things that may affect how the survivor is able to show love, affection, or have sex. There are also a number of things that can affect you as a caregiver as well. Put an X beside the things listed below that you think are problems for you or the stroke survivor.

Stroke survivor problems

- ☐ No longer feels they are attractive because of the stroke
- ☐ Does not show affection, or seems distant
- ☐ Seems like they no longer care about you
- ☐ Role changes have changed the relationship
- ☐ Feels depressed or anxious
- ☐ Personality has changed
- ☐ Speech or communication is difficult
- ☐ Fear of having another stroke during sex
- ☐ Fear of being rejected
- ☐ Fear of not being able to perform
- ☐ Paralysis or sense of touch is different
- ☐ Bad timing, or too tired all the time
- ☐ Trouble concentrating, poor memory, or difficulty thinking
- ☐ Unable to get comfortable or in the mood
- ☐ Makes unwanted advances toward you as a caregiver

- ___ Has inappropriate sexual behaviors or undresses in public
- ___ Other _____
- ___ Other _____

Caregiver problems

- ___ The stroke has changed the relationship
- ___ Feels depressed or anxious
- ___ Can't communicate with the survivor
- ___ Fear of hurting the survivor
- ___ Too tired or can't seem to relax
- ___ Not sure of how to handle inappropriate sexual behaviors
- ___ Other _____
- ___ Other _____

- Brain damage from a stroke may cause emotional changes that can affect the survivor's ability to show love and affection. For example:
 - Depression
 - Anger
 - Apathy
 - Crying for no reason
 - Fear of being rejected
 - Fear of not being able to perform
 - Body image, or not feeling attractive after stroke
 - Trouble showing that they care about you
- Sexual behaviors may also be caused by brain damage. Some changes from the stroke that might affect behaviors include:
 - No attention or affection
 - Trouble with speech or communication
 - Trouble concentrating, poor memory, or difficulty thinking
 - Paralysis or loss of sense of touch
 - Inappropriate sexual behaviors
- **Don't take changed emotions and behaviors personally.** These changes are often from the stroke, not because of you.



How can I as a caregiver deal with love, affection, or sexuality issues?

- If the survivor no longer feels attractive because of the stroke –** Help the survivor feel more attractive by helping them with personal care, grooming, and selecting attractive clothing. Complement the survivor on how they look, especially if they have taken the extra effort to look good.
- Feelings of depression or anxiety –** A variety of emotions can occur after stroke. **See Tip Sheet #9 Dealing with the survivor's emotions and Tip Sheet #10 Dealing with the stroke survivor's feelings about himself or herself.** These tip sheets are full of strategies about how to help the survivor feel better and how to deal with emotions after stroke.
- Speech and communication issues –** These issues can make showing love and affection very difficult. **See Tip Sheet #14 Communicating with the stroke survivor** for ideas on how to better communicate. Talk to the survivor. Tell them what is pleasing. They cannot read your mind. Ask them what they like. The more you can let each other know about what is pleasurable, the better.
- Personality changes –** Relationships can be very different after stroke. Brain damage from the stroke can cause personality changes. **See Tip Sheet #12 Dealing with the Stroke Survivor's Changed Personality** for some ideas on how to handle some of these changes. Do not take these changes personally as a caregiver. They are most often due to the stroke itself.
- Role changes can interfere with love and affection.** Whether you are an adult child, spouse, or other type of caregiver, role changes can affect your relationship. Try to allow the stroke survivor to be as independent as possible. **See Tip Sheet #10 Dealing with the stroke survivor's feelings about himself/herself.** If you are a

spouse caregiver, work on keeping an adult relationship. Whether you are a younger or older couple, providing care can sometimes interfere with feelings of intimacy and sexual attraction. Try to keep some fun and playfulness in your relationship.



- **Does not show affection, seems distant, or has trouble concentrating. The survivor might seem like they no longer care about you.** Try not to blame yourself or the stroke survivor. These personality changes may be due to the damage caused by the stroke. The survivor might have trouble concentrating and may miss the chance to show that they care. **See Tip Sheet #13 Dealing with the survivor's problems with thinking** for ideas.
- **Bad timing or feeling too tired –** Fatigue or feeling tired after stroke is very common for the survivor as well as the caregiver. See **Tip Sheet #6 How to Manage Specific Problems the Stroke Survivor May Have**, for information about feeling tired after stroke. Choose a time when the survivor is not too tired for lovemaking, usually in the morning after they have had a good night's rest. **Tip Sheet #32 Keeping my energy level up** is a good place to look if you as a caregiver are tired or worn out.
- **Fears about having another stroke during sex -** Many survivors and their caregivers worry about this. The chance of having another stroke during sex is very low. The survivor's heart rate may beat faster much like it would with any physical activity. **Ask the doctor about having sex after stroke.** This may help to reduce these fears.
- **Fear of rejection or fear of inability to perform –** Talk with the survivor about having sex and any feelings that they may have. Reassure them that you care. **Tell the survivor to talk with their doctor before taking any medications or treatments to improve sexual function.** These types of medications or treatments may be dangerous if taken with medications or treatments for stroke.



- **Unable to get comfortable or in the mood** – Stroke can make finding the right position for lovemaking difficult for both the survivor and the caregiver. You and the survivor may need to experiment with different positions to find what is most comfortable. You and the survivor may also want to try making up a fantasy in your minds to concentrate on in order to get in the mood. Be creative! Use touch on various areas of the body. Feathers, scented oils, other things may help. **Ask the doctor or a therapist if they know of any good books or resources that can help in this area.**



- **Inappropriate sexual behaviors** – Some stroke survivors may become confused and suddenly take their clothes off. They may forget to put their clothes on after going to the bathroom. They may fondle or touch themselves in public. They may make unwanted advances on you as a caregiver or others. They might say rude things.
 - If the survivor undresses, calmly lead the person to a bathroom or their room. You may bring a robe to put over them in a matter-of-fact way if you have one available.
 - If the survivor fondles or touches themselves in public, try to distract them with something else. Ask them to look at something. Ask them a question. The survivor has probably forgotten their social manners and is only doing what feels good.
 - If the survivor exposes himself or herself in public, or tries to touch or make advances on others, calmly lead them to the

bathroom and tell the person, “He forgets where he is” or “She forgets where she is.”

- If the survivor says something rude, tell the person, “He doesn’t realize what he is saying sometimes” or “She doesn’t realize what she is saying sometimes.”
- If the survivor makes unwanted advances on you as a caregiver, tell them how you feel. Tell them you are not interested and why. Open communication is important. Do not assume they can read your mind. **If the survivor is confused, distract them with something else.** It can be especially troubling if you are an adult child who is caring for a parent. The parent may mistake you for their spouse or partner. **Whatever the situation, do not allow the stroke survivor to make sexual advances on you against your will.** Get professional help if needed.



Where do I find out more information about handling love, affection, or sexuality issues the survivor may have?

- Ask your doctor about any questions that you may have. **See Tip Sheet #7 Which health professional to call for advice.** Consulting a neuropsychologist, psychiatrist, therapist, rehabilitation doctor, or rehabilitation nurse may be helpful in dealing with love, affection, and sexuality issues. A marriage counselor can be helpful for spouses who are dealing with stroke.
- **See Tip Sheet #8 Where to find resources** to see what organizations might be able to help. Getting to know other stroke survivors and caregivers might also be helpful. There is a list of stroke support groups in Tip Sheet #8.
- Call the American Stroke Association’s toll-free “Warm-line” at 1-800-478-7653.

- Call the American Stroke Association's toll-free number at 1-800-787-6537.

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