

# Stroke and the Family

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A NEW GUIDE

Joel Stein, M.D.

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## Impact on Marriage and Relationships

Peter and Lilly have been married for thirty years and have raised two children who are now grown and living in another state. Peter's career as a successful executive in a Fortune 500 company creates substantial demands on his life even when he's not in the office. Lilly returned to work as a social worker after their children were grown. She has played an important role in Peter's professional life as a spouse and hostess and has provided him with significant emotional support. Peter has always been very loving to Lilly but has to a large extent depended on her to manage their family and social life. Friends and business associates have long admired their successful relationship.

Their marriage is put to the test by Lilly's sudden stroke. She experiences left-sided weakness, cognitive difficulties, and a loss of social skills. At first Peter is unable to accept the changes in Lilly, and devotes his energies to finding her "the best" treatment, which he believes will return her to her previous function. Gradually he comes to accept that while Lilly has improved significantly, she will have some permanent disability. He arranges twenty-four-hour assistance for Lilly at their home and is largely able to resume his prior work schedule. Fortunately, he is able to curtail his work-related travel schedule and is home with Lilly every evening. Peter remains frustrated by his new situation, however. He confides in a close friend that even though his wife is home, he "misses the old Lilly." He feels that he no longer has the emotional support he has always counted on, and has lost his primary confidante and best friend. Lilly seems largely unaware of the changes in their relationship, though she sometimes unexpectedly accuses Peter of no longer loving her. How can Peter and Lilly adapt to the changes in their relationship?

Stroke does not just affect the stroke survivor; it affects all those around him. Usually the spouse is the person most directly impacted. In cases of disabling stroke, a spouse who was once a strong partner may suddenly be recast in a more dependent role. A spouse who formerly was a source of support and nurture now may not only be unable to provide this support, but may require nurture himself.

Peter and Lilly's situation is not uncommon. There is no "going back" after a stroke, and understanding the changes in the relationship is a difficult but important step in moving forward. A healthy spouse may find that her husband is no longer able to meet her emotional needs after a stroke. By turning to friends and family for support she may actually help remove some of the pressure from the marriage and establish a new equilibrium. In Peter's case, his relationship with his brother is a major source of strength for him. Whereas he once turned to his wife for advice about his career, he now learns to rely on his brother.

Providing care to a spouse after a stroke creates multiple challenges for a relationship. The time requirements of providing assistance or supervision can be daunting in their own right. This is particularly true if the healthy spouse is still working or if children are still at home. Many people struggle with conflicting demands between family responsibilities and work even without contending with the aftereffects of a stroke. Sometimes a stroke can feel like the straw that broke the camel's back.

The physical demands of caregiving can also be substantial, to the point of becoming unmanageable. An older spouse may have medical problems of his own that interfere with his ability to provide assistance to his wife.

Spouses are generally accustomed to a substantial degree of intimacy, but the care needs after a stroke may require accepting new roles and breaking down former barriers of privacy. Helping a spouse with toileting, for example, may cause emotional discomfort for some couples. Injecting a spouse with insulin may be difficult emotionally for some individuals. Fortunately, we are all often more capable of adapting to new situations than we give ourselves credit for. Most spouses can meet the challenge of providing care to a partner in ways they never felt possible. In cases where healthy spouses simply cannot manage on their own, other resources, such as home health aides or personal-care attendants, can be called upon to reduce the burden to a manageable level.

Accepting assistance from anyone can be very difficult for some stroke

survivors, and even more so if this assistance is being provided by a spouse. A stroke survivor who has always been highly independent or is used to being the dominant partner in the marriage will often struggle with her newly dependent role. Identifying this challenge is the first step in addressing it. Lifelong habits and behaviors can be difficult to change, so it is essential for both spouses to work together to reach a new arrangement.

Communication between spouses is essential after stroke. This is easiest when cognitive abilities and language are spared by a stroke, but even when these areas have been affected, the healthy spouse needs to make certain that a dialogue continues. Spending time discussing the changes in their lives and marital roles may be helpful to both members of the marriage. Many couples feel better simply by airing the emotional issues that they face individually and together. Marital counseling may be useful for couples who find it difficult to work through these issues on their own.

Some marriages end in divorce after stroke. Sometimes stroke represents the final stressor for a marriage that was already in trouble before the stroke. In other cases, the healthy spouse is unable to accept her partner's altered behavior and abilities. More commonly, stroke induces a review of priorities. Many couples find that dealing with a major life stressor such as stroke can actually strengthen their relationship.

Physical closeness in the form of hugging, cuddling, and touching may be a source of strength in a marriage after a stroke. Sex can also be a shared pleasure that continues to be a significant support for the marriage, though some adaptations to physical disability imposed by the stroke may be necessary.

## Sex

Frank is a fifty-nine-year-old married insurance salesman with diabetes and hypertension. He wakes one morning to find that he cannot stand and is weak on his left side. Though he makes a relatively rapid and substantial recovery from his stroke, he develops depression and is given fluoxetine (Prozac) by his physician. He seems to be doing well when he comes to his primary care doctor for a visit. As he is leaving the exam room, however, he asks the physician if he would be able to take Viagra (sildenafil). After his physician has him return to the room and discuss the issue further, it be-

comes clear that Frank was having difficulty maintaining erections even before his stroke, and has had increased difficulties since his stroke. He also reports a loss of libido (sex drive). Lastly, he reports that both he and his wife are worried about precipitating another stroke during sex. Should Frank and his wife worry that sex might cause another stroke? If not, are his sexual problems treatable? What is causing these symptoms?

Sex plays an important role in marriage and long-term relationships beyond its direct physical pleasures. Owing to the serious and often disabling nature of stroke, healthcare practitioners often neglect the topic of sexuality after stroke. Stroke survivors themselves may be embarrassed to raise the issue, or they may assume that their disability precludes resumption of sexual activity. Despite the apparent public preoccupation with sexuality, it is often given insufficient attention in the context of illness such as stroke.

Sexual function may be negatively impacted by a number of aspects of stroke, and it may be difficult in some cases to determine what the primary limiting factors are. Loss of sensation can occur with stroke, directly impacting sexual function in both men and women. The weakness and abnormal muscle tone that accompany stroke can directly interfere with the mechanics of intercourse. Couples may find it helpful to explore alternative positions in which the stroke-affected partner can participate in sex with fewer physical challenges. For example, intercourse may be easier for both people if the affected partner lies on his or her back during intercourse.

Although many couples find it difficult to talk about sex, discussing the challenges faced with a physician or nurse can be enormously helpful. For example, the abnormal muscle spasms sometimes triggered by sex can be controlled with medications in many cases.

Medication side effects are quite common and can lead to reduced libido, arousal, or orgasm in men and women. Men may experience erectile dysfunction (impotence or inability to achieve an erection) or ejaculatory dysfunction. Many antihypertensive medications are known to cause erectile dysfunction in some men and may contribute to sexual dysfunction in women as well, with beta-blockers such as propranolol (Inderal) a particularly common culprit. Antidepressant medications can cause loss of interest in sex as well as impotence or delayed orgasm in some cases.

Antidepressants in the Prozac family, such as Celexa (citalopram), Zoloft (sertraline), and Paxil (paroxetine), are particularly common causes of sexual dysfunction.

Common medical conditions, such as diabetes, that are risk factors for stroke can themselves affect sexual functioning. In some cases, such as Frank's, these other conditions affect sexual function before a stroke to some extent, and then become more symptomatic in combination with the stroke itself. Viagra and related medications can be quite effective in the appropriate circumstances in helping restore sexual function in men, and perhaps in some women as well. Because of the risk of interaction with other medications and medical issues, these medications should be obtained and used only after discussion with a physician, and then taken only as prescribed.

For men affected by erectile dysfunction who are unable to use medications because of medical contraindications, or for whom these medications are ineffective, other options exist to facilitate resumption of sexual activity. These include injections of medications or the use of a suction device to produce an erection, or the use of surgical penile implants in appropriate cases. Consultation with a urologist specializing in erectile dysfunction is advisable.

Sexual dysfunction in women after stroke is less well studied and understood than sexual dysfunction in men. There are also fewer established treatments for women experiencing sexual dysfunction after a stroke. Women should consult a urologist or gynecologist specializing in sexual dysfunction if review of medications and other initial efforts are unsuccessful.

Psychological factors play a key role in many cases of sexual dysfunction after illness. Many stroke survivors feel they are less sexually attractive than before the stroke. Healthy partners can help resolve the problem by confirming that they are still attracted to the stroke survivor and truly wish to resume their prior sexual relationship. Fears of precipitating another stroke or other medical complications are common among both stroke survivors and their partners, but are generally unfounded. There is no evidence that sexual activity is likely to precipitate a stroke. Nonetheless, before leaving the hospital patients should confirm with their physician that it is safe to resume sex (with appropriate contraception when needed).

Fatigue is common after stroke, and some individuals may also experience changes in their libido. Rather than waiting to have sex until going to bed at night, some couples find that having sex earlier in the day is more practical, especially when excessive fatigue is an issue. Anxiety may interfere with sex initially, but it typically resolves as a couple becomes reacquainted with each other.

Spouses whose partners require significant help with daily activities sometimes find it hard to switch out of the caregiver role. Helping their significant other get dressed, use the bathroom, and so on may make it difficult for the caregiving spouse (or affected partner) to resume a more romantic role. As with many of the issues surrounding sexual activity after a stroke, understanding and patience are important steps in surmounting this problem. Caregiver support groups provide a helpful forum for discussing with others in the same situation the emotional consequences of providing care for a stroke survivor.

Aphasia can affect the social context for sex, including making it difficult for the stroke survivor to let his partner know when he is interested in sex. While these communication difficulties can be overcome (sex is, after all, a nonverbal form of communication to some extent), the inability to have the verbal interchange that leads up to sex can be awkward at first. Working through this together can help partners establish new and effective ways of communicating about a very important issue.

Cognitive or behavioral changes in the stroke survivor may impact a healthy spouse's interest in sex. Sexual attraction to a partner is based on both physical and emotional interactions. Some unaffected partners may no longer feel sexually attracted to a stroke survivor whose behavior has changed, or whose ability to interact verbally has been diminished. In other cases, the healthy partner may feel that it is wrong to have sex with a partner who is cognitively impaired. The healthy partner must recognize these feelings in order to deal with them constructively. Remembering that sex is mutually enjoyable and a source of pleasure for the stroke survivor may help the healthy partner overcome initial reservations about resumption of sexual activity.

Physical intimacy in a relationship consists of much more than sex. Many couples find that they can reestablish a physical bond by hugging, cuddling, caressing, and kissing. Stroke survivors and their partners should not let the stroke and its residual effects interfere with these important and mutually beneficial physical affections.