

“If I can’t have sex the way I used to, forget it!” Sexual therapists remind us that our society tends to view sex as a goal-oriented activity directed towards achievement of orgasm. While this is, of course, a worthwhile goal, it may be helpful to refocus on a broader range of sexual activities that bring physical and psychological pleasure and wellbeing. A willingness to try new approaches to romance and sexual stimulation will open new doors to positive expression of affection and sexuality and this will have benefits for the relationship beyond the bedroom.

It is absolutely appropriate to discuss sexual function after spinal cord injury with your neurologist. However, in truth, very few neurologists have any sort of formal training during their residencies in sexual function or spinal cord injury. Therefore, forgive your neurologist if he or she is inexperienced and unable to tell you much and try to work with him/her to address these various issues. You may also find assistance from seeking out neurologists, nurses, urologists, sex therapists or physiatrists who care for patients who have experienced spinal cord trauma or multiple sclerosis, especially at a large hospital, rehabilitation center or university center. The National Multiple Sclerosis Society (1-800-FIGHT MS) also has some literature on sexual dysfunction and MS which is applicable to TM.

References:

Derry F, Gardner BP, Glass C et al. Sildenafil (Viagra): a double blind, placebo controlled single dose two way cross-over study in men with erectile dysfunction caused by traumatic spinal cord injury (abstract). J Urol 1997; 154:181.

Ducharme SH and Gill KM. Sexuality after Spinal Cord Injury:

Answers to Your Questions. Paul W. Brookes Publishing Co. Baltimore. 1997.

Foley FW and Werner MA. Sexuality in Kalb RC. Multiple Sclerosis - The Questions You Have, The Answers You Need. Demos Vermande, New York, 1996: pp. 223-247. (This is an excellent chapter on sexuality in MS. It is set up as common questions followed by detailed answers. **Highly recommended**).

Geiger RC. Neurophysiology of Sexual Response in Spinal Cord Injury. Sexuality and Disability. Vol 2 (4). Winter 1979.

Kalb RC and LaRocca NG. Sexuality and Family Planning in Halper J, Holland N. Comprehensive Nursing Care in Multiple Sclerosis. Demos Vermande. New York, 1997: pp. 109-125.

Kaplan HS. The Illustrated Manual of Sex Therapy (2nd edition). New York: Brunner Mazel Publishers, 1987.

Neistadt ME, Freda M. Choices: A Guide to Sex Counseling with Physically Disabled Adults. Malabar, FL: Robert E. Krieger Publishing, 1987.

The Foley and Werner chapter in the Kalb book also lists several catalogue sources for sexually oriented materials not specifically targeted towards people with TM, but potentially helpful:

Eve’s Garden International, Ltd. 1-800-848-3837.

Good Vibrations, Inc. 1-800-289-8423.

Lawrence Research 1-800-242-

2823.

Thinking About Return to Work after Severe Injury and Illness

Denise Rabold, Ph.D. and James A. Arnett, Ph.D.

Drs. Rabold and Arnett have been writing a series of articles for the TMA Newsletter on the process of adaptation to the effects of severe injury and illness. Dr. Arnett is a faculty member in the Division of Rehabilitation Psychology, Department of Physical Medicine and Rehabilitation at The Ohio State University. Dr. Rabold has a private practice. Rehabilitation Psychology is a specialty of psychology that serves individuals with disabilities as they adjust, adapt, and progress toward healthy and satisfying lifestyles. Psychologists working in rehabilitation use education, remediation, counseling, and advocacy to minimize effects of impairments due to disabling medical conditions and promote wellness through optimal psychological and social functioning. Dr. Arnett has a broad base of experience with a range of disabling conditions, and specializes in evaluation of mental performance and adjustment issues associated with impaired brain function. Dr. Rabold is licensed as both a psychologist and speech-language pathologist. She specializes in counseling and cognitive remediation for work, school, and community re-entry after acquired brain injury.

As noted in our second article about adjustment and adaptation following severe disabling injury and illness

(Dealing With Change. TMA Newsletter, Volume 2, Issue 2), the adaptation process involves moving beyond a focus on losses. This is a difficult process, and unique to the individual. It is often very difficult to move the focus of attention to the future when so much appears to have been taken away. Adapting to crisis involves restoring emotional balance, dealing with effects of illness, establishing and maintaining relationships, and planning for the future. Restoring and maintaining emotional health must involve dealing with these adaptive tasks. Moving forward toward a more functional, independent, and productive lifestyle means moving away from the illness and its effects. Time is an important healing agent; although the time required to effectively manage these adaptive tasks varies greatly among individuals.

Work, whether for pay or not, is a major part of life. Regular involvement in some productive activity brings structure and meaning to life, along with a feeling of control. To work means to be on a schedule, which in turn leads to planning ahead for activities outside of work. Work also brings human interaction, which is stimulating and essential to basic human needs. For those persons who were employed before illness onset, the return to work helps greatly to restore a sense of normalcy, competence, and self-worth.

The effects of illness vary greatly. Consideration of the return to work process must allow for great variations in severity of physical impairment, and the physical demands of certain jobs. We will attempt to address two rehabilitation processes: First, return to the same job held before the disabling illness; and second, considerations of work

when it appears return to the old job will not be possible because of the effects of illness. We must also make the assumption that the effects of the illness are stabilized and relatively permanent.

Returning to the Old Job

In many cases, a person with new physical impairments can return to a formerly held job, with reasonable accommodations. Work involving primary activities of thinking, reasoning, problem solving, and communicating fall into this category. The first step in the return-to-work process is to determine whether or not it is possible to perform the former job with present functional status.

Returning to a former job and work environment can be frightening and possibly overwhelming. The process can be simplified by mobilizing a support system to assist with education, problem solving, advocacy, and implementation of needed accommodations.

A first step in the return-to-work process may be a referral to the Bureau of Vocational Rehabilitation (BVR). BVR is a government-funded agency whose goal is to assist individuals with disabilities in returning to gainful employment. Services provided include evaluation, training, work adjustment, and identification of modifications and accommodations that may be needed to facilitate the individual's success.

As a second step, the assistance of a Rehabilitation Psychologist should be considered. This professional is trained to provide needed education, remediation, adjustment counseling, and

advocacy to assist the individual in realizing their potential. It is often important to work with a professional who can view the case holistically, giving consideration to impairments, potential, work demands, and employer demands. The Rehabilitation Psychologist will consider individual perceptions of job demands and concerns from the perspectives of both the employee and the employer. Contact with the employer is often made to obtain a job description, and possibly to visit and evaluate conditions at the job site.

Changes in job duties are increasingly a factor in return to work. In our experience, a person who is off work for three months or more is very likely to find significant changes have been made to the job they left. Change compounds the difficulty of returning to work. The individual not only must manage some level of disability, but must also deal with a job that has changed to some degree.

Following a severe and protracted illness, a gradual return to work is always recommended. Returning to the old job after an extended absence can be an emotional and physical "shock." In spite of efforts at physical conditioning, most individuals returning to work after a long absence find the effort very exhausting, both physically and mentally. Useful guidelines involve a return-to-work schedule, which includes part-time employment for a period of two or more weeks. Plans vary greatly; and as an example, the initial workweek may involve two to four hours per day, or four hours every other day. Of equal importance to hours per day, is the definition and assignment of responsibilities. Most jobs, no matter how well they are described on paper, involve many, often small,

undefined or poorly defined duties. These “as needed” duties can be time consuming and can easily interfere with early return success. A clear description of work assignments is helpful during the return-to-work phase. Our practice is to always attempt to place the returning individual in a situation where they can experience success and a feeling of control from the very start of the return process. It is not productive and often harmful to have the returning individual experience a failure in trying to meet work demands in a job they once did well. A feeling of success and a feeling of “I can do more” is always preferred to the experience of anxiety about failure and questions of performance.

Considering New and Different Work

In many cases the effects of illness make it impossible to return to the formerly held job. Often jobs involving a high demand for physical labor will no longer be possible. The individual must now consider other options including exploration of opportunities and investigation of their interests and abilities. The individual with new physical limitations may need to think about new and different occupations, many of which were never considered before illness.

We have found that the career typology theory of John Holland is a useful way of describing and thinking about work and work interests (Osipow, 1983). Holland’s theory has been widely researched and offers an excellent way of evaluating career interests. A career interest inventory, The Self-Directed Search, which is based on Holland’s theory and used by Psychologists and Vocational Counselors, is a very commonly used device for helping explore work interests.

Briefly, Holland’s theory divides all jobs into six types (Holland refers to Occupational Environments): Realistic, Investigative, Artistic, Social, Conventional, and Enterprising. As the theory goes, these six environment descriptors can be used to describe any job. Going a step further, by examining the interests an individual has in different jobs, it is possible to describe that individual’s interests in terms of a “Holland Code” made of the three strongest Occupational Environments.

The Holland occupational environments offer a useful and interesting way of thinking about work and work interests. As job descriptors, the occupational environments work this way: Realistic jobs are characterized by active behavior, interest in activities requiring motor coordination, skill, and physical strength. Truck Driver is a good example of a “realistic” occupation. Investigative jobs are characterized by thinking, organizing and understanding. These jobs are well represented by chemists, biologists, and laboratory technicians. Artistic jobs involve self-expression and relating to others through artistic expression. Social jobs involve working with others in a teaching or helping way, as do Teachers, Social Workers, and Therapists. Enterprising jobs require verbal skills and influencing others, as with sales and politics. Conventional jobs involve following procedures, rules, and regulations. Bookkeeper and Bank Teller are examples of conventional job types.

As noted, the Holland theory is a useful way of describing jobs, and

a useful way of exploring interests. Most people’s interests are best described by three of the Holland work environments; although, there may be one type that is strongest. As an example, a person with a “Holland Code” of S-E-C (Social, Enterprising, Conventional) may find interests in a large number of jobs that are assigned to one or more of these three environments. Working with a Vocational Counselor or Rehabilitation Psychologist can be helpful in considering work interests and options. Again we encourage the use of agencies such as the Bureau of Vocational Rehabilitation.

We have found many inspirational comments in the “In Their Own Words” section of the TMA Newsletter. Two of these appear very relevant to this article: “[Adapting meant] Coming to terms with the fact that it is unlikely that I’m going to achieve the goals and aspirations that I had set for myself in the future, especially in terms of things like work.” Success may involve setting new goals, and considering new opportunities. It is vital not to close doors. Develop a support team by getting connected with friends and others who can help. We must also recommend “supportive group” activities involving others with similar experiences. As another TMA member writes, “I cannot state strongly enough the need for a positive attitude.”

Reference:

Osipow, S.H. Theories of Career Development. (3rd Ed.) (1983). P Englewood Cliffs, N.J: Prentice-Hall.

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