

# Sexuality and Reproductive Health in Adults with Spinal Cord Injury:

**A Clinical Practice Guideline  
for Health-Care Professionals**



Administrative and financial support provided by Paralyzed Veterans of America

# **Consortium for Spinal Cord Medicine Member Organizations**

Academy of Spinal Cord Injury Professionals  
American Academy of Orthopaedic Surgeons  
American Academy of Physical Medicine and Rehabilitation  
American Association of Neurological Surgeons  
American College of Emergency Physicians  
American Congress of Rehabilitation Medicine  
American Occupational Therapy Association  
American Physical Therapy Association  
American Psychological Association  
American Spinal Injury Association  
Association of Academic Physiatrists  
Association of Rehabilitation Nurses  
Christopher and Dana Reeve Foundation  
Congress of Neurological Surgeons  
Insurance Rehabilitation Study Group  
International Spinal Cord Society  
Paralyzed Veterans of America  
Society of Critical Care Medicine  
U. S. Department of Veterans Affairs  
United Spinal Association

# **Sexuality and Reproductive Health in Adults with Spinal Cord Injury:**

## **A Clinical Practice Guideline for Health-Care Providers**

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Consortium for Spinal Cord Medicine

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*This guideline has been prepared based on scientific and professional information available in 2007. Users of this guideline should periodically review this material to ensure that the advice herein is consistent with current reasonable clinical practice. The websites noted in this document were current at the time of publication; however, because web addresses and the information contained therein change frequently, the reader is encouraged to stay apprised of the most current information.*

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# Foreword

Thirty years ago the idea of addressing sexual and fertility issues during rehabilitation was controversial and seldom done. Even today many professionals are uncomfortable providing information about sexuality within the context of rehabilitation after spinal cord injury. Yet people with spinal cord injury (SCI) have always had questions about their sexuality, and these questions cannot be ignored. Early after injury, people with SCI often ask questions about their attractiveness, relationships, and ability to conceive and possibly have children. As a result, many clinicians understand the importance of discussing these issues. However, there has been little agreement as to when, how, and who should be answering questions related to sexuality and reproduction. Thirty years ago there were few answers and even fewer people who felt comfortable discussing the subject. Research on sexuality and fertility after SCI was simply not available.

Since that time, a great deal of work has been accomplished. Thanks to ongoing medical advances and a focus on quality of life, people with spinal cord injury are enjoying satisfying and rewarding sexual lives. Independent living programs and consumer-focused organizations have helped people with SCI gain independence and integrate back into their communities. Today, we realize that life does not end after a spinal cord injury nor does the ability to have fulfilling intimate relationships and a satisfying sexual life.

In the first months following a spinal cord injury, it is natural for individuals to be focused on physical recovery and rehabilitation. However, coming to terms with sexuality after spinal cord injury is an important step toward making a healthy adjustment. Sexual expression is a fundamental part of being human and an important component of our identity as men and women. After spinal cord injury, people have a choice to be sexually active or not. As clinicians, it is our role to ensure that they have accurate information about sexuality and the emotional support to make that decision.

Under the guidance of the Consortium for Spinal Cord Medicine, our panel of experts had the opportunity to review the literature and gather the latest information regarding sexuality and reproductive health following spinal cord injury. Our group was composed of experts from many disciplines and our focus throughout this process was to provide multidisciplinary recommendations that address basic needs and uncertainties related to sexuality after SCI. We have tried to maintain a balance between the physical and the psychological in developing our recommendations.

Sexuality is most often expressed in the context of relationships. However, we realize that sexuality is a complex integration of biological, cultural, spiritual, social, relational, and psychological factors. Sexual expression is not only what occurs in the privacy of one's home but goes to the core of how we relate to other people and how we feel about ourselves.

Throughout this guideline we have written our recommendations to ensure that privacy and respect are maintained for the individual with a spinal cord injury. We believe this to be paramount above all else. In addition, we recognize the importance of maintaining professional boundaries, especially when sensitive topics, such as sexuality and fertility, are being addressed.

From the onset the panel realized that empirical research on sexuality and reproductive health was not as robust as it is in other fields of medicine and psychology. This is a relatively new area of inquiry for spinal cord medicine, and for some people the topic of sexuality is still associated with a certain level of discomfort. In spite of the paucity of research, we believe that sexuality should be addressed in an organized, nonjudgmental manner while the individual is undergoing rehabilitation and during life-long follow-up. As has been the practice

with previous consortium guidelines, we relied on the strength of panel opinion to support our recommendations when published research was lacking.

The Consortium for Spinal Cord Medicine and our panel of experts hope that this clinical practice guideline will provide the information that needs to be communicated to individuals with SCI and their partners. Most important, it has been our intention throughout this process to emphasize the importance of maintaining a positive attitude and providing encouragement to learn about this fundamental aspect of human existence.

Finally, the panel believes that it is important for people with SCI and their partners to be given the opportunity to have an open dialogue regarding sexuality with their health-care providers. For many people, issues regarding sexuality become increasingly important in the months and years following injury. At those times it is unfortunate that the number of informed, open-minded professionals who are comfortable discussing sexuality may be significantly lacking. We hope that this guideline will help to ensure that an increasing number of knowledgeable professionals are available to support people in reclaiming their sexuality after injury.

Stanley H. Ducharme, PhD  
*Chair, Consortium CPG Development Panel*

# Preface

**A**s chair of the Steering Committee of the Consortium for Spinal Cord Medicine (consortium), I am pleased to introduce our 11th clinical practice guideline, *Sexuality and Reproductive Health in Adults with Spinal Cord Injury: A Clinical Practice Guideline for Health-Care Providers*. This guideline was developed by a multidisciplinary panel comprised of experts representing the various professional disciplines that care for people with spinal cord injuries.

Sexuality is complex; it encompasses physical, psychological, and social issues. It is a critical aspect of human life, one that is unique to each individual and continues to evolve throughout one's life. The goal for individuals with spinal cord injuries, as for all people, is to have a fulfilling and productive life. It is hoped that this guideline will assist in making sexuality part of achieving that goal.

This guideline addresses a wide range of topics related to sexuality. It includes recommendations that address physical, interpersonal, emotional, and medical concerns. The guideline addresses the importance of privacy and individuality as well as the practical needs of individuals with spinal cord injuries.

Development of clinical practice guidelines results in a useful document for clinicians; invariably it also reveals the need for more research to support clinical practice. The recommendations in this guideline express best clinical practice based on research and expert opinion. Our intention is that this guideline will be used by clinicians to improve the lives of individuals with spinal cord injuries.

The consortium steering committee thanks Dr. Stanley H. Ducharme for his diligent leadership of the distinguished guideline development panel. Each panelist contributed her or his unique expertise to the development process. Special appreciation goes to the representatives of the consortium's 20 member organizations and the field reviewers who reviewed the guideline.

The development of consortium clinical practice guidelines is dependent upon the outstanding resources provided by Paralyzed Veterans of America (PVA). The Consortium for Spinal Cord Medicine is profoundly grateful to PVA's Executive Committee, led by its national president, Randy L. Pleva, Sr. (2004–2009). Our sincere thanks is extended to PVA's Research and Education department, including Thomas E. Stripling, director of Research and Education; Caryn Cohen, MS, associate director, Clinical Practice Guidelines; and Kim S. Nalle, manager of Clinical Practice Guidelines.

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# Acknowledgments

As Paralyzed Veterans of America continues its vital role sponsoring the development of clinical practice guidelines, much is owed to the hard work and extensive experience of PVA's clinical practice guideline team, comprised of Kim S. Nalle, manager, and Caryn Cohen, associate director. Without their hard work and tireless ability to guide this complicated process, this CPG could not have been completed.

We extend our appreciation to the editors of BioScience Writers, LLC for their excellent technical review and editing of this clinical practice guideline. We thank PVA's Communications Department for editing and design of this publication.

Appreciation is expressed to the PVA Board of Directors and PVA's senior officers, including National President Gene A. Crayton; Immediate Past President Randy L. Pleva, Sr.; Executive Director Homer S. Townsend, Jr.; Deputy Executive Director Maurice L. Jordan; and Director of Research and Education Thomas E. Stripling.

A special thank you goes to Rachel Hoeft, PVA's associate director for Education, for her excellent editing and proofreading skills.

We have been supported in this work by many unnamed colleagues who have reviewed sections of the guideline and made helpful suggestions. Thank you.

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# Summary of Recommendations

## Importance of Sexuality and Reproduction to the Individual

1. Maintain an open discussion and provide access to education about sex in both formal and informal settings throughout the treatment continuum.
2. Consider using a treatment framework, such as the Permission, Limited Information, Specific Suggestions, and Intensive Therapy (PLISSIT) model, for education.
3. Encourage individuals to take an active role in obtaining information related to sexual issues.
4. Provide assurance to the individual as soon as feasible (preferably during early acute care) that basic information about sexuality will be provided and that more extensive information will be available throughout care.
5. Introduce the topic of sexuality by discussing the subject in a straightforward and nonjudgmental manner. Ask open-ended questions that encourage an ongoing dialogue whenever possible.
6. Maintain a nonjudgmental attitude regarding sexual orientation and gender identity in order to elicit honest and productive discussion, while providing maximum privacy and maintaining confidentiality.
7. Determine the individual's interest and readiness to learn about sexual function and expression following his or her SCI. Be aware that some people with SCI may not feel comfortable in raising the topic directly.
8. Encourage people with SCI to explore the role of sexuality in their lives and the various ways in which they may express their sexuality.
9. Ensure that, for all individuals in rehabilitation or institutional settings, sexual expression is treated with privacy, respect, and dignity.

## Sexual History and Assessment

10. Include general questions about sexuality and sexual function as early as possible in the rehabilitation

process. Ask direct, open-ended questions to facilitate a discussion of sexual matters.

11. Ask individuals with SCI if they have experienced any previous sexual trauma, sexual dysfunction, or sexually transmitted disease that could affect their sexual function following injury.
12. Consider the individual's life context (cultural, environmental, spiritual, and social) during sexual education and counseling.
13. Ensure that a medical assessment of the sexual reproductive system is conducted after SCI. The assessment should include a thorough examination of breasts and genitalia, as well as screenings for cervical, ovarian, uterine, breast, prostatic, and testicular cancers. Screening for sexually transmitted diseases, including HIV/AIDS, should be provided as deemed appropriate through consultation with the individual. Provide counseling about human papillomavirus (HPV) immunization as appropriate.
14. Perform a physical examination using the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI), with special attention to the preservation of sensation from T11–L2 and S2–5 along with determination of the presence of voluntary anal contraction and reflexes to assess sexual function.
15. Assess the impact of the individual's injury on sexual responses, i.e., genital responses, based on a neurologic examination, such as the International Standards to Document Remaining Autonomic Function after Spinal Cord Injury.
16. Perform a detailed neuromusculoskeletal examination and functional assessment. Use the results of the examination to assist in counseling regarding sexual activity.
17. Develop a sexual education and treatment plan with the individual consistent with the results of the sexual history, interview, relationship status, and physical exam findings.
18. Perform full physical examinations and neurological assessments regularly, in order to detect changes over time that may affect sexual function. The assessments should include the International Standards to Document Remaining Autonomic Function after Spinal Cord Injury to determine the neurological level and extent of injury.

19. Educate persons with SCI about the effects of medication on sexual response and fertility. Medications include prescription, over-the-counter, or herbal remedies and/or supplements.
20. Educate the individual about the effects of alcohol, tobacco, and other drugs, as well as unhealthy eating habits and obesity, on sexual response and fertility.
21. Evaluate the individual with SCI for a diagnosis of depression or other psychological disorders if he or she exhibits such symptoms as loss of libido, poor concentration, fatigue, and/or changes in sleep or appetite.
22. Evaluate for a diagnosis of testosterone deficiency in men with SCI presenting with suppressed libido, reduced strength, fatigue, or poor response to phosphodiesterase type 5 inhibitors (PDE5is) for erection enhancement.

## Education

23. Maintain professional boundaries under all circumstances when addressing sexual issues with individuals with SCI and their partners.
24. Consider age at onset of injury and previous sexual experience when assessing the sexual knowledge of the adult individual with SCI. Provide sexual education and counseling accordingly.
25. If explicit educational media (videos, pictures, books, magazines, etc.) are going to be used for education, evaluate the individual's readiness to view such material and use material only when health-care providers with counseling skills are available to help the individual process the information and gauge his or her reaction to the media. Use these materials only in accordance with state and/or institutional laws.

## Maintaining Sexual Well-Being

26. Provide information on methods to enhance sensuality by using all available senses.
27. Provide information on sexual assistive devices (sex toys) that are sometimes used to enhance sexual experiences. Provide appropriate cautions about contraindications as well as information regarding skin protection, prolonged penile constriction, and dysreflexia. Inform individuals

that sexual enhancement devices may be modified to accommodate limited mobility.

28. Encourage individuals to consider expanding their sexual repertoire to enhance their sexual pleasure following injury. Discuss the broad range of options for sexual expression and pleasure for individuals with SCI.

## Physical and Practical Considerations

### Bladder and Bowel

29. Encourage individuals to consider bladder care prior to sexual activity and to explore contingency plans, as necessary, if incontinence should occur.
30. Encourage individuals to consider bowel care prior to sexual activity and to explore contingency plans, as necessary, if incontinence should occur.

### Skin Care

31. Inform individuals that existing pressure ulcers do not necessarily preclude engagement in sexual activity and discuss ways to avoid injuring skin or exacerbating existing pressure ulcers.
32. Instruct individuals to inspect insensate skin surfaces, particularly around the genitalia and buttocks, immediately after sexual activity as these areas may have received excessive friction, pressure, or tears.

### Secondary Medical Complications

33. Educate individuals with SCI about optimal positioning during sexual activity in order to protect limbs from damage.
34. Inform individuals with SCI that it is common for their level of spasticity to change as a result of sexual activity.
35. Educate individuals about the relationship between sexual activity and the possible onset of autonomic dysreflexia (AD), with or without symptoms, especially in people with injuries at or above T6. Instruct individuals with SCI to modify sexual activity if they experience AD.
36. Ensure that individuals with SCI understand that they remain at risk for acquiring or transmitting sexually transmitted infections (STIs), also

commonly known as STDs (or sexually transmitted diseases).

## Optimal Positioning for Sexual Activity

37. Educate individuals about obtaining assistance from caregivers in their preparation for sexual activity.
38. Ascertain the necessary spine precautions specific to the individual and translate that information into safe levels of sexual activity. After spinal cord injury, intimacy and affection are encouraged; however, individuals need to be cognizant of the potential risk of further injury.
39. Suggest environmental modifications that enhance the quality of the sexual experience.
40. Teach the person with SCI optimal positioning and bed mobility in accordance with his or her injury.
41. Educate individuals with SCI and their partners about safety measures to consider when engaging in sexual activity while in a wheelchair. Encourage individuals to learn about the safety limits of their particular chair.
42. Discuss safety issues related to the use of shower and shower equipment for sexual activity (e.g., burns induced by hot water, risks of slipping or falling, and weight limits that may apply to shower chairs). Inform the individual that high-weight-capacity shower chairs are available.
43. Discuss the use of adaptive equipment required by aging individuals with SCI and people with aging partners.

## Effect of Injury on Sexual Function, Responsiveness, and Expression

44. Discuss the fluctuations that may occur with sexual desire and interest following SCI.
45. Discuss the potential for discovering and developing new areas of the body that may stimulate sexual arousal (erogenous zones) and lead to sexual pleasure and possible orgasm.
46. Explain that reflex erections may occur with either sexual stimulation or nonsexual stimuli.
47. Explain to the individual the potential impact of injury on arousal and orgasm.

48. Discuss the potential ability for men to achieve ejaculation and genitally induced orgasm following SCI.
49. Support individuals with SCI if they wish to experiment with giving and receiving erotic pleasure through touch.
50. When appropriate, educate individuals with SCI that masturbation can be an enjoyable form of sexual expression.

## Treatment of Dysfunction

51. Provide resources for sex education, counseling, and sex therapy when indicated.
52. Caution men and women with SCI about the potential risks related to services or products available without a prescription.
53. Treat erectile dysfunction (ED) in men with SCI with the least invasive methods before prescribing interventions that may produce an adverse reaction. Encourage men with SCI to enhance their existing sexual function before using medical interventions.
54. Consider testosterone replacement therapy for men with SCI if a testosterone deficiency is determined to be a contributing factor in the man's sexual dysfunction or lack of libido.
55. Inform men with SCI about the full range of options for treating erectile dysfunction and develop an individualized treatment plan as needed.
56. Educate men with SCI about oral medications to treat erectile dysfunction.
57. Educate men with SCI about intracavernosal injections for the treatment of erectile dysfunction.
58. Educate men with SCI about vacuum devices for the treatment of erectile dysfunction.
59. Educate men with SCI about using intraurethral medications to treat erectile dysfunction.
60. Provide information about penile implants for the treatment of erectile dysfunction (also known as implantable penile prostheses) when nonsurgical treatments are ineffective or unsatisfactory.
61. Discuss the potential risk of penile trauma for men with SCI.
62. Inform women with SCI about external devices that are available to enhance genital arousal and orgasmic potential.

# Effects on Fertility

## Female Fertility

63. Ensure that women with SCI have proper information regarding the effect of injury on menstruation.
64. Ensure that women with SCI are informed about reproductive health and obstetric and gynecological services specific to their needs.
65. Determine the safest birth control method for the woman with SCI. Risks associated with the various birth control methods should be assessed and discussed with the woman.
66. Provide women with SCI information about fertility and pregnancy.
67. Outline the steps that can be taken to ensure the best medical outcomes for the pregnant woman with SCI. Recommend that a medical provider with SCI expertise be involved throughout the pregnancy.
68. Ensure that wheelchair seating will allow for an upright seated posture with proper alignment throughout pregnancy; this will require repeated adjustments to the wheelchair.
69. Ensure the implementation of safe transfer techniques during pregnancy.
70. Regularly assess the status of activities of daily living to ensure that safe and efficient movements and positioning are being used during pregnancy. Determine if assistive devices need to be modified or changed.
71. Plan for labor and delivery to accommodate the particular needs of the woman with SCI, and carefully monitor the potential onset of autonomic dysreflexia during labor and delivery.
72. Educate women with SCI about the effects of perimenopause and menopause after SCI.

## Male Fertility

73. Discuss the prognosis for biological fatherhood and options for assisted fertility.
74. Perform semen analysis for men interested in biological fatherhood in order to provide information and make recommendations for achieving pregnancy.

## For Men and Women

75. Provide education about adoption as an option for some individuals with SCI.

## Relationship Issues

76. Encourage individuals with SCI to discuss any concerns that they may have regarding relationships postinjury.
77. Provide opportunities for people with SCI to include their partners in discussions regarding intimacy, sexuality, and fertility.
78. Provide opportunities for partners to ask questions and get information about sexuality and fertility whenever possible. In so doing, providers must protect the confidentiality of both parties.
79. Assist with education and problem solving for people with SCI who may be interested in a sexual relationship with another person who also has a disability.
80. Discuss the maintenance of healthy interpersonal relationships that existed prior to injury. Assist individuals with developing social skills that will promote healthy interpersonal and sexual relationships.
81. Offer guidance on using the Internet to meet potential partners for intimate relationships and marriage.
82. Encourage individuals with SCI to develop and/or maintain positive relationships with their children.
83. Support the individual with his or her reintegration into the family.
84. Ensure that individuals with SCI receive counseling that promotes a positive body image and encourages a respect for one's body after SCI.
85. Discuss options for providing assistance for activities of daily living from someone other than the romantic partner.

# The Consortium for Spinal Cord Medicine

The Consortium for Spinal Cord Medicine was established in 1995 to develop clinical practice guidelines (CPGs) to facilitate optimal medical care for individuals with spinal cord injuries. The consortium is a group of 22 professional, payer, and consumer organizations. Its funding and administrative support is provided by Paralyzed Veterans of America. Its mission is to direct the development and dissemination of clinical practice guidelines and companion consumer guides; this mission is solely aimed at improving the health care and quality of life for individuals with spinal cord injury (SCI).

After studying the processes used to develop other guidelines, the consortium steering committee unanimously agreed on a new, modified, clinical/epidemiologic, evidence-based model derived from the Agency for Healthcare Research and Quality. The model is:

A steering committee was established to

- advance the guideline development process;
- identify and prioritize CPG topics;
- assist in the expert panel selection process;
- provide an initial explication of the topic to serve as the basis of the CPG outline;
- monitor the guideline development process; and
- collaborate with the panel and coordinating office to develop a comprehensive dissemination and utilization plan.

The steering committee is comprised of one representative from each consortium member organization. PVA staff members (the “coordinating office”) provide administrative support to the consortium. The process used to develop the guidelines is based on the model derived from the Agency for Health Research and Quality (AHRQ). The model is

- interdisciplinary, to reflect the multidisciplinary needs of the spinal cord medicine practice community.
- responsive, with a well-managed timeline for completion of each guideline.
- reality-based, making use of the scientific literature where it exists and using practical

and clinical expertise where there are gaps in the scientific literature.

The Consortium for Spinal Cord Medicine is unique to the clinical practice guideline field in that it employs highly effective management strategies based on the availability of resources in the health-care community; it is coordinated by a recognized national consumer organization with a reputation for providing effective service and advocacy for people with spinal cord injury and disease; and it includes third-party and insurance payer organizations at every level of the development and dissemination processes. The consortium expects to initiate work on two or more topics per year, with evaluation and revision of previously completed guidelines as new research demands.

## Guideline Development Process

In conjunction with the coordinating office, the steering committee identifies a topic that is currently relevant to individuals with SCI or is known to be an up-and-coming topic. Once a topic is chosen, steering committee members suggest panel members to develop a guideline on the selected topic. Panel members must be recognized experts in the selected topic field (i.e., they must have conducted independent research related to the topic, be published in renowned scientific journals, and have firsthand experience providing health care to people with SCI). The steering committee chairperson then selects a panel chairperson from the list of suggested panel members. The panel chair along with the coordinating office selects a group of potential panel members (primarily from the suggestions provided by the steering committee)—each with a specific expertise related to the topic. This prospective panel is presented to the steering committee chair for approval; if approved, invitations are sent to potential panel members. Once a CPG development panel is chosen, the panel chair, the coordinating office, and a methodologist from a recognized scientific consulting firm determine the parameters of the systematic literature search. Upon completion of the literature search, each panel member is provided with a list of accepted articles, their evidence level (I–V), and the full text of the article. It is expected

that each panel member will read the literature provided as a result of the systematic review. Panel meetings are scheduled with the following goals: 1) develop an outline for the CPG based on the explication provided by the steering committee, 2) assign each panel member writing assignments, and 3) determine deadlines for assignments. As the coordinating office receives completed assignments from panel members, a document is created. This document becomes the CPG working draft. When all elements of the CPG outline are completed and a draft manuscript of the guideline is prepared, field review is conducted. Field reviewers are then chosen by the steering committee to provide feedback on the draft CPG. Field reviewers must 1) be well versed in the topic area, 2) be peers of the panelists, and 3) represent the consortium member organizations in some way. Panel members may also suggest reviewers. When field reviewer comments are received by the coordinating office they are transmitted to the panel chair.

Based on the references cited in the rationales for each recommendation, “scientific evidence” and “grade of recommendation” are assigned to each recommendation. A final meeting of the panel is convened to vote on the “strength of panel opinion” for each recommendation. The guideline goes through a three-tiered editing process: 1) medical review by a recognized technical review firm, to ensure that all medical references are properly cited and that there are no medical errors; 2) legal review, to ensure that there are no copyright infringement or liability issues; and 3) stylistic editing, for grammar, spelling, and continuity. Once editing and design have been completed, the clinical practice guideline is posted on the Paralyzed Veterans of America website and published in the *Journal of Spinal Cord Medicine*.

The benefits of clinical practice guidelines for the spinal cord medicine practice community are numerous. Consortium CPGs provide

- clinical practice options,
- a resource for education and training,
- building blocks for assessment and treatment algorithms,
- a basis for evaluation studies of guideline use and outcomes,
- research gap identification,
- a source for cost and policy studies for improved ability to measure outcomes related to CPG usage,

- a primary source for consumer information and public education, and
- a knowledge base for improved professional consensus building.

## Methodology

### Retrieval and Grading of the Scientific Evidence

#### BACKGROUND

Spinal cord injuries are one of the most debilitating and devastating injuries, with an estimated annual incidence of approximately 12,000 cases per year in the United States; it is estimated that in this country alone between 227,080 and 300,938 individuals were living with SCI as of 2007 (National SCI Statistical Center, 2008). It has become increasingly clear to the health-care community that issues related to sexuality and fertility must be addressed for this population.

#### OBJECTIVE

This review is intended to provide panel members developing this guideline with the best evidence and to assist them with assessment of the strength of evidence for their recommendations. United BioSource Corporation (UBC) provided methodologic support for the development of this guideline by conducting a systematic review of the recent English-language literature related to sexuality and reproductive health as these subjects relate to spinal cord injured individuals.

#### METHODOLOGY

UBC performed a systematic review of the literature published between January 1, 1995, and September 1, 2007 (time of review) that describes issues related to sexuality and reproductive health in individuals with spinal cord injuries. Procedures for this review followed the best methods used in the evolving science of systematic review research. Systematic review is a scientific technique designed to minimize bias and random error by employing a comprehensive search process and a preplanned process for study selection.

#### LITERATURE SEARCH

The literature search involved identifying and retrieving all potentially relevant literature describing sexual and reproductive health in people with SCI. The literature search included both electronic and manual components. The electronic search was performed in MEDLINE (via PubMed), PreMEDLINE, Cinahl, SocioFile, PsychINFO, and the Cochrane Library.

MEDLINE was searched via PubMed back to 1995 using the following terms:

1. "Spinal Cord Injuries" OR Spinal Cord Injuries [MeSH] OR "Spinal Cord Trauma"
2. Paraplegia OR Paraplegia[MeSH] OR Quadriplegia OR Quadriplegia[MeSH] (including the terms: Quadriplegias, Tetraplegia, Tetraplegias, Spastic Quadriplegia, Quadriplegia, Spastic, Quadriplegias, Spastic, Spastic Quadriplegias, Spastic Tetraplegia, Spastic Tetraplegias, Tetraplegia, Spastic, Tetraplegias, Spastic, Paralysis, Spinal, Quadriplegic, Quadripareisis, Quadripareses, Flaccid Quadriplegia, Flaccid Quadriplegias, Quadriplegia, Flaccid, Quadriplegias, Flaccid, Flaccid Tetraplegia, Flaccid Tetraplegias, Tetraplegia, Tetraplegias, Flaccid, Locked-In Syndrome, Locked In Syndrome, Locked-In Syndromes, Syndrome, Locked-In, Syndromes, Locked-In)
3. "Reproductive Behavior" OR Reproductive Behavior [MeSH] OR Reproduction OR Reproduction [MeSH] OR Fertility OR Fertility [MeSH] OR Infertility OR Infertility [MeSH] OR Sexual Dysfunction, Physiological [MeSH] OR Sexual Dysfunction, Psychological [MeSH] OR "Sexual Behavior" OR Sexual Behavior [MeSH] OR "sexual dysfunction"
4. (#1 OR #2) AND #3

Limits: Human, publication dates 1995–present, NOT reviews, letters, comments, or editorials.

PreMEDLINE was searched via PubMed using the following terms:

1. "Spinal Cord Injuries" OR Spinal Cord Injuries OR "Spinal Cord Trauma"
2. Paraplegia OR Paraplegia OR Quadriplegia OR Quadriplegia
3. "Reproductive Behavior" OR Reproductive Behavior OR Reproduction OR Reproduction OR Fertility OR Fertility OR Infertility OR Infertility OR Sexual Dysfunction, Physiological OR Sexual Dysfunction, Psychological OR "Sexual Behavior" OR Sexual Behavior OR "sexual dysfunction"
4. (#1 OR #2) AND #3

Limits: Human, publication dates 1995–present

Cinahl was searched using the following terms:

1. *spinal cord injuries.mp. or exp Spinal Cord Injuries*
2. *paraplegia.mp. or exp PARAPLEGIA*
3. *quadriplegia.mp. or exp QUADRIPLEGIA*
4. *1 or 2 or 3*
5. *reproductive behavior.mp*
6. *exp REPRODUCTION*
7. *exp FERTILITY*
8. *exp INFERTILITY*
9. *sexual behavior.mp*
10. *exp Sexual Dysfunction, Male/or sexual dysfunction.mp*
11. *5 or 6 or 7 or 8 or 9 or 10*
12. *4 and 11*

Limits: Human, publication dates June 13, 2003–present

SocioFile was searched using the following terms:

1. "spinal cord injury" OR "spinal cord injuries" OR "spinal cord trauma" OR paraplegia OR paraplegic OR quadriplegia OR quadriplegic
2. "reproductive behavior" OR reproduction OR fertility OR infertility OR "sexual behavior" OR "sexual dysfunction"
3. #1 AND #2

Limits: Human, publication dates 1995–Present

PsychINFO was searched using the following terms:

1. *AnyField: [paraplegia or quadriplegia or "spinal cord injuries" or "spinal cord injury" or "spinal cord trauma"] AND AnyField-[ "sexual dysfunction" or "sexual behavior" or reproduction or infertility or fertility or "reproductive behavior"]*
2. *Publication Types: Journals*
3. *Dates: 1995–present*

4. Query: *\*hide details\* (AnyField: (paraplegia or quadriplegia or "spinal cord injuries" or "spinal cord injury" or "spinal cord trauma") AND AnyField: ("sexual dysfunction" or "sexual behavior" or reproduction or infertility or fertility or "reproductive behavior")) AND (PublicationType:0100)*

Also, the Cochrane Library was searched for any recent systematic review of the subject, which could be a source of further references. A manual check of the reference lists of all accepted studies and of recent reviews and meta-analyses was performed to supplement the aforementioned searches and ensure optimal and complete literature retrieval.

A MEDLINE search cutoff date of September 1, 2007, was used with a cut-off date for retrieval of articles from libraries no later than one week prior to completion of the study listing. A listing of any studies that remain outstanding at the time of retrieval cutoff is provided to the sponsor as a part of the study listing deliverable.

#### STUDY SELECTION

To be eligible for inclusion in this study listing for possible systematic review, studies yielded from the search above must satisfy none of the following exclusion and contain at least one eligible inclusion criteria:

**EXCLUSION CRITERIA** (used to eliminate abstracts in level I screening):

- Reviews or meta-analyses
- Animal or in vitro studies
- Pediatric studies (subjects younger than 18 years of age) or mixed populations where more than 15 percent are pediatric patients
- Studies offering no intervention for sexual and reproductive health of those with SCI
- No study not related to the sexual and reproductive health of people with SCI
- Studies published only in abstract form
- Studies published before 1995
- Languages other than English

**INCLUSION CRITERIA** (used to accept publications in level II screening):

- Any published and unpublished study, reported in English, involving any research design, enrolling male and/or female adult populations with SCI.

- Design: article reports a fertility intervention, including pre- and postintervention fertility rates. Article contains original report of a measure of fertility rates in males, females, or both, and reports original intervention trial after spinal cord injury. Regarding male sexuality, the article reports pre- and postmeasures for sexual dysfunction after SCI, contains original report of a measure of sexual dysfunction, and discusses an intervention for sexual dysfunction.
- Studies reporting interventions of physical, prescription medication, surgical, and laboratory interventions. Regarding male sexuality, studies reporting cognitive/behavioral, prescription medications, surgical, or hormonal interventions.
- Studies reporting outcomes of pregnancy, live birth rates, sperm motility, successful sperm harvesting, ejaculations, sperm count, percent viable sperm, hormonal, ovulation rates, cycle function, other measures of sperm morphology, volume of ejaculation. For male sexuality, outcomes also regarding psychological and physiological outcomes.

After level I and level II screening was completed, a study listing with bibliographies of all papers retrieved and screened (accepted and rejected studies at level II) was submitted to PVA for review and comment.

#### SEARCH YIELD

After an initial search was performed, all of the abstracts were downloaded and a level I screening was performed in which abstracts were reviewed for exclusion criteria. The full article was then obtained for all accepted abstracts and for those abstracts for which a clear determination could not be made at level I screening. The full articles of accepted studies underwent a level II screening in which inclusion and exclusion criteria were applied. On completion of level II screening, all accepted articles were then eligible for data extraction. Any studies rejected at this level were reviewed by two researchers and listed in a reject log. This process resulted in 145 papers being accepted for data extraction.

#### EVIDENCE REVIEW

During the panel deliberations and preparation of the recommendations, it became clear that the expert panel also drew extensively on a substantial literature base, providing support for their recommendations. Often a recommendation is based on older studies of SCI patients or on studies of more heterogeneous groups of acutely injured patients with or without SCI, studies that were felt to be

generalizable to the early SCI population. UBC independently graded these studies.

## EVIDENCE ANALYSIS

All studies accepted for data extraction were graded for level of evidence using the criteria from the Centre for Evidence-Based Medicine in Oxford, UK, [www.cebm.net](http://www.cebm.net); accessed January 16, 2008, described in the following section. In addition, randomized clinical trials were assessed using the Jadad Quality Score Assessment. Industry sponsorship was also noted.

### Levels of Evidence

The concept of levels of evidence grew out of the work of the Canadian Task Force for the Periodic Health Examination, in which recommendations for preventive health measures were tied to an assessment of the supporting evidence in the published literature. The assignment of levels of evidence in this review was based on the following guidance from the Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer, published by the Canadian Medical Association:

- I. Evidence based on randomized controlled clinical trials (or meta-analysis of such trials) of adequate size to ensure a low risk of incorporating false-positive or false-negative results.
- II. Evidence based on randomized controlled trials that are too small to provide level I evidence. These may show either positive trends that are not statistically significant or no trends and are associated with a high risk of false-negative results.
- III. Evidence based on nonrandomized, controlled, or cohort studies; case series; case-controlled studies; or cross-sectional studies.
- IV. Evidence based on the opinion of respected authorities or of expert committees as indicated in published consensus conferences or guidelines.
- V. Evidence that expresses the opinion of those individuals who have written and reviewed this guideline, based on experience, knowledge of the relevant literature, and discussions with peers.

These five levels of evidence do not directly describe the quality or credibility of evidence. Rather, they indicate the nature of the evidence being used. In general, a randomized, controlled trial (level I) has the greatest credibility; however, the trial may have defects that diminish its value,

and these should be noted. Evidence that is based on too few observations to give a statistically significant result is classified as level II. In general, level III studies carry less credibility than level I or II studies, but credibility is increased when consistent results are obtained from several level III studies carried out at different times and in different places.

Decisions must often be made in the absence of published evidence. In these situations, it is necessary to use the opinion of experts based on their knowledge and clinical experience. All such evidence is classified as “opinion” (levels IV and V). A distinction is made between the published opinion of authorities (level IV) and the professional opinion of those who have contributed to this guideline (level V). However, it should be noted that by the time level V evidence has gone through the exhaustive consensus-building process used in the preparation of this guideline, it has achieved a level of credibility that is at least equivalent to level IV evidence.

Some of the publications collected for this guideline did not fit entirely in any of the categories of the scoring system. However, for consistency the Centre for Evidence-Based Medicine system was used and the numeric scores were supplemented with additional descriptive categorization: prognostic, diagnostic, or therapeutic.

### Grading the Guideline Recommendations

After the guideline was drafted, each recommendation was graded according to the level of scientific evidence supporting it. The framework used is outlined in table 1. These ratings, like the level of evidence table ratings, represent the strength of the supporting evidence, not the strength of the recommendation itself. The strength of the recommendation is indicated by the language describing the rationale.

**TABLE 1**  
Categories of the Strength of Evidence Associated with the Recommendations

| Category | Description                                                                                |
|----------|--------------------------------------------------------------------------------------------|
| A        | The guideline recommendation is supported by one or more level I studies.                  |
| B        | The guideline recommendation is supported by one or more level II studies.                 |
| C        | The guideline recommendation is supported only by one or more level III, IV, or V studies. |

Sources: Sackett, D.L., Rules of evidence and clinical recommendation on the use of antithrombotic agents, *Chest* 95 (2 Suppl) (1989), 2S-4S; and the U.S. Preventive Health Services Task Force, *Guide to Clinical Preventive Services*, 2nd ed. (Baltimore: Williams and Wilkins, 1996).

Category A requires that the recommendation be supported by scientific evidence from at least one properly designed and implemented randomized, controlled trial, providing statistical results that consistently support the guideline statement. Category B requires that the recommendation be supported by scientific evidence from at least one small randomized trial with uncertain results; this category also may include small randomized trials with results where statistical power is low. Category C recommendations are supported by either nonrandomized, controlled trials or by trials for which no controls are used.

If the literature supporting a recommendation comes from two or more levels, the number and level of the studies are reported (e.g., in the case of a recommendation that is supported by two studies, one a level III, the other a level V, the "Scientific evidence" is indicated as "III/V").

### Grading of Panel Consensus

The level of agreement with the recommendation among panel members was assessed as either low, moderate, or strong. Each panel member was asked to indicate his or her level of agreement on a 5-point scale, with 1 corresponding to neutrality and 5 representing maximum agreement. Scores were aggregated across the panel members and an arithmetic mean was calculated. This mean score was then translated into low, moderate, or strong, as shown in table 2. Panel members could abstain from the voting process for a variety of reasons, such as lack of expertise associated with a particular recommendation.

**TABLE 2**  
Levels of Panel Agreement with Recommendations

| Level    | Mean Agreement Score   |
|----------|------------------------|
| Low      | 1.0 to less than 2.33  |
| Moderate | 2.33 to less than 3.67 |
| Strong   | 3.67 to 5.0            |

### REFERENCES FOR METHODOLOGY

Cook, D.J., C.D. Mulrow, and R.B. Haynes. Systematic reviews: Synthesis of best evidence for clinical decisions. *Ann Intern Med* 126 (1997): 376–80.

Harris, R.P., M. Helfand, S.H. Woolf, et al. Current methods of the U.S. Preventive Services Task Force. *Am J Prev Med* 20 (3 S) (2001): 21–35.

Jadad, A.R., R.A. Moore, D. Carroll, et al. Assessing the quality of reports of randomized clinical trials: Is blinding necessary? *Controll Clin Trials* 17 (1996): 1–12.

Sacks, H.S., J. Berrier, D. Reitman, et al. Meta-analyses of randomized controlled trials. *N Engl J Med* 316 (8) (1987): 450–55.

Steering Committee on Clinical Practice Guidelines for the Care and Treatment of Breast Cancer. *Can Med Assoc J* 158 (3 Suppl) (1998): S1–S2.

West, S., V. King, T.S. Carey, et al. Systems to rate the strength of scientific evidence. Evidence Report/Technology Assessment No. 47. Prepared by Research Triangle Institute–University of North Carolina Evidence-Based Practice Center under contract no. 290–970011. AHRQ Publication no. 02–E016. Rockville, MD: Agency for Healthcare Research and Quality, April 2002.

### INTERNET SOURCES FOR GUIDELINE DEVELOPMENT

- Canadian Task Force on Preventive Health Care. <http://www.ctfphc.org/> (accessed January 16, 2008).
- Centre for Evidence-Based Medicine, Oxford University. <http://www.cebm.net/> (accessed January 16, 2008).
- New Zealand Guidelines Group. <http://www.nzgg.org.nz/> (accessed January 16, 2008).
- Scottish Intercollegiate Guidelines Network. <http://www.sign.ac.uk/> (accessed January 16, 2008).

**TABLE 3**  
Levels of Evidence for Primary Research Question

|                  | Types of Studies                                                                                                                                                                                                                                                                                                                                               |                                                                                                                                                                                                                                                                                                                                                                                          |                                                                                                                                                                                                                                                       |                                                                                                                                                                                                                  |
|------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                  | Therapeutic Studies:<br>Investigating the Results<br>of Treatment                                                                                                                                                                                                                                                                                              | Prognostic Studies:<br>Investigating the Effect<br>of a Patient<br>Characteristic on the<br>Outcome of Disease                                                                                                                                                                                                                                                                           | Diagnostic Studies:<br>Investigating a<br>Diagnostic Test                                                                                                                                                                                             | Economic and Decision<br>Analyses: Developing an<br>Economic or Decision<br>Model                                                                                                                                |
| <b>Level I</b>   | <input type="checkbox"/> High-quality randomized controlled trial with statistically significant difference or no statistically significant difference but narrow confidence intervals<br><br><input type="checkbox"/> Systematic review <sup>2</sup> of level I randomized controlled trials (studies were homogeneous)                                       | <input type="checkbox"/> High-quality prospective study <sup>4</sup> (all patients were enrolled at the same point in their disease with $\geq 80\%$ follow-up of enrolled patients)<br><br><input type="checkbox"/> Systematic review <sup>2</sup> of level I studies                                                                                                                   | <input type="checkbox"/> Testing of previously developed diagnostic criteria in series of consecutive patients (with universally applied reference "gold" standard)<br><br><input type="checkbox"/> Systematic review <sup>2</sup> of level I studies | <input type="checkbox"/> Sensible costs and alternatives; values obtained from many studies; multiway sensitivity analyses<br><br><input type="checkbox"/> Systematic review <sup>2</sup> of level I studies     |
| <b>Level II</b>  | <input type="checkbox"/> Lesser quality randomized controlled trial (e.g., $< 80\%$ follow-up, no blinding, or improper randomization)<br><br><input type="checkbox"/> Prospective <sup>4</sup> comparative study <sup>5</sup><br><br><input type="checkbox"/> Systematic review <sup>2</sup> of level II studies or level I studies with inconsistent results | <input type="checkbox"/> Retrospective <sup>6</sup> study<br><br><input type="checkbox"/> Untreated controls from a randomized controlled trial<br><br><input type="checkbox"/> Lesser quality prospective study (e.g., patients enrolled at different points in their disease or $< 80\%$ follow-up)<br><br><input type="checkbox"/> Systematic review <sup>2</sup> of level II studies | <input type="checkbox"/> Development of diagnostic criteria on basis of consecutive patients (with universally applied reference "gold" standard)<br><br><input type="checkbox"/> Systematic review <sup>2</sup> of level II studies                  | <input type="checkbox"/> Sensible costs and alternatives; values obtained from limited studies; multiway sensitivity analyses<br><br><input type="checkbox"/> Systematic review <sup>2</sup> of level II studies |
| <b>Level III</b> | <input type="checkbox"/> Case-control study <sup>7</sup><br><br><input type="checkbox"/> Retrospective <sup>6</sup> comparative study <sup>5</sup><br><br><input type="checkbox"/> Systematic review <sup>2</sup> of level III studies                                                                                                                         | <input type="checkbox"/> Case-control study <sup>7</sup>                                                                                                                                                                                                                                                                                                                                 | <input type="checkbox"/> Study of nonconsecutive patients (without consistently applied reference "gold" standard)<br><br><input type="checkbox"/> Systematic review <sup>2</sup> of level III studies                                                | <input type="checkbox"/> Analyses based on limited alternatives and costs; poor estimates<br><br><input type="checkbox"/> Systematic review <sup>2</sup> of level III studies                                    |
| <b>Level IV</b>  | Case series <sup>8</sup>                                                                                                                                                                                                                                                                                                                                       | Case series                                                                                                                                                                                                                                                                                                                                                                              | <input type="checkbox"/> Case-control study<br><br><input type="checkbox"/> Poor reference standard                                                                                                                                                   | No sensitivity analyses                                                                                                                                                                                          |
| <b>Level V</b>   | Expert opinion                                                                                                                                                                                                                                                                                                                                                 | Expert opinion                                                                                                                                                                                                                                                                                                                                                                           | Expert opinion                                                                                                                                                                                                                                        | Expert opinion                                                                                                                                                                                                   |

1. A complete assessment of the quality of individual studies requires critical appraisal of all aspects of the study design.
2. A combination of results from two or more prior studies.
3. Studies provided consistent results.
4. Study was started before the first patient enrolled.
5. Patients treated one way (e.g., with cemented hip arthroplasty) compared with patients treated another way (e.g., with cementless hip arthroplasty) at the same institution.
6. Study was started after the first patient enrolled.
7. Patients identified for the study on the basis of their outcome (e.g., failed total hip arthroplasty), called "cases," are compared with those who did not have the outcome (e.g., had a successful total hip arthroplasty), called "controls."
8. Patients treated one way with no comparison group of patients treated another way.

*Source:* This chart was adapted from material published by the Centre for Evidence-Based Medicine, Oxford, UK. For more information, please see [www.cebm.net](http://www.cebm.net).

# Recommendations

**This clinical practice guideline on sexuality and reproductive health was written for all health-care providers who care for individuals who have a spinal cord injury (SCI). In developing this guideline, we took the position that all health-care professionals have a role in promoting sexual health and that a positive attitude that encourages questions and education about sexuality must be conveyed by everyone who works with individuals with SCI. As in all areas of medicine, it is imperative that providers be aware of their personal limitations and specific areas of expertise. Questions and concerns about sexuality should be referred to an appropriate specialist when a provider feels ill-equipped or uncomfortable answering a question or discussing a concern. Most important, discussion and education about sexuality needs to be tailored to each individual's specific needs and comfort level. Under all circumstances, ethical boundaries must remain the highest priority for everyone involved in the care of the people with SCI.**

## Importance of Sexuality and Reproduction to the Individual

Sexuality, perhaps more than any other single factor, influences feelings about one's self and about one's relationships. It is at the core of our identity. Sexuality encompasses one's sense of self, biological makeup, interpersonal relationships, and moral and cultural beliefs, as well as the way in which individuals relate to their surroundings and our society. For most people, to lose a sense of one's sexuality is to lose an essential part of one's self that is necessary for happiness, fulfillment, and connectedness with others. Sexuality can be expressed in many different ways—within the context of romantic relationships, friendships, the way in which one presents himself or herself to the world, or privately in the context of self-exploration or masturbation.

Sexuality is often one of the first concerns for people who sustain a spinal cord injury (SCI). SCI affects individuals and their relationships in multiple domains. As medical science has advanced, researchers have made great strides in understanding and restoring an individual's ability to function after a devastating trauma such as SCI. However, over the past quarter century, rehabilitation professionals, as well as people with SCI, have come to realize that the medical management of SCI is

insufficient without addressing fundamental quality of life issues that affect relationships, self-esteem, and the family.

For these reasons, most health-care professionals have adopted the belief that issues related to sexuality need to be addressed within the context of rehabilitation programs and during ongoing health-care provision to people with SCI. Ultimately, armed with information about sexuality and sexual function, an individual with SCI must make informed decisions regarding the importance of sexuality in his or her life following injury. The role of health-care providers is to ensure that people with SCI have access to the information they need to make informed decisions.

There are many ways to express one's sexuality after SCI; correspondingly, there are many solutions to the difficulties one experiences after injury. Ensuring that an individual understands all the options and possibilities to enhance sexuality after SCI will be key to his or her ability to keep a positive attitude and complete sense of self.

### **1. Maintain an open discussion and provide access to education about sex in both formal and informal settings throughout the treatment continuum.**

(Scientific evidence—IV; Grade of recommendation—C; Strength of panel opinion—Strong)

**Rationale:** Sexuality consistently is identified as one of the most important topics for individuals after spinal cord injury (Widerstrom-Noga, 1999). In addition, a comprehensive review of the literature and clinical practice both suggest that sexual satisfaction can remain part of one's life after an SCI (Reitz et al., 2004). Health-care providers play a critical role in ensuring that people with SCI have access to information and services that promote a healthy sexual adjustment following injury (Fisher et al., 2002). To be effective, health-care providers must be knowledgeable and comfortable discussing sexuality; conversely, they should consider individual readiness to hear such information from providers and know when it is appropriate to refer the individual to professionals with additional expertise in this area. Generally, discussions about sex and related issues should be integrated into assessment, planning, and ongoing therapeutic sessions. Specific classes and counseling sessions regarding sexuality should be established as a component of the rehabilitation program. Frequently, however, education about sexuality occurs during informal discussions between the person with SCI and his or her health-care providers (Byfield et al., 2000).

**2. Consider using a treatment framework, such as the Permission, Limited Information, Specific Suggestions, and Intensive Therapy (PLISSIT) model, for education.**

(Scientific evidence–IV/V; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** All health-care personnel providing care to individuals with SCI need to have an understanding of their own sexual values, biases, and limitations. In addition, health-care providers should address any personal issues that could interfere with provision of optimal care related to sexual health. One framework for intervention related to sexuality, known as the PLISSIT model, was designed to identify various levels of service depending on the needs of the individual (McBride and Rines, 2000; McInnes, 2003). PLISSIT is an acronym for four levels of intervention: permission, limited information, specific suggestions, and intensive therapy. “Permission” refers to creating an atmosphere in which it is clear to individuals that discussion about sex will be well received, not literal “approval” or “authorization” to talk about sex. “Limited information” relates to an individual’s readiness to receive information regarding the impact of his or her specific condition on sexual expression. An individual’s readiness to hear and discuss issues of sexuality will vary from one individual to another. Some people may want health-care providers to do nothing more than dispel myths or clear up misconceptions; others may be ready to listen to more detailed information about their sexual function. “Specific suggestions” are particular ideas aimed at helping to solve an individual’s specific sexual difficulties. This level may require advanced knowledge and clinical skill on the part of the health-care provider because it involves obtaining a detailed sexual history, identifying specific problems, and setting goals (e.g., specific interventions, education, or compensatory strategies). The highest level, “intensive therapy,” requires formal training and documented competence in sex therapy, sexuality counseling, or psychotherapy. For individuals with more complex sexual histories, this level of intervention may be necessary. In these cases, referral to a specialist is indicated.

**3. Encourage individuals to take an active role in obtaining information related to sexual issues.**

(Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong)

**Rationale:** After spinal cord injury, individuals become responsible for maintaining their physical

and emotional health. Physically, this involves such factors as maintaining skin integrity, following proper bowel and bladder programs, monitoring body temperatures, etc. In addition, people with SCI should be encouraged to monitor their emotional well-being and to seek services when and if they feel unusually sad, unhappy, depressed, hopeless, or unduly anxious. At such times, individuals and their partners should be encouraged to be proactive in seeking professional interventions and counseling. To ensure that correct information regarding sexuality is obtained, individuals with SCI also should be encouraged to seek information and ask questions about sexuality and fertility at any time they have questions. In order to accomplish this, it is necessary to seek providers who are comfortable and knowledgeable in the field. Not all health-care providers have the same level of knowledge and comfort level with the topic of sexuality. As a result, a person with SCI may need to meet with several providers before finding an informed health-care provider with whom he or she feels comfortable.

**4. Provide assurance to the individual as soon as feasible (preferably during early acute care) that basic information about sexuality will be provided and that more extensive information will be available throughout care.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Initially, upon admission to a health-care facility after injury, life-sustaining medical issues will likely predominate concerns related to long-term adjustment, such as sexuality and fertility. However, even as an individual is being stabilized, he or she is likely focused on the future, including how and if relationships and sexual function will be maintained or regained. Once the acute crisis has passed, initial questions regarding sexuality are commonplace: “Will I be able to have sex again?” “Will I be able to have a child?” “Will I be able to maintain a relationship?” Although people most certainly have to adjust their previous sexual and reproductive behaviors, the answer to these questions is generally “yes.” After answering their questions, health-care providers should reassure individuals that more information will be available at a future time during their acute rehabilitation and throughout ongoing follow-up care. It also is necessary to encourage the individual to maintain an open dialogue with health-care providers regarding these issues. Finally, it is always important to emphasize that persons with SCI remain sexual beings and can continue

to participate in both pleasurable and fulfilling sexual activity (Reitz et al., 2004).

**5. Introduce the topic of sexuality by discussing the subject in a straightforward and nonjudgmental manner. Ask open-ended questions that encourage an ongoing dialogue whenever possible.**

(Scientific evidence–IV/V; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Sensitivity is needed in any discussion about sex. Some people will be very open to discussion on the subject while other people may be more reserved. Introducing sexuality as a routine part of the interview process sends the message that sexuality is an integral part of the initial and continuing rehabilitation process (Ide and Fugl-Meyer, 2001).

Presenting open-ended questions candidly and with a respectful attitude may encourage people with SCI to begin to ask questions and seek answers for their particular circumstances. Health-care providers should be aware of what they are communicating to the person with SCI in both their verbal and nonverbal messages. Acceptance, validation, and a nonjudgmental attitude need to be conveyed. Use active listening techniques, such as frequently repeating the individual's questions or summarizing their concerns, to ensure that communication is clear and that both parties are discussing the same issues. In addition, it is helpful to use positive and open-ended questions, such as, "I am pleased that you have been experiencing some sexual desires. Can you tell me more about what you have been feeling?" Finally, whenever possible, ensure that there is ample time for sufficient discussion once the topic has been opened. If time is consistently limited, consider directing the individual to someone who does have the time, comfort level, and knowledge needed (Miller and Marini, 2007). If possible, talk with the individual to determine with whom they would feel most comfortable discussing this topic.

**6. Maintain a nonjudgmental attitude regarding sexual orientation and gender identity in order to elicit honest and productive discussion, while providing maximum privacy and maintaining confidentiality.**

(Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong)

**Rationale:** Through open discussion, acceptance, and careful listening, health-care providers should be sensitive regarding an individual's sexual orientation and gender identity.

It is imperative that health-care providers who work with individuals with SCI be prepared to address the unique sexual health issues of all individuals regardless of sexual orientation and sexual identity. To be effective, providers must be aware of their own values and attitudes toward sexual orientation to be certain that these do not negatively impact the rehabilitation, education, or counseling provided to the individual with SCI. Emotional support and advocacy are important for all individuals with SCI regardless of sexual orientation or gender identity.

**7. Determine the individual's interest and readiness to learn about sexual function and expression following his or her SCI. Be aware that some people with SCI may not feel comfortable in raising the topic directly.**

(Scientific evidence–IV/V; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Most people who have experienced a spinal cord injury will want information about sexuality and relationships at some point postinjury (Ferreiro et al., 2005; Fisher et al., 2002). As the topic of sexuality is addressed (informally or formally), the individual's readiness for further discussion should be noted by observing body language, eye contact, and comments. Keep in mind that different people will be ready for information at different times during the recovery process. Some individuals may not have specific questions until they return to their homes and become more comfortable with the changes in their lifestyle. Other people may not feel comfortable asking questions while in the hospital. For this reason, information on how and where an individual can access information on sexuality after discharge should be provided. Some people tend to broach questions or concerns through joking or making "risqué" or "off-color" comments. Such questions or comments may be an indication of anxiety regarding the topic. When such comments or behaviors are observed, bring up the subject in an open and positive manner by asking the individual if he or she would like to talk further. Sometimes it is helpful to use such statements as "many people with spinal cord injuries have questions regarding [here fill in an issue you believe is relevant to your patient]." This normalizes any concerns or questions that the individual may have. A sense of openness and encouragement should always be provided, as well as an atmosphere that helps people realize that sexual adjustment is an integral and legitimate component of the ongoing rehabilitation process. Individuals should feel that their questions are appropriate and welcomed (Taylor and Davis, 2006).

**8. Encourage people with SCI to explore the role of sexuality in their lives and the various ways in which they may express their sexuality.**

(Scientific evidence—III/IV/V; Grade of recommendation—C; Strength of panel opinion—Strong)

**Rationale:** Decisions regarding the importance and expression of sexuality are personal choices (Valtonen et al., 2006; Reitz et al., 2004). Sexual expression is determined by multiple factors, including culture, religion, childhood and adolescent experiences, early education about sexuality, the existence of a relationship, comfort level, and physical, social, and psychological issues. Most people place a high value on sexuality, intimacy, and love (Yim et al., 1998). The choice to be sexual and the manner in which one chooses to express sexuality following SCI need to be respected by all members of the health-care team. Although health-care providers may have their own values regarding the importance and expression of sexuality, it is essential that each individual's decisions regarding sexuality be respected. In some cases, individuals may not have been sexually active before SCI or may choose not to be involved in sexual education during rehabilitation and/or may decide not to be sexually active following the injury. These decisions do not necessarily reflect psychological difficulties. The decision to refrain from sexual activity, however, should not be made based on a false belief that there is no other choice. Ultimately, the goal of sexual education and counseling is to promote an individual's understanding that sexual expression and intimate relationships do not stop following SCI.

**9. Ensure that for all individuals in rehabilitation or institutional settings sexual expression is treated with privacy, respect, and dignity.**

(Scientific evidence—IV; Grade of recommendation—C; Strength of panel opinion—Strong)

**Rationale:** Time, respect, and privacy are critical if an individual or couple is to feel safe exploring sexual changes following spinal cord injury (Byfield et al., 1999). Offering a separate apartment or hospital room that allows the person with SCI and his or her partner to be intimate is an important statement and first step in restoring sexual intimacy postinjury. For many couples, cuddling, holding each other, or lying in bed together is an excellent way to support each other emotionally and begin rebuilding intimacy. At these times, communication between the couple often is

enhanced. In settings where it is not out of the ordinary, simply hanging a “Do Not Disturb” sign on the door ensures a sense of privacy for the individual or couple. As always, make sure that a “nursing call bell” is available should the person with SCI need help from the clinical staff. Providing a private location for sexual exploration and communication imparts the important message that sexuality and intimacy are important and can be continued after injury. After the couple has had the opportunity to be alone, let them know that there are opportunities for discussion with a staff member should they have any questions or need help with problem solving.

## **Sexual History and Assessment**

Taking a sexual history from individuals with SCI establishes the precedent that issues of sexuality are an essential component of the rehabilitation and follow-up process. The sexual history opens a dialogue in which sexual problems can be discussed in a concrete and factual manner. In many cases, the sexual history is the first step in sexual education because it introduces the topic and establishes a rapport between the individual with SCI and the health-care professional.

Following spinal cord injury, neurologic factors play a significant role in determining an individual's ability to function sexually. As a result, the sexual history is often neglected or seen as somewhat irrelevant since neurological issues are so prevalent. However, sexual function constitutes more than the neurologic level and encompasses emotional and psychological factors, medical conditions, and previous sexual experiences, as well as past and current relationships. All of these factors must be considered and can contribute to an individual's sexual difficulties following the injury. In addition, sexual function is not a static entity; it changes over time with functional recovery or loss and varies depending on one's age, medical condition, partner and quality of relationship, emotional well-being, culture, spiritual beliefs, and other factors.

**10. Include general questions about sexuality and sexual function as early as possible in the rehabilitation process. Ask direct, open-ended questions to facilitate a discussion of sexual matters.**

(Scientific evidence—NA; Grade of recommendation—NA; Strength of panel opinion—Strong)

**Rationale:** Any history of medical comorbidity, rape, sexual abuse, domestic violence, emotional problems, substance abuse, performance-related

issues, or relationship factors must be identified early in rehabilitation. Raising issues about sexuality early in rehabilitation provides ample opportunity to address problems and issues throughout the hospitalization. In addition, sexual-related materials, such as abuse histories, may affect how rehabilitation will proceed and how relationships with health providers will develop. Interpersonal conflicts may be diminished if staff members have an understanding of contributing factors and the person's early developmental history. Often individuals are reluctant to bring up the subject of sex unless the health-care provider asks direct but open-ended and nonthreatening questions. For assessing sexual issues, it is appropriate to first ask the person with SCI whether he or she has an interest in discussing sexual concerns and then proceed accordingly. Examples of questions include:

"Can you tell me about your sexual activity prior to your injury?"

"Did you have any sexual difficulties prior to being injured?"

"Can we talk a little about what was going on at the time?"

"After a spinal cord injury, most people have questions related to sexuality and sexual activity; can you tell me about your concerns?"

"Were you sexually active before your injury, and if not, do you have specific questions at this time?"

"Would you like me to provide you with some information?"

When taking a sexual history, make certain the individual is comfortable with the physical surroundings and the level of privacy in the room.

**11. Ask individuals with SCI if they have experienced any previous sexual trauma, sexual dysfunction, or sexually transmitted disease that could affect their sexual function following injury.**

(Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong)

**Rationale:** As sexual education and counseling proceed after SCI, it is important to have a comprehensive understanding of the individual's past psychological, medical, and sexual history. First, assess preinjury sexual concerns, specifically whether there were any problems prior to injury

and whether or not the person was sexually active before the injury or had only limited experience with sex. Education for people without previous sexual experience may include counseling on dating, social skills, relationships, communication, and preparation for sex. It is important to ask about other preinjury psychological factors, such as relationship issues, body image concerns, and self-esteem. Sexual difficulties, anxiety, and dysfunction are common in the general population. They also are common in persons with a history of depression, substance abuse, hypertension, diabetes, and cardiovascular disease. Such issues as abuse, rape, STDs, and previous sexual dysfunction may have a significant impact on how counseling will proceed or how sexual information is presented. For example, a woman with a history of abuse may not feel comfortable in a mixed-gender sexual education class. In some cases, she may prefer learning about sexuality in conversations with a female staff member. In other cases, individuals with previous sexual difficulties may have unresolved performance anxiety issues or comorbid medical problems that can complicate their sexual adjustment and function. Persons with preexisting sexual problems generally will need to be referred to a specialist, such as a sexual counselor, therapist, gynecologist, or urologist.

**12. Consider the individual's life context (cultural, environmental, spiritual, and social) during sexual education and counseling.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Sexuality encompasses many areas of one's life. Having discussions about how sexuality is viewed by family or in the culture may help determine how to proceed with conversations and education about this topic. If sexuality is addressed within the cultural context of the individual, sexual problem solving likely will be more comfortable for the person with SCI. As such, the health-care provider can encourage people to begin thinking about body image issues, quality of relationships, and resumption of sexual activity if desired (Ide and Fugl-Meyer, 2001; Sakellariou et al., 2006).

**13. Ensure that a medical assessment of the sexual reproductive system is conducted after SCI. The assessment should include a thorough examination of breasts and genitalia, as well as screenings for cervical, ovarian, uterine, breast, prostatic, and testicular cancers. Screening for sexually transmitted diseases, including HIV/AIDS, should be provided as**

**deemed appropriate through consultation with the individual. Provide counseling about HPV immunization as appropriate.**

(Scientific evidence–I/III/IV/V; Grade of recommendation–A; Strength of panel opinion–Strong)

**Rationale:** Often, physical assessment of the breast and genitalia is not considered essential after spinal cord injury (Tas et al., 2007; Schmid et al., 2003; Sharma et al., 2006). Physicians frequently neglect this critical part of the examination because sexual difficulties are most likely considered a result of the neurologic condition. However, an assessment of the individual's reproductive and sexual systems should be performed to ensure that any potential problems, whether or not they are related to the SCI, are not overlooked. Persons with SCI are vulnerable to the same medical concerns as anyone else, but because of the spinal cord injury, routine screenings are not always provided. As a result, symptoms that indicate the need for further evaluation may not be recognized; therefore, explain the necessity of regular screenings to the person with SCI as well as the importance of identifying any comorbid conditions early in his or her etiology. Persons with SCI need this information to be strong advocates for their own care in the future. In an outpatient setting, it is important to maintain an up-to-date list of specialists who work specifically with people with a SCI (i.e., with accessible offices and accessible examination tables) (Welner et al., 1999).

**14. Perform a physical examination using the International Standards to Document Remaining Autonomic Function after Spinal Cord Injury (ISNCSCI), with special attention to the preservation of sensation from T11–L2 and S2–5 along with determination of the presence of voluntary anal contraction and reflexes to assess sexual function.**

(Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong)

**Rationale:** A physical examination using ISNCSCI [available online at [www.asia-spinalinjury.org/bulletinBoard/AutonomicStandardsPaper.pdf](http://www.asia-spinalinjury.org/bulletinBoard/AutonomicStandardsPaper.pdf) – accessed October 2009] should be performed in order to assess the impact of injury on sexual response. In the vast majority of SCI cases, remaining neurological function can be used to predict remaining sexual responses. Additionally, evidence of severe spasticity, areas of hypersensitivity, and the presence of contractures should be assessed. Medical problems that could affect sexual function or expression should be sought through a general physical examination. Examples

of such problems include ventilator dependence, difficulty breathing, skin problems, and vascular problems (all of which may or may not be related to the SCI). Genitalia should be assessed to ensure there is no evidence of trauma, infection, or malformation.

**15. Assess the impact of the individual's injury on sexual responses, i.e., genital responses, based on a neurologic examination, such as the International Standards to Document Remaining Autonomic Function after Spinal Cord Injury.**

(Scientific evidence–II/III; Grade of recommendation–B; Strength of panel opinion–Strong)

**Rationale:** The health-care provider should determine the individual's sexual function classification based on a reliable neurologic exam, such as the International Standards for Neurologic Classification of SCI's autonomic standards [available online at [www.asia-spinalinjury.org/bulletinBoard/AutonomicStandardsPaper.pdf](http://www.asia-spinalinjury.org/bulletinBoard/AutonomicStandardsPaper.pdf) – accessed October 2009], and document the effects of the injury on sexual function in the medical record. Reflexogenic erections and psychogenic erections are generally attributed to parasympathetic nervous system stimulation. However, psychogenic control also is considered possible via the sympathetic pathway (Sipski et al., 2007). Similar pathways are believed to control female genital arousal (Sipski et al., 2001). The impact of SCI on arousal can be determined by assessing the bulbocavernosus reflex and degree of completeness of injury at the S4–5 and T11–L2 levels (Sipski et al., 2006). For an individual with either complete or incomplete SCI (preservation of sensation and or voluntary motor control at the S4–5 area) and an intact or hyperactive bulbocavernosus reflex, reflexogenic erection, or lubrication is generally possible. For people with an incomplete injury at S4–5 along with a hypoactive bulbocavernosus reflex, the ability to obtain reflexogenic erection or lubrication is generally preserved. The ability to obtain a psychogenic erection or lubrication is related to the degree of preservation of sensation in the T11–L2 dermatomes. (Note: most individuals in this group do not make a practical distinction between the two types of arousal.) For people with a complete injury at S4–5 along with an absence of the bulbocavernosus reflex, the ability to have reflexogenic erections or lubrication is lost and the capacity for psychogenic erection or lubrication is related to the degree of preservation of the ability to perceive pinprick and light touch sensation in the T11–L2 dermatomes.

The effect of SCI on orgasm can be determined by assessing the impact of injury on the bulbocavernosus and anal wink reflexes and the degree of completeness of injury at the S4–5 level. It is unlikely that individuals with complete injuries at the S4–5 level with an absent bulbocavernosus and anal wink reflex will be able to achieve a physiological orgasm (Sipski et al., 2001).

**16. Perform a detailed neuromusculoskeletal examination and functional assessment. Use the results of the examination to assist in counseling regarding sexual activity.**

(Scientific evidence–II/IV/V; Grade of recommendation–B; Strength of panel opinion–Strong)

**Rationale:** In persons with spinal cord injury, sensation, motor function, mobility, and specific sexual functions can vary widely (Courtois et al., 2004; Sharma et al., 2006). While completing an assessment, determine how the SCI has affected the individual's sexual function. Each individual will have a unique sexual profile. For example, some men with incomplete injuries may have only relatively mild problems with erectile function or ejaculation while men with complete upper motor neuron SCI may have reflex erections but may not be able to ejaculate with intercourse. In contrast, men with lower motor neuron lesions may have neither reflex nor psychogenic erections. The examination should assess strength, sensation, range of motion, and reflex function. During the rectal examination, the prostate, anal wink, sensation, voluntary contraction, and tone should be assessed (Bird et al., 2001). The examination also should explore the possible presence of peripheral nerve and muscle disease, which may result from medical (metabolic) disturbances, such as diabetes, or medications (e.g., statins). The results of the assessment ultimately should lead to individualized counseling on prognosis and treatment options (McBride and Rines, 2000).

**17. Develop a sexual education and treatment plan with the individual consistent with the results of the sexual history, interview, relationship status, and physical exam findings.**

(Scientific evidence–NA; Grade of recommendation–NA; Strength of panel opinion–Strong)

**Rationale:** The health-care provider should develop a treatment plan based on the individual's physical exam, sexual history, and personal concerns. The treatment plan should be developed

in collaboration with the person who has the injury and his or her partner, if desired. Referrals to specialists for further evaluation and treatment may be warranted. Practitioners are encouraged to develop working relationships with specialists, such as physiatrists, urologists, gynecologists, psychiatrists, psychologists, sex therapists, and sexual health nurses. The discussion between the health-care provider and the person with SCI should include any components of the sexual response cycle that the person feels may have changed since injury and any previous injury to the perineum area. Relevant comorbidities, such as tobacco use, alcohol use, drug use, vascular disease, psychiatric issues, or disorders related to the endocrine, metabolic, or neurological systems (other than SCI), should be discussed and evaluated. Use language that the person with SCI or couple can clearly understand (i.e., avoid medical terminology that may not be familiar to most people), and use this time to review relevant prescription and nonprescription drugs associated with sexual dysfunction. A detailed listing of medications should be obtained and the list should be checked to determine potential sexual side effects. In particular, review the use of narcotics, antidepressants, antihypertensives, anticholinergics, birth control pills, and antispasmodics (e.g., baclofen), as many of these can contribute to sexual dysfunction. If prescription medications are contributing to an individual's sexual dysfunction, initiate a consultation with the prescribing health-care provider to discuss the sexual implications. Individuals should not discontinue a prescribed medication that is being used to treat another condition without a thorough discussion of all options and possible outcomes.

**18. Perform full physical examinations and neurological assessments regularly, in order to detect changes over time that may affect sexual function. The assessments should include the International Standards to Document Remaining Autonomic Function after Spinal Cord Injury to determine the neurological level and extent of the injury.**

(Scientific evidence–III/IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** In order to properly assess sexual function and the capacity for sexual activity, a full physical examination and neurological assessment should be conducted annually for the first two years postinjury and once every five years thereafter. Any changes regarding sexual function should be documented in the medical record.

Generally, sexual function can be somewhat predicted by the level and completeness of the injury although individual differences can occur (Westgren et al., 1997, Sipski et al., 2006). Documentation of motor, sensory, autonomic, and functional abilities will help form more realistic expectations regarding sexual function, positioning, spasm, and other activities that affect sexuality. The International Standards to Document Remaining Autonomic Function provide a system with which to communicate the effects of specific spinal cord injuries on autonomic functions, including sexual function. Neuromuscular assessments, such as the Functional Independence Measure (FIM), may be helpful in determining the ability to perform activities of daily living, including sexual activities. A proper, inclusive physical assessment assists in defining the extent of sexual changes, facilitating education for the individual, and formulating realistic expectations and treatment options. Changes in the examination results over time may indicate an alteration in sexual capacities. These changes may further necessitate a new approach to areas, such as erection enhancement. Additionally, if the sexual status (or bladder and bowel function) has deteriorated between assessments, this may indicate altered neurological status, which would require more urgent attention.

**19. Educate persons with SCI about the effects of medication on sexual response and fertility. Medications include prescription, over-the-counter, or herbal remedies and/or supplements.**

(Scientific evidence–V; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** More than 100 specific medications or classifications of medications have been associated with sexual dysfunction (Thomas, 2003). Some classes of medications that can affect sexual function include antidepressants, (including selective serotonin reuptake inhibitors, heterocyclic and tricyclic medications), neuroleptics, anxiolytics (e.g., diazepam), anticonvulsants, antispasmodics, cardiovascular medications, sympatholytic agents, diuretics, lipid-lowering agents, vasodilators, gastrointestinal medications, opioids, anticholinergics, and chemotherapeutic agents. Side effects include erectile or ejaculatory dysfunction, vaginal dryness, impaired libido, and priapism. On the other hand, some medications have beneficial effects on sexual function and may be indicated to ameliorate the negative side effects of other medications (Thomas 2003). For example, bupropion is often used to improve the impaired

libido seen commonly with the use of selective serotonin reuptake inhibitors (SSRIs). Over-the-counter preparations have not been well studied, but include many of the same medications that require prescriptions when used at a higher dose.

**20. Educate the individual about the effects of alcohol, tobacco, and other drugs, as well as unhealthy eating habits and obesity, on sexual response and fertility.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** Individuals need to understand that healthy erectile function and vaginal lubrication are dependent on adequate circulation and blood flow to the genital areas. Circulation of blood can be negatively affected by cigarette smoking, alcohol consumption, and substance abuse. Persons with SCI need to be aware that these activities ultimately can result in reduced blood flow and diminished sexual responsiveness. Alcohol, drugs, and tobacco also can cause or contribute to other conditions that interfere with sexual function (e.g., neurologic diminishment, sleep disorders, mental confusion, depression, reduced lung capacity, and cancer). Unfortunately, these systemic issues, which can contribute to sexual dysfunction, often are minimized or not discussed with individuals with SCI.

**21. Evaluate the individual with SCI for a diagnosis of depression or other psychological disorders if he or she exhibits such symptoms as loss of libido, poor concentration, fatigue, and/or changes in sleep or appetite.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Emotional issues are fundamental to the relationship and quality of sexual function (Reitz, 2004, Dahlberg, 2007). Persons who exhibit symptoms of depression should undergo differential diagnosis by a mental health professional. If diagnosed with depression, individuals should be referred for specialized treatment, such as psychotherapy and/or medication. Depression often contributes to sexual problems and can have a negative impact on libido and function. Untreated, depression also can be self-defeating and potentially dangerous. Psychotherapy and medication either alone or in combination are the most common and effective treatments for depression. These treatments can significantly improve appetite and sleep, restore energy, and ultimately, renew sexual interest. When

depression has been treated or eliminated as a potential diagnosis, other suggestions for dealing with stress, fatigue, and anxiety can be offered. Partner depression and fatigue also need to be considered in discussions regarding sexual activity. Providers should encourage persons with SCI to be sensitive and honest (to themselves and their partner) about their energy levels, sexual needs, and desires. In the context of a relationship, clear communication about emotions and sexuality can reduce performance anxiety and ultimately improve the likelihood of satisfying sexual encounters. Honest and open communication about sexual desire is important in any healthy relationship.

**22. Evaluate for a diagnosis of testosterone deficiency in men with SCI presenting with suppressed libido, reduced strength, fatigue, or poor response to phosphodiesterase type 5 inhibitors (PDE5is) for erection enhancement.**

(Scientific evidence—III/IV/V; Grade of recommendation—C; Strength of panel opinion—Strong)

**Rationale:** Testosterone deficiency occurs commonly in men with SCI (Bauman and Spurgeon, 2000), or it may have been unrecognized prior to the SCI (Tsitouras et al., 1995). Suspected causes of hypogonadism after SCI include chronic illnesses, bladder and testicular infections, concomitant brain injury, hyperprolactinemia, metabolic syndrome, diabetes, and use of medications that increase prolactin or suppress testosterone (e.g., opioids or gastrointestinal medications). Treatment of these illnesses and/or alterations in medications may assist in return of normal testosterone levels.

The use of testosterone replacement in men with SCI must only be considered after documented sexual symptomatology or other effects (e.g., fatigue, strength, or osteopenia) and biochemical confirmation of morning low serum free or bioavailable testosterone. If gonadotropin and prolactin levels are not elevated and no other cause of hypogonadism is found and/or treated (i.e., medication side effects or diagnosed illness), primary hypothalamic/pituitary pathology then must be ruled out prior to initiation of testosterone replacement. Monitoring of hemoglobin or hematocrit for polycythemia as well as prostate-specific antigen and rectal examinations need to be done following the usual recommendations for testosterone replacement in the able-bodied population. Exogenous testosterone replacement will suppress spermatogenesis and therefore should not be the treatment of choice in hypogonadal men with SCI wishing to pursue

biological fatherhood. The use of testosterone replacement for women for low libido is applicable in only a small percentage of women who have been skillfully evaluated. Use of testosterone has not been specifically evaluated in women with SCI. Furthermore, its use in all women is still considered investigational for numerous reasons (Basson, 2008).

## Education

When treating individuals with SCI, it is necessary to provide education about sexuality and fertility as they relate specifically to the injury as well as a more general discussion regarding the effects of SCI on relationships. In providing education, the attitude of the health-care provider is as important as the content provided. The message to people with SCI should be that sexuality is a vital, positive component of life and can still be gratifying and satisfying after the injury. Health-care providers should educate not only about the mechanics and practicalities of sexual activity, but also integrate a person's personal needs, questions, life views, and life context as these relate to sexuality. Sexuality should be understood in the context of a person's life rather than as a separate and distinct entity. Finally, it is important for health-care providers to be cognizant of and responsive to the individual's emotional reaction to the provided information.

**23. Maintain professional boundaries under all circumstances when addressing sexual issues with individuals with SCI and their partners.**

(Scientific evidence—N/A; Grade of recommendation—N/A; Strength of panel opinion—Strong)

**Rationale:** In the period following an injury, individuals with SCI often lack confidence in their sexual attractiveness, ability to develop intimate relationships, and capacities for sexual expression. As a result, these insecurities can be expressed consciously or unconsciously in their behavior toward the treating health-care providers. The close interaction between health-care provider and patient along with frequent physical contact can create a comfort level and environment in which the patient may believe it is appropriate to flirt or may begin to experiment with expressing his or her sexual feelings. It is critically important that health-care providers set limits and maintain professional boundaries at all times and do not engage in or encourage sexual activity with patients. Consultation with other health-care professionals is often helpful in maintaining healthy boundaries.

**24. Consider age at onset of injury and previous sexual experience when assessing the sexual knowledge of the adult individual with SCI. Provide sexual education and counseling accordingly.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Knowledge of sexuality and sexual practices changes significantly across one’s life span. For example, when SCI occurs at a young age, individuals may not have been sexually active prior to injury and may have little information regarding their sexuality. Individuals whose injury occurred during childhood may be naive about peer relationships and may have never experienced independence from their parents (Valtonen et al., 2006; Westgren and Levi, 1998; Widerstrom et al., 1999; Pentland et al., 2002). Individuals of child-bearing age may need specific information regarding fertility and birth control, while older individuals may need more information on the relationship between sexuality and aging. Older individuals also may need emotional support if they have lost partners or close friends. Regardless of the person’s age at the time of onset, sexual education and counseling should be provided according to the developmental level and needs of the individual at the time.

**25. If explicit educational media (videos, pictures, books, magazines, etc.) are going to be used for education, evaluate the individual’s readiness to view such material and use material only when health-care providers with counseling skills are available to help the individual process the information and gauge his or her reaction to the media. Use these materials only in accordance with state and/or institutional laws.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** It is important for the health-care provider to check local and state laws before using explicit sexual media. Media depicting sexual activity after SCI should only be used after in-depth discussion between the person with SCI and the health-care provider. Explicit media should be used only if the individual specifically states that he or she is amenable to this form of education. Personal, cultural, or religious beliefs may make this form of education unacceptable to some people. Use of explicit media requires preparation and readiness on the part of the person with SCI and the health-care provider: the person with SCI should be informed that the materials contain explicit

depictions of sexual activity and the health-care provider should be familiar with the material and be prepared to discuss its content. Individuals in a relationship may prefer to view the material with their partner. The health-care provider should view the material with the individual or partner and be prepared to stop and discuss issues at any time. Follow-up discussion is essential immediately after viewing the material and is recommended in the days following should additional questions or emotions arise. Explicit sexual media should never be used as a substitute for in-person discussion and education.

## **Maintaining Sexual Well-Being**

In order to achieve a feeling of sexual well-being, people with SCI need to understand how their bodies function after injury. This understanding may be accomplished through a variety of methods, such as education, discussion with peers, masturbation, self-stimulation, or experimentation with a partner. Health-care providers who treat people with SCI have the responsibility to instruct and educate in accordance with the individual’s needs and wishes.

**26. Provide information on methods to enhance sensuality by using all available senses.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Incorporating all sensory areas into a sexual interaction will encourage people to use every available sensory channel. Depending on the nature of the injury, these areas could include hearing, sight, smell, taste, and touch. Fantasy, past memories, or mental images may also enhance the level of arousal (Anderson et al., 2007b). Examples include the following:

- **Hearing:** Verbal expression of desires, fantasies, and pleasurable feelings can enhance sexual interactions. Music can be used to set a mood and bring to mind positive memories and feelings.
- **Sight:** Some people are stimulated by watching contact or penetration that they cannot feel. Other people may become stimulated by watching their partner become aroused (a hand mirror may be useful when immobility makes it difficult to see part of the body). Images in movies or books can be sexually arousing. Lighting (candles or dimming lamps) may enhance a romantic mood.

- **Smell:** Some people find the smells associated with sexual activity to be arousing. The use of perfume, room fragrances, candles, or incense can enhance a romantic mood.
- **Taste:** Some people find tastes associated with kissing or oral stimulation to be arousing. Many people find certain foods and flavors sexually stimulating, e.g., strawberries, chocolates, certain alcoholic beverages (individuals should be advised to ensure that anything edible is not contraindicated by medications or health conditions).
- **Touch:** The person with SCI should be educated about how his or her level of injury may affect the ability to touch and be touched. Individuals with SCI should be encouraged to take time to explore and develop new erogenous zones, such as on the neck, face, under the arm, or around the nipple area. Many activities, such as kissing, massaging sensate parts of the body, holding hands, or being held by one's partner, may provide a sense of intimacy and sensuality (Stubbs et al., 2000).
- **Imagination:** Often, sharing fantasies with a partner can be stimulating and arousing. Communication should be encouraged; this may include the use of sexual fantasies or imagination to enhance levels of sexual arousal.

**27. Provide information on sexual assistive devices (sex toys) that are sometimes used to enhance sexual experiences. Provide appropriate cautions about contraindications as well as information regarding skin protection, prolonged penile constriction, and dysreflexia. Inform individuals that sexual enhancement devices may be modified to accommodate limited mobility.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** Many individuals with SCI find sexual devices such as vibrators helpful in improving arousal. Such devices can often help to compensate for areas of diminished sensation. For some individuals, using vibrators and sexual devices may be preferred over prescribed medical treatments to improve erections. When providing information about sex toys, health-care providers should discuss the cautions, contraindications, and possible complications associated with such devices. For example, penile rings can interfere with normal blood flow from the penis and should never be kept

in place for longer than 30 minutes. In addition, vibrators may cause dysreflexia in individuals with SCI at T6 and above. Any device that causes friction on the skin may lead to skin breakdown.

**28. Encourage individuals to consider expanding their sexual repertoire to enhance their sexual pleasure following injury. Discuss the broad range of options for sexual expression and pleasure for individuals with SCI.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** SCI poses multiple changes in body image, movement, sensation, and function (Anderson et al., 2007a). It is important to create a safe atmosphere in which to discuss the possibility of exploring new or different sexual practices or positions to enhance sexual experiences and pleasure. This discussion may include, but should not be limited to, different or alternative sexual positions, use of the mouth and tongue for sexual pleasure, manual stimulation, and the use of sexual enhancement devices and toys. Sex and sexual expression for people with or without SCI encompasses multiple activities beyond penis-vagina intercourse. However, some individuals may consider “intercourse” and “sex” to be synonymous. Health-care providers who provide information on sexuality to people with SCI should always encourage individuals to explore a broader range of sexual practices and activities. For all people, limiting one's sexual activity strictly to intercourse may greatly reduce the opportunities for sexual satisfaction and pleasure (Dahlberg et al., 2007).

## Physical and Practical Considerations

After SCI there are physical and practical considerations that need to be understood for optimal safety and sexual satisfaction. Basic questions, such as, “How do I move my body to get into position?” or “What do I do with my equipment?” need to be answered. In addition, it is important that people with SCI and their partners understand how such issues as bladder and bowel management, skin care, and risk of autonomic dysreflexia (AD) can impact their sexual function. Because many people may not become sexually active until long after the injury occurs, they may not be aware of the full impact of the injury on their sexual activity. Nevertheless, it is important that individuals and couples be prepared for and educated about the practical matters and issues they will encounter when they become sexually active.

The issues addressed in this section will vary for each person depending on level of injury, completeness of injury, presence of a relationship, and age. Regardless of individual circumstances, discussions about relationships and sexuality serve two basic purposes. First, they provide factual knowledge about a specific area of function. Second, discussions about these issues convey an important message that relationships and sexuality are still important and can still be enjoyed after injury. Ultimately, for most people, a healthy sense of one's sexuality has positive implications for self-care, interpersonal relationships, self-esteem, and community reintegration.

## Bladder and Bowel

### **29. Encourage individuals to consider bladder care prior to sexual activity and to explore contingency plans, as necessary, if incontinence should occur.**

(Scientific evidence–II/IV; Grade of recommendation–B; Strength of panel opinion–Strong)

**Rationale:** Although bladder incontinence during intimate activity may be a source of anxiety (Anderson et al., 2007c), it does not necessarily preclude the enjoyment of sexual activity for people with SCI (Anderson et al., 2007a). Men should determine if having a full bladder assists with or impairs their ability to achieve an erection and should use this information to determine when to empty their bladders. However, a full bladder may cause increased sympathetic activity that can result in autonomic dysreflexia. This possibility must be discussed and contingency plans put in place should AD occur. Emptying leg bags prior to sexual activity will prevent spilling of urine should breakage occur. Towels or disposable protective bed pads can be used in case leakage or secretion of bodily fluids occurs. Persons with SCI using indwelling urethral catheters need to take precautions to prevent dislodging or contamination during sexual activity. For some people, removing the catheter and replacing it after sexual activity is preferred, although this may be problematic if assistance from an untrained partner is necessary. Some men who use indwelling catheters fold the tubing down the shaft of the penis or clamp the end of the catheter and place a condom over the penis and tubing prior to intercourse. These men should be aware that this technique can damage the balloon port tubing and cause the balloon to remain inflated. Damage to the balloon port may cause bladder distention, ultimately resulting in a urinary tract infection, sepsis, or autonomic dysreflexia in those men who have injuries at T6

and above. In a significant number of cases, autonomic dysreflexia occurs in the absence of noticeable symptoms (Claydon et al., 2006), making it more important to take every precaution to prevent it. As a result of the issues associated with an indwelling catheter, some people with SCI find that a switch to a suprapubic catheter may be more conducive to sexual activity. Cleaning urethral catheters and their insertion sites is advisable before and after sexual activity.

### **30. Encourage individuals to consider bowel care prior to sexual activity and to explore contingency plans, as necessary, if incontinence should occur.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Concerns related to bowel accidents during sexual activity can create anxiety, thus inhibiting sexual responses and enjoyment (Anderson et al., 2007c). Coordinating bowel care and developing contingency plans in the case of a bowel accident may help alleviate anxiety and allow for more enjoyment of intimate activities. In general, successful bowel management enhances the ability of persons with SCI to participate in life activities (Consortium for Spinal Cord Medicine, 1998). This is true for sexual activity as well. Some people prefer to empty their bowels prior to sexual activity; however, people with SCI should be made aware that even with an empty bowel, residual bowel emptying or mucus discharge can occur from the effect of digital rectal stimulation or some medications, such as bisacodyl. It may be helpful for persons with SCI to discuss the possibility of an unplanned bowel movement with a partner in order to reduce anxiety (Ducharme, 1999). In a sexual situation, any reduction of anxiety leads to a more positive sexual experience.

## Skin Care

### **31. Inform individuals that existing pressure ulcers do not necessarily preclude engagement in sexual activity and discuss ways to avoid injuring skin or exacerbating existing pressure ulcers.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** The presence of pressure ulcers does not necessarily preclude sexual activity. However, sexual activity likely will need to be modified and appropriate precautions need to be taken to avoid further skin breakdown. Wound care should be managed so that dressings do

not become loosened or damaged during sexual activity. Both the individual with SCI and his or her partner should be advised to avoid putting weight on existing ulcers. Bandages that become loosened or damaged need to be replaced at the conclusion of sexual activity (Consortium for Spinal Cord Medicine, 2000).

**32. Instruct individuals to inspect insensate skin surfaces, particularly around the genitalia and buttocks, immediately after sexual activity as these areas may have received excessive friction, pressure, or tears.**

(Scientific evidence–III; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Decreased sensation makes it difficult to detect excessive pressure, shearing, or friction during sexual activity. Routine inspection and intervention when needed after sexual activity can prevent the progression of skin breakdown. After SCI, women may experience decreased or absent genital lubrication (Matzaroglou et al., 2005) and men may experience decreased preejaculatory fluid. Decreased lubrication may result in irritation of the skin during intercourse. Use of artificial water-soluble lubricants (preferably gels) can provide additional lubrication, but it is recommended that lubricants be uncolored and unflavored (since remnant sugars encourage yeast growth) and that warming gels be avoided when temperature is not able to be detected. Silicone gels, while extending the duration of lubrication, are also harder to remove from the skin. The gel should be applied to the genitals prior to intercourse. If the person with SCI has limited hand mobility, the partner can apply the lubrication as part of the sexual encounter. Lubricating gel may need to be reapplied during prolonged sexual activity.

## Secondary Medical Complications

**33. Educate individuals with SCI about optimal positioning during sexual activity in order to protect limbs from damage.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** In the presence of contractures or when there are limitations in range of motion, limbs should be supported with pillows or bolsters. In addition, there should be no forceful pressure when positioning the body for sexual activity. Impaired sensation in combination with high sexual arousal can sometimes lead to dislocation, ligamentous injury, or fracture. Osteopenia and osteoporosis often occur after SCI. A significant

loss of bone mass increases the risk of fractures after SCI. Such fractures can result from even relatively minor trauma.

**34. Inform individuals with SCI that it is common for their level of spasticity to change as a result of sexual activity.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Spasticity is known to interfere with sexual activity in some persons with SCI (Alaca et al., 2005). For other individuals, tone or spasticity may be useful for functional mobility or stability. In either case, individuals with SCI need to be aware of potential instability due to the reduction in systemic tone after orgasm. In treating spasticity, all factors that increase or decrease tone should be considered. During genital stimulation, spasticity is more likely to be increased and autonomic dysreflexia may occur, thus requiring temporary cessation of sexual activity. In addition, ejaculation has been reported to decrease spasticity for up to 24 hours (Halstead et al., 1993; Laessoe, 2003).

**35. Educate individuals about the relationship between sexual activity and the possible onset of autonomic dysreflexia (AD), with or without symptoms, especially in people with injuries at or above T6. Instruct individuals with SCI to modify sexual activity if they experience AD.**

(Scientific evidence–I/II; Grade of recommendation–A; Strength of panel opinion–Strong)

**Rationale:** All persons with SCI who have an injury at T6 or above have the potential to experience autonomic dysreflexia (Sheel et al., 2005; Consortium for Spinal Cord Medicine, 2001). Individuals with SCI who are at risk for AD should receive early basic education on how to prevent, respond to, and intervene if AD should occur. Sexual activity, especially orgasm and ejaculation, can trigger the onset of AD. Wounds (such as pressure ulcers) or an unperceived noxious stimulus to the skin, bladder, joints, or bones can exacerbate this likelihood. Autonomic dysreflexia, while usually symptomatic, can be silent (that is, the person with SCI may be unaware of symptoms) despite significantly elevated blood pressure (Claydon et al., 2006). If an individual experiences AD during sexual activity, the activity should stop and the person should sit up immediately while the medical provider is notified. Even if warning signs subside, the individual should be instructed to call a health-care provider.

Symptoms and signs of AD may include very high blood pressure, slowed heart rate, pounding headache, sweating, flushing, pallor, nasal congestion, blurred vision, nausea, and piloerection (body hair stands up). These symptoms may be more severe with ejaculation and orgasm. The use of prophylactic medication, such as nifedipine, prazosin, or nitropaste, to reduce the symptoms of AD can be considered after physician assessment. Nitropaste (nitroglycerine ointment) has the advantage of being able to be removed as soon as the sexual stimulation is stopped but should not be used if the individual is also taking PDE5is for erection enhancement. In emergency situations of high blood pressure, nifedipine can be used and the individual monitored (Consortium for Spinal Cord Medicine, 2001; Krassioukov et al., 2006).

**36. Ensure that individuals with SCI understand that they remain at risk for acquiring or transmitting sexually transmitted infections (STIs), also commonly known as STDs (or sexually transmitted diseases).**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** General information regarding STIs should be provided to all people. As with the non-SCI population, certain precautions, such as male and female condoms, can reduce, but not eliminate, the risk for transmitting STIs. Some individuals may not be familiar with the proper placement of a condom on the penis or the use of female condoms. Such instruction should be made readily available to ensure that individuals are comfortable with condom use at the time of intercourse. Protection should be used when engaging in vaginal, oral, or anal sex. Physical limitations of the arms and hands may make protected sexual activity difficult to achieve without assistance. The risk of contracting an STI is greatly increased when individuals engage in sex with multiple partners, sex with people whose sexual history is not known, or sex with strangers. Anal sex is also associated with a higher risk of disease transmission. The use of alcohol or other drugs can impair judgment, thus increasing the risk of engaging in potentially dangerous sexual behavior. It sometimes is difficult to ask a new partner about personal sexual practices; however, it is important to have such a conversation. Unfortunately, some individuals with STIs do not disclose their infection status. Individuals who are not in an exclusive relationship need routine and early testing for STI. Early diagnosis is advantageous since treatments can be much more effective if started soon after

the infection is contracted. Individuals should be encouraged to advocate for themselves and request screening for STIs whenever there are concerns. Women should be informed about HPV vaccination.

## Optimal Positioning for Sexual Activity

**37. Educate individuals about obtaining assistance from caregivers in their preparation for sexual activity.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** For people with tetraplegia, some people with high paraplegia, and other persons with SCI (as a result of age, body weight, or health problems), it is often necessary for caregivers to provide physical assistance prior to sexual activity. In such instances, caregivers may need to assist with undressing, preparation, and positioning for sexual activity. The extent of assistance provided depends on the skills, training, and professional characteristics of the caregiver. In addition, the comfort level of both parties needs to be considered. In cases where assistance is necessary, it is important that an open and honest discussion occur prior to the sexual encounter. Certain people in the family, such as children, are not appropriate to provide assistance for personal matters such as intimacy. Health-care providers should be prepared to discuss caregiving roles, limitations, and the extent to which formal caregiving resources are available.

**38. Ascertain the necessary spine precautions specific to the individual and translate that information into safe levels of sexual activity. After spinal cord injury, intimacy and affection are encouraged; however, individuals need to be cognizant of the potential risk of further injury.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** During the period of healing after a new spinal cord injury, persons must be carefully monitored for instability at the zone of injury. Generally, after stabilization surgeries, the surgeon will set spinal precautions (limitation of motions and the duration of the limitations) or in cases with no surgical intervention, the neurologist or attending physician may set the spinal precautions. The intent of these precautions is to allow optimal healing and avoid further injury to the spinal cord. Persons interested in engaging in sexual activity during the postsurgery healing period should be offered suggestions regarding safe positioning

based on the individual's surgical procedure and physical condition. Touching, kissing, and intimate stroking may be more appropriate than sexual activity requiring repositioning during these times. It may be helpful to inform individuals and their partners that with healing and time sexual activity likely will become less restrictive. The fear of further injury is common among partners, and it should be explained that additional injuries are unlikely once healing has occurred.

### **39. Suggest environmental modifications that enhance the quality of the sexual experience.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** After discharge from an inpatient setting, persons with SCI initially may require a hospital bed for use at home. It also may be necessary to use a more accessible room in the house as the “bedroom” if the original bedroom is not accessible. Ultimately, many people with SCI are able to transition back to a standard bed and to their own bedroom. For many people, the use of a queen or king size adjustable bed provides the necessary functions of a hospital bed and is more satisfying for sharing with another person. When doing a home assessment, the health-care provider can address sexuality and suggest modifications, such as providing privacy via curtains or decorative screens, setting up an area for private phone or Internet conversations, and using rooms not previously considered for sexual activity. Other suggestions for home modifications may include arranging furniture to increase accessibility, encouraging transfers to a sofa where the couple may sit together and using remote controls to dim lights, turn off televisions, or turn on romantic music. More unconventional locations for sexual activity may be considered (e.g., tables, sofas, or vans); however, accessibility and safety must be considered.

### **40. Teach the person with SCI optimal positioning and bed mobility in accordance with his or her injury.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** Level and nature of injury, range of joint motion, and relationship status need to be considered when discussing possible sexual positions with the person with SCI. Health-care providers often discuss positioning and can demonstrate various safe positions while keeping in mind the comfort level of the individual and his

or her partner. Any demonstrations or practicing of possible sexual positions are conducted while all parties are fully clothed. If the person has a partner, involvement during therapy can determine the extent to which he or she can help the individual with SCI get into a position for sexual activity. Physical and occupational therapists are often trained to determine, explain, and demonstrate techniques for optimal positioning. In the absence of sensation, care should be taken not to assume positions that can be detrimental to joints, causing long-term medical problems. For example, hip dislocation is a particular concern. Posterior hip dislocation is likely to occur with a forceful combination of hip flexion, hip internal rotation, and adduction. If the posterior soft tissue element is over-stretched, there will be a greater tendency toward hip dislocation. Therefore, persons with SCI should be cautioned to avoid over-stretching the hamstring muscles. Hip dislocation can have a number of detrimental sequelae, including increased risk of skin breakdown and postural deviations that can cause further negative complications, such as respiratory compromise and upper extremity musculoskeletal pain. Any joint placed in an extreme position may be sprained but the greatest concern is the area of limited sensation.

### **41. Educate individuals with SCI and their partners about safety measures to consider when engaging in sexual activity while in a wheelchair. Encourage individuals to learn about the safety limits of their particular chair.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** When the male partner has an SCI, it often is easier to engage in intercourse when he is supported by a backrest and is in a seated position. Thus, the wheelchair is a potential location for sexual activity. When the female partner has an SCI, it often is difficult to use the wheelchair during sexual intercourse. However, other sexual activities while the woman is seated in the chair may include manual or oral stimulation, use of sexual devices, kissing, touching, and hugging. In general, remaining in the wheelchair can be a viable option for sexual activities because persons with high levels of injury may require assistance with transferring out of a power wheelchair. In all cases, advise individuals to take appropriate precautions to prevent slipping out of the chair, tipping the chair, or other mishaps. Such measures may include securing chair locks, using anti-tip bars for stabilization, ensuring the power is off

and secured in that position, protecting electronic devices from damage, complying with weight limits specified by the wheelchair manufacturer, and positioning the chair next to a sturdy piece of furniture or a wall for stability. Tilting or reclining seats may reduce stability. Extra pillows can provide support.

**42. Discuss safety issues related to the use of shower and shower equipment for sexual activity (e.g., burns induced by hot water, risks of slipping or falling, and weight limits that may apply to shower chairs). Inform the individual that high-weight-capacity shower chairs are available.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** Some individuals and couples find that the slippery effect of water and soap can enhance sensual pleasure and arousal. Using water and soap to facilitate body exploration or stimulation can increase intimacy and enhance sensation. The increased visual stimulation of shared showering can also increase sexual pleasure. Adjustable shower heads (e.g., jets and vibratory water massage) can facilitate sexual stimulation and arousal. However, for people with SCI there are always risks involved in showering or bathing. With reduced sensation, the potential for burns from hot water can be high. In a state of heightened sexual arousal, some of these risks can be intensified. Health-care providers should discuss the potential benefits of shared showering as well as the safety concerns, such as slipping and falling, burning one's skin, hitting one's head or other body part on a hard surface, or skin injury due to the hard surfaces in a bath or shower.

**43. Discuss the use of adaptive equipment required by aging individuals with SCI and people with aging partners.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** With age, physical dexterity can become even more limited for persons with SCI (Pentland et al., 2002) and partners. Physical and occupational therapists as well as other rehabilitation team members can be excellent resources for the aging person with SCI and partners of individuals with SCI (Sakellariou and Sawada, 2006). Persons working in rehabilitation may be able to suggest accommodations or modifications to help deal with functional decline. They also may be able to suggest adaptive equipment, such as mechanical transfer lifts, or provide

instruction in alternative mobility techniques to facilitate sexual activity. Health-care providers should also pay attention to the emotional reactions of the individual. Often persons with SCI and their partners may have an emotional reaction to using new adaptive equipment. For example, new equipment may make an individual feel more disabled. As a result, time for discussion of both physical and emotional issues should be allowed.

## **Effect of Injury on Sexual Function, Responsiveness, and Expression**

The effect of SCI on sexual function depends on the level and completeness of injury along with the personal and psychological characteristics of the person with SCI. In men, alteration in erectile quality and ejaculatory dysfunction are fairly common, resulting in functional as well as fertility issues. Women may experience changes in sex drive, vaginal lubrication, or arousal. Both men and women with SCI may experience changes or disruptions in their experience of orgasm.

Personal and psychological issues are equally important. After an injury, sexual confidence may be low and self-esteem may be diminished. Depression, anxiety, and negative body image may make sexual activity feel intimidating. In addition, relationships may seem tentative, fragile, or even unstable. All of these factors will play a role in how the individual with SCI perceives and expresses sexuality.

**44. Discuss the fluctuations that may occur with sexual desire and interest following SCI.**

(Scientific evidence–II/III/IV/V; Grade of recommendation–B; Strength of panel opinion–Strong)

**Rationale:** Sexual desire can be affected specifically by emotional and physical factors after SCI (Dahlberg et al., 2007; Tay et al., 1996). Temporary loss of sexual desire can be expected after any traumatic occurrence. However, continued loss of libido over prolonged periods of time should be investigated for such etiologies as depression, concurrent medical conditions (e.g., urinary tract infection), alterations in hormones (especially hypotestosteronemia or hyperprolactinemia), distress over altered sexual function or fertility, negative consequences of sexual activity (i.e., pain or spasm, bladder, bowel incontinence, etc.), loss of partner secondary to the injury, or medication use (Thomas, 2003). Health-care providers

should be aware that some individuals may have a low sexual drive or emotional difficulties because they do not have a partner and fear that future relationships may not be possible (Fisher et al., 2002). Obtaining proper medical and psychological histories can help address or mediate these issues with proper treatment (Rutberg et al., 2008).

**45. Discuss the potential for discovering and developing new areas of the body that may stimulate sexual arousal (erogenous zones) and lead to sexual pleasure and possible orgasm.**

(Scientific evidence—III/V; Grade of recommendation—C; Strength of panel opinion—Strong)

**Rationale:** Many people are not aware that other parts of the body can provide sensual pleasure other than the genitals, breasts, tongue, lips, and mouth. Areas of the body not commonly associated with sexual pleasure may prove to provide erotic pleasure, such as the head, hair, face, ears, neck, chest, abdomen, back, arms, underarms, hands, fingers, legs, feet, and toes. Adequate stimulation of any of these areas may result in sexual arousal and possibly orgasm (Stubbs, 2000). Techniques, such as sensate focus exercises (Miller and Marini, 2007) or pleasure mapping (Stubbs et al., 2000), can improve sexual communication and pleasure. In general, the amount of stimulation necessary for sexual arousal will vary from person to person depending on both physiological and psychological factors (Whipple et al., 1996).

Typically after SCI, some areas of the body retain sensation while sensation in other areas is altered or completely absent. Often a region of skin exists just below the last region of skin with preinjury levels of sensation that has some altered sensation. This area, known as “the transition zone,” typically has altered sensation and often is perceived as a source of erotic pleasure. This area often is used for sexual activity and stimulation of this area can be arousing for both partners. Individuals should be encouraged to explore their own transition zone and determine how best to receive sexual pleasure using stimulation to this area (Tepper, 2002).

**46. Explain that reflex erections may occur with either sexual stimulation or nonsexual stimuli.**

(Scientific evidence—II/III; Grade of recommendation—B; Strength of panel opinion—Strong)

**Rationale:** After acute injury, men with complete or incomplete suprasacral lesions will likely experience reflex erections in nonsexual situ-

ations following spinal shock (Deforge et al., 2006). These erections often subside within a short period of time (less than 5 minutes) and may not be suitable for intercourse. Penile stimulation from clothing, sheets, catheterization, etc., may induce reflex erections. The erection typically will subside when the external stimulus is removed. Lack of reflex erection following spinal shock may signify a lower level lesion or complicating peripheral nerve damage. Men with cervical complete lesions will likely experience a heightened occurrence of reflex erections due to loss of supraspinal control (Courtois, 1999). Because reflex erections may not prove sustainable for sexual intercourse, erection enhancement techniques may be used to assist with improving the quality and duration of erections.

**47. Explain to the individual the potential impact of injury on arousal and orgasm.**

(Scientific evidence—II/III/IV; Grade of recommendation—B; Strength of panel opinion—Strong)

**Rationale:** Persons with SCI should be counseled that achieving arousal and orgasm may take longer to achieve after injury. Although reaching orgasm after injury may be difficult for some people, research has demonstrated that the presence of spinal cord injury does not necessarily preclude the ability to do so (Sipski et al., 2001; Sipski et al., 2007). Health-care providers should apprise individuals with SCI of issues that can impair their ability to have orgasms, such as diminished sensation, level of injury, and certain medications, and encourage them to discuss any difficulties they have achieving arousal or orgasm (Sipski et al., 2006). Information about the level of injury, medical and psychological history, neurologic examination, and feedback from the person with SCI will inform the discussion. Some individuals may not have genital arousal or genital orgasm but may have the experience of arousal and or orgasm in extragenital or psychological forms. It is important for all people to remember that sexual activity does not necessarily result in orgasm. In general after spinal cord injury, achieving either a physically or psychologically based orgasm is likely to take longer, require more intense stimulation, and involve the use of fantasy, memories, and multiple sensory input (Dahlberg et al., 2007). Practice and experimentation should be encouraged.

**48. Discuss the potential ability for men to achieve ejaculation and genitally induced orgasm following SCI.**

(Scientific evidence—I/II/IV; Grade of recommendation—A; Strength of panel opinion—Strong)

**Rationale:** Many men with SCI are unable to ejaculate during intercourse but can do so via manual or partner masturbation. The use of a vibrator in either genital or nongenital areas also may significantly improve the chances for ejaculation (Heruti et al., 2001; Jadid and Ashraff, 2003; Pryor et al., 1995). Positive indications that a man will be able to ejaculate after SCI either with self or partner stimulation include degree of genital sensation and voluntary anal control, incomplete lower motor neuron (LMN) versus complete upper motor neuron (UMN) lesion, presence of a strong bulbocavernosus reflex, absence of medications that may interfere with the ejaculatory reflex (i.e., antispasmodics, such as baclofen, or antidepressants), and passage of time (during which experience and experimentation may produce positive results). Despite the difficulty associated with ejaculation, many men describe pleasurable sensations that they characterize as orgasms (Courtois et al., 2001; Courtois et al., 1999). Vibrators, designed specifically for persons with SCI, have been developed for this purpose (to retrieve sperm in clinical settings and for home use for pleasure). With stimulation, however, autonomic dysreflexia (Sheel et al., 2005) is a possibility for people with injuries at T6 and above. Health-care providers should encourage individuals and couples to remain vigilant in monitoring any symptoms of AD.

**49. Support individuals with SCI if they wish to experiment with giving and receiving erotic pleasure through touch.**

(Scientific evidence—N/A; Grade of recommendation—N/A; Strength of panel opinion—Strong)

**Rationale:** Erotic pleasure from touching, kissing, and intimate stroking is an important part of a healthy sexual experience (Stubbs et al., 2000). After spinal cord injury, sensual exploration between partners gives the couple important information about how erotic pleasure can be achieved or restored. Rehabilitation staff members should encourage intimate caressing among partners when appropriate. Often individuals with SCI and their partners need to be educated that touch on insensate areas may still be sensual, arousing, and pleasurable. Finding methods to enhance this sensual experience may take some time and experimentation. When indicated, health-care providers should encourage individuals to consider the use of alternative means of stimulation,

such as external or penetrative vibrators. Lubricants should be used as needed. The use of vibrators or pulsating shower heads, for example, for penile, clitoral, vaginal, cervical, or anal stimulation may increase arousal and the possibility of orgasm. Encouragement and discussion from health-care providers will help engender a sense of acceptance for sexual and sensual exploration.

**50. When appropriate, educate individuals with SCI that masturbation can be an enjoyable form of sexual expression.**

(Scientific evidence—III; Grade of recommendation—C; Strength of panel opinion—Strong)

**Rationale:** For some people masturbation is associated with negative societal or cultural messages. However, masturbation offers a safe method of self-pleasuring and exploration. Individuals with SCI should be counseled that masturbation is a healthy means to learn about sexual responsiveness and one's body without the potential stress of including another person (Whipple and Komisaruk, 2002). Regardless of the presence of a relationship, masturbation can be a healthy, enjoyable method to receive sexual pleasure and to enjoy the experiences of sexual arousal. Health-care providers need to convey a supportive, nonjudgmental attitude regarding masturbation and should dispel any negative myths associated with it.

## Treatment of Dysfunction

Over the past two decades, the availability of psychological and medical interventions to improve sexual function has grown considerably. In addition, medications for the treatment of sexual dysfunction generally have become universally accepted and part of the cultural landscape. Medical treatments for sexual dysfunction range from pharmaceutical agents to medical devices and surgical interventions. Psychotherapy focusing on sexuality and sex therapy is also a viable course for many people. An individual with SCI and his or her partner need to know about the available treatments that may improve and enhance sexual function and enjoyment following SCI. Many people with SCI may not have ready access to resource information on sexuality and fertility after they leave inpatient rehabilitation. Therefore, this information should be provided prior to discharge into the community and made available during subsequent follow-up care.

**51. Provide resources for sex education, counseling, and sex therapy when indicated.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Sexuality, by its nature, can be associated with discordant relationships, early trauma, and unresolved issues. Such factors may complicate sexual adjustment following injury. Working with a counselor or sex therapist may be beneficial for individuals with difficult relationships, preexisting sexual problems, or a history of sexual abuse (Dahlberg et al., 2007). In such cases, sexual intimacy often is entangled with long-standing emotional or relationship issues that need to be addressed. In the United States, sex counselors and sex therapists are certified by the American Association of Sexuality Educators, Counselors and Therapists. These professionals are trained to treat people with sexual difficulties and have experience providing suggestions aimed at improving sexual health and well-being. Many people with SCI find that professional assistance in this area is especially helpful in the months following discharge from the hospital when issues regarding sexual activity begin to surface (Fisher et al., 2002).

**52. Caution men and women with SCI about the potential risks related to services or products available without a prescription.**

(Scientific evidence–III; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Since the release of Sildenafil (Viagra) in March 1998, many over-the-counter treatments for erectile dysfunction and sexual enhancement have been marketed for consumer use. These range from herbal remedies, devices to enlarge the penis, various non-FDA approved medications, penile stretching exercises, non-FDA approved vacuum devices, and transdermal patches to improve sexual desire (Denil et al., 1996). Consumers should be aware that these devices, herbal supplements, and sexual medicines may not be as safe and effective as reported by their developers. Medications typically sold online may not be approved by the FDA, may be considered illegal by the U.S. government, and may contain unknown or potentially harmful substances. In addition, these compounds and herbal treatments often lack a list of ingredients or warning labels. Before an individual begins a regimen of online medications, a discussion with a physician should occur. In addition, before engaging in any procedures (such as penile stretching exercises or using a vacuum device to straighten a penile

curvature), medical clearance should be obtained to prevent damage to the genital tissues.

**53. Treat erectile dysfunction (ED) in men with SCI with the least invasive methods before prescribing interventions that may produce an adverse reaction. Encourage men with SCI to enhance their existing sexual function before using medical interventions.**

(Scientific evidence–III; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Before using medications or treatments to enhance erectile dysfunction, the clinician should first assess the individual's capacity to become aroused naturally. Initially, the health-care provider should discuss genital and nongenital stimulation that may facilitate arousal through unexplored neurological or psychological pathways. In addition, health-care providers should discuss treatments that can be used to address pain, spasm, incontinence, or other intervening factors. Although some methods of erection enhancement are more effective than others, decisions need to be guided with respect to individualized risk-benefit ratios and life situations. Often a man's age, financial situation, and relationship status will determine the preferred treatment for his erectile difficulties. For example, single men who are dating may prefer treatments that can be somewhat more portable, spontaneous, and natural. Thus, vacuum constrictive devices might not be a positive recommendation for this population because these often are perceived as mechanical and unnatural (Denil et al., 1996). In some cases, men who are having frequent sexual encounters may prefer oral medications, such as certain PDE5is, which have a longer half-life, allowing the man to have erectile responsiveness for up to 36 hours.

**54. Consider testosterone replacement therapy for men with SCI if a testosterone deficiency is determined to be a contributing factor in the man's sexual dysfunction or lack of libido.**

(Scientific evidence–III/V; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Sexual dysfunction and low sexual desire in men with SCI can be a result of multiple etiologies, including hormonal and neurogenic ones. Testosterone deficiency occurs commonly in men with SCI (Bauman and Spungen, 2000), especially men with chronic illness or recurrent infections that suppress testosterone levels (Tsitouras et al., 1995). Men with documented hypogonadism should be treated with testosterone

replacement therapy because testosterone deficiency can potentially affect the overall health (i.e., cardiovascular, bone health, and body fat composition), mood, fertility, and sexual function of men with SCI. Men on testosterone replacement need to be monitored with serum testosterone levels and other biochemical markers as indicated by current best clinical practices for testosterone replacement therapy.

**55. Inform men with SCI about the full range of options for treating erectile dysfunction and develop an individualized treatment plan as needed.**

(Scientific evidence—III; Grade of recommendation—C; Strength of panel opinion—Strong)

**Rationale:** Men with erectile dysfunction should be assessed for the capacity to achieve psychogenic or reflexogenic erection (Deforge et al., 2006). The man's erectile function and difficulties prior to injury should be thoroughly discussed as well. Men with SCI who are not able to attain or maintain an erection following injury need to be informed of all current medical options for treating ED, along with the efficacy, possible adverse reactions, and cost of each. This information enables the man to make informed decisions. The decision not to pursue medical treatment for erectile dysfunction needs to be respected as well.

**56. Educate men with SCI about oral medications to treat erectile dysfunction.**

(Scientific evidence—III; Grade of recommendation—C; Strength of panel opinion—Strong)

**Rationale:** Phosphodiesterase type 5 inhibitors (PDE5is) are highly effective in the SCI population, except for those individuals with cauda equina and conus medullaris injuries. These medications have an excellent safety record and have been well tolerated by men with SCI (Deforge et al., 2004). Absolute contraindications to the use of PDE5is include the concomitant use of nitrates, certain alpha blockers, or the presence of retinitis pigmentosa. Relative contraindications include symptomatic hypotension and use of other erection enhancement therapies. Sildenafil (Viagra) was approved by the FDA in 1998, and since then, two other PDE5is— vardenafil (Levitra prn) and tadalafil (Cialis prn and OD)—have been approved for use with men with erectile dysfunction. PDE5i medications prevent the intracorporal breakdown of cyclic GMP (Deforge et al., 2006), consequently enhancing the quality of erection by prolonging smooth muscle relaxation. They do not create an erection de novo (without physical or mental stimulation). PDE5is

are rapidly absorbed after oral administration and generally are taken approximately 1 to 2 hours before sexual activity. They are most effective for men who are capable of achieving reflex erections and can assist the man in gaining further penile rigidity and in sustaining the erection for penetration (Ducharme, 1999).

**57. Educate men with SCI about intracavernosal injections for the treatment of erectile dysfunction.**

(Scientific evidence—NA; Grade of recommendation—NA; Strength of panel opinion—Strong)

**Rationale:** Intracavernosal injections are commonly used when oral medications are deemed to be ineffective. With this method of erectile enhancement, the man with SCI receives an injection of alprostadil (prostaglandin E1) or alprostadil with various combinations of papaverine and phentolamine (B-mix or Tri-mix). After the man or his partner receives instruction on the penile injection method, a careful titration of the medication is used to determine the correct dose and strength of the compound to allow for an erection to occur within 5 to 10 minutes and last approximately 1 hour. Some men with sensation in the penis may experience a short period of minor pain at the injection site, which can be reduced with proper injection technique. Care should be given to avoid penile scarring at the injection site. This can be accomplished by maintaining pressure on the site for a period of several minutes. Priapism is another potential complication of injection therapy. Priapism is the potentially harmful medical condition in which the erect penis does not return to its flaccid state despite the absence of physical and psychological stimulation within 4 hours. Men with SCI should be informed that priapism is considered a medical condition that should receive proper treatment by a qualified medical professional.

**58. Educate men with SCI about vacuum devices for the treatment of erectile dysfunction.**

(Scientific evidence—III; Grade of recommendation—C; Strength of panel opinion—Strong)

**Rationale:** A vacuum constrictive device (VCD) consists of an elongated tube that is placed over the shaft of the penis. A vacuum is then created in the tube either by a battery operated device or manual pumping action. As the vacuum is created, blood gradually fills the corporal chambers of the penis. When the penis achieves a satisfactory degree of rigidity, an elastic penile

ring is slipped off the tube and placed over the base of the penis to contain the blood and maintain the erection so that sexual intercourse can occur. The individual with SCI must transfer out of his wheelchair and be in a recumbent position to obtain a good vacuum seal at the base of the penis. The constriction ring should never be left in place for more than 30 minutes. The device is considered economical and effective; however, it requires some degree of manual dexterity. For many men with tetraplegia, the partner must assist with the procedure. Vacuum devices tend to be more accepted by men in established sexual relationships where spontaneity is not a major issue. Complaints regarding the vacuum device range from unnatural erections, coldness of the penis, pain, and lack of spontaneity (Denil et al., 1996). However, VCDs are contraindicated for men with SCI who are taking blood thinners or who have been diagnosed with sickle cell disease. VCDs have lost some of their popularity as new methods for treating ED have become available.

**59. Educate men with SCI about using intraurethral medications to treat erectile dysfunction.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** Intraurethral medications currently are considered to be ineffective in men with SCI and are seldom prescribed. They consist of a vasodilating agent, usually alprostadil, in the form of a pellet that is delivered into the man's urethra prior to sexual intercourse. Complaints regarding these medications have ranged from burning sensations, pain during urination, poor-quality erections, and lack of erection consistency. A constriction ring placed at the base of the penis may allow for more effective medication containment. Although intraurethral medications have been popular in the past, they are less available and have been found to be less effective than intracavernosal injections in the SCI population (Ducharme, 1999).

**60. Provide information about penile implants for the treatment of erectile dysfunction (also known as implantable penile prostheses) when nonsurgical treatments are ineffective or unsatisfactory.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Although penile implants can be highly effective and satisfying, they remain the last option for restoring sexual function. The insertion

of an implant destroys the tissues of the corporal bodies; therefore, this alternative is used as a last resort because other reversible methods of erectile enhancement would then be ineffective if the implant subsequently were to be removed (Gross, 1996; Zermann et al., 2006).

There are two types of implants on the market: a silicone malleable prosthesis and a more complex inflatable hydraulic prosthesis. The malleable prosthesis consists of two bendable rods, which are surgically implanted in the corporal chambers of the penis. With the malleable device, the penis is always semirigid and needs only to be moved into the right position for penetration. The malleable implant can be helpful in keeping a condom catheter in place; however, it is less popular because it maintains the penis in an erect state, which may have cosmetic disadvantages.

The inflatable implant consists of a pair of inflatable cylinders that are surgically implanted into the erectile chambers. A pump for the implant is also surgically inserted into the scrotum. A reservoir for the pump fluid is placed within the abdominal cavity. In what is referred to as a two-piece inflatable implant, a scrotal fluid reservoir is substituted for the abdominal reservoir. When a man desires an erection, he or his partner squeezes the pump, which moves fluid (usually saline) into the inflatable cylinders and allows the cylinders to become rigid. When deflated, the penis returns to a naturally flaccid state (Gross et al., 1996).

**61. Discuss the potential risk of penile trauma for men with SCI.**

(Scientific evidence–III; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Due to diminished or absent sensation, men with SCI are at a higher risk for penile bending (Peyronie's disease) secondary to trauma of the tunica albuginea that surrounds the corpora cavernosa. During vigorous thrusting of the penis, unintentional blunt force on the erect penis, which would normally be very painful, may go unnoticed in men with diminished or no sensation. This force can tear or stretch the tunica, causing scarring and plaque formation (curvature), which is palpable by physician examination. Trauma from injections into the cavernosal tissue through the tunica (for erection enhancement) may cause inflammation. This may result in tunica scarring, microhemorrhage along the needle track, and calcium deposits, which may lead to penile curvature (Deforge et al., 2006). Consultation with a urologist is necessary if the curvature exceeds 30 degrees and/or if Peyronie's disease is suspected.

**62. Inform women with SCI about external devices that are available to enhance genital arousal and orgasmic potential.**

(Scientific evidence—III; Grade of recommendation—C; Strength of panel opinion—Strong)

**Rationale:** Preliminary research suggests that the ability of women with SCI to achieve orgasm may be improved through the use of a clitoral vacuum suction device (Eros™) that is FDA approved to treat orgasmic dysfunction in women (Sipski et al., 2007). This suction device improves sexual response by increasing blood flow to the clitoris and external genitalia. Commonly, such a device uses a cuplike apparatus that is placed over the clitoris. When a vacuum is created, increased blood flow creates clitoral engorgement. Increased blood flow to the genitalia often results in increased vaginal lubrication and enhanced ability to achieve orgasm.

## Effects on Fertility

When individuals of reproductive age sustain a spinal cord injury, they often are concerned about their biological ability to have children. Although the reproductive functions in men (erection, ejaculation, and semen quality) often are affected by SCI, there are effective interventions for retrieving sperm (e.g., assisted ejaculation, vibrostimulation, electroejaculation, and aspirative sperm retrieval) and implanting sperm (e.g., intravaginal or intrauterine insemination, in vitro fertilization, and intracytoplasmic sperm injection). Once women regain menses, their reproductive function is usually unaffected by the injury. Most women with SCI can successfully conceive, carry, and deliver a baby; however, there are complications related to pregnancy and delivery specific to women with SCI (e.g., increased risk of urinary tract infections, autonomic dysreflexia, changes in respiratory function, and biomechanical issues), which necessitate that an SCI specialist oversee the pregnancy. Assertive interventions to maintain good physical health and safe wheelchair positioning during pregnancy are essential. Thus, the proactive and informed health-care provider should be a major participant in the adjustment and positive approach to fertility issues after SCI.

### Female Fertility

**63. Ensure that women with SCI have proper information regarding the effect of injury on menstruation.**

(Scientific evidence—IV/V; Grade of recommendation—C; Strength of panel opinion—Strong)

**Rationale:** Women with SCI may experience exacerbated premenstrual and menstrual symptoms (such as dysmenorrhea and cramping) compared to uninjured women. Anti-inflammatory agents, such as naproxen, ibuprofen, or mefenamic acid, can alleviate these symptoms. In women with SCI, premenstrual symptoms may include increased autonomic symptoms (sweating, flushing, headaches, or goose flesh), frequent bladder spasm, and worsening of muscle spasticity. Menstrual length does not appear to change postinjury. Thus, any alterations in the menstrual cycle (after the initial months of amenorrhea have passed) should be investigated. Hormonal and psychological effects of SCI on premenstrual syndrome per se have not been studied adequately (Jackson and Wadley, 1999). Because the return of menses often occurs after the woman has been discharged from rehabilitation (6 months postinjury), information on the application and management of feminine hygiene products should be included in early postinjury care. Such education might include the use of mirrors to observe insertion as well as the use of splinting to improve hand function. Some women also may benefit from counseling on how to instruct attendants to assist with these products (Reamme, 1992).

**64. Ensure that women with SCI are informed about reproductive health, obstetric, and gynecological services specific to their needs.**

(Scientific evidence—IV/V; Grade of recommendation—C; Strength of panel opinion—Strong)

**Rationale:** Gynecological complications in women with SCI include problems common to all women as well as issues specific to women with SCI. Some women with SCI may not experience symptomatic complaints or they may have insufficient information to prompt them to seek appropriate gynecological care (Jackson and Wadley, 1999). An apparent lack of attention to reproductive and gynecological health care for women with SCI in the health-care community raises the concern that these women are not receiving preventative health-care services. Health-care providers should emphasize the importance of routine gynecological procedures and screenings. Physical barriers, such as inaccessible offices, and a lack of information about gynecological issues postinjury may delay screening and subsequent diagnosis of certain types of gynecological cancers and sexually transmitted diseases (Welner, 1998). Regular sexual health care, including annual pelvic exams, screening and testing for breast cancer, and

menopausal education and care, must be a part of the comprehensive health care provided to women with SCI (Welner, 1999).

**65. Determine the safest birth control method for the woman with SCI. Risks associated with birth control methods should be assessed and discussed with the woman.**

(Scientific evidence–IV/V; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** More than 70 percent of women use birth control after SCI, with a preference for condoms, followed by permanent sterilization and oral contraceptive pills (OCPs) (Jackson and Wadley, 1999). The available data do not indicate that risks associated with OCPs are greater in women with SCI. OCPs and other forms of hormonal birth control (i.e., depot-medroxyprogesterone acetate (DPMA) injections or subdermal implants) must be prescribed with caution and avoided altogether in women within 1 year of injury, women who smoke, and women with a history of cardiovascular or circulatory problems (Jackson and Wadley, 1999). DMPA may have the advantage of reducing menstrual flow, but it contributes to bone loss, which is already a problem after SCI. Barrier methods, such as intrauterine devices, are associated with higher risk of pelvic inflammatory disease, which is exacerbated in women with SCI due to their susceptibility to frequent urinary tract infections and the inability to detect pain. Diaphragms (which must be kept in place for 6 hours), cervical caps, and vaginal sponges require hand dexterity, and the prolonged pressure of a diaphragm may create vaginal wall breakdown. Basal body temperature methods of birth control are not recommended for women with SCI (Reame, 1992). Important medical considerations include quality of circulation in the lower extremities, clotting abnormalities, remaining genital sensation, manual dexterity, and potential problems with menstrual hygiene.

**66. Provide women with SCI information about fertility and pregnancy.**

(Scientific evidence–II/IV; Grade of recommendation–B; Strength of panel opinion–Strong)

**Rationale:** Research has shown that the quality of life for a woman with SCI increases after childbirth despite the additional demands and challenges of raising a child (Westgren et al., 1993). Still, women with SCI face unique problems associated with pregnancy; these issues should be discussed so that women can make informed decisions if they are considering becoming

pregnant. Women with SCI have reported receiving little information about pregnancy postinjury and the information provided often is found to be inadequate (Ghidini et al., 2008). For example, pregnant women with SCI have an increased risk of urinary tract infections, a significant risk of experiencing autonomic dysreflexia, potential changes in respiratory function, and specific biomechanical needs related to being in a wheelchair. Health-care providers should advise women to consult with a specialist before making a decision regarding pregnancy. Some women with SCI will need extra assistance during pregnancy for such activities as transfers, dressing, monitoring skin surfaces, and bowel and bladder care. In addition to the physical challenges, there are psychological demands that need to be considered, such as the emotional aspects of the pregnancy as well as the psychological issues of raising a child while using a wheelchair (Westgren and Levi, 1994). Health-care providers should apprise women with SCI of the possibility of developing postpartum depression (Ghidini et al., 2008) and inform them of the associated signs and symptoms.

**67. Outline the steps that can be taken to ensure the best medical outcomes for the pregnant woman with SCI. Recommend that a medical provider with SCI expertise be involved throughout the pregnancy.**

(Scientific evidence–II/IV; Grade of recommendation–B; Strength of panel opinion–Strong)

**Rationale:** Prenatal care should begin as soon as the mother decides to have a child. Early involvement with an obstetrician is critical in order to provide the mother with information on nutritional needs and medication compliance, particularly if the woman is taking medications for health issues related to SCI (Westgren and Levi, 1994). For most women with SCI, weight gain, skin breakdown, immobility, bladder and bowel incontinence, digestion issues, and respiratory difficulties may accompany pregnancy (Ghidini et al., 2008). All pregnant women should eat properly and refrain from smoking, drinking alcohol, or using any illegal substances or medications not approved by their obstetrician.

**68. Ensure that wheelchair seating will allow for an upright seated posture with proper alignment throughout pregnancy; this will require repeated adjustments to the wheelchair.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** It is imperative that a seating specialist be involved in adjusting wheelchair seating throughout pregnancy because is necessary to sequentially increase the inside seat-to-back angle to allow for the increasing abdominal mass. Similarly, maximizing respiration and maintaining an upright-seated posture is achieved by maintaining a near vertical backrest and progressively reversing the seat plane so that by the final trimester there is a downward slope (front lower) of the seat. This is especially important for women with truncal paralysis. Conversely, the seating configuration needs to be reverted to the original appropriate orthotic wheelchair support postpartum. If the woman has two wheelchairs, it is ideal to have one chair progress through her pregnancy and the other set in the proper orthotic configuration for her postural needs after pregnancy. Throughout the pregnancy, the cushion interface should be monitored to ensure that adequate pressure distribution is maintained given the added weight and change of body habitus.

**69. Ensure the implementation of safe transfers during pregnancy.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** During pregnancy, a woman is heavier and her movements are more cumbersome. The basic mechanics of leaning forward and flexing over the hips for transfer are impeded by the mass of the pregnant abdomen. Protection of the upper limbs and skin may require changes in transfer techniques. Physical therapists and other health-care providers should consider changes or modification of either equipment or the environment in order to lessen the physical demands of transfers during pregnancy. Women with SCI should be encouraged to seek a rehabilitation consultation regarding transfers should they become pregnant following initial rehabilitation.

**70. Regularly assess the status of activities of daily living to ensure that safe and efficient movements and positioning are being used during pregnancy. Determine if assistive devices need to be modified or changed.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Previously learned techniques and strategies for movement may be ineffective during pregnancy because of changes in size, shape, and weight distribution. For example, some women who previously were able to enter the tub without assistance may need a tub bench, and other women who previously used a tub bench may require a

roll-in shower chair. Indwelling catheters may need to be replaced by intermittent catheterization and bowel programs may need to be adjusted. Women who typically use a standard bed may require a hospital bed at some time during pregnancy. Seatbelts and other driving equipment may have to be moved or adjusted to accommodate changes in size. Joints are more at risk during pregnancy, particularly during the last trimester, due to hormonal changes that increase laxity. With such issues in mind, health-care providers should provide assessment and education as deemed necessary throughout the pregnancy. Informed discussions regarding seating and transfers help the pregnant woman with SCI to be aware of her own body mechanics and self-care needs. These needs change throughout pregnancy and a woman's ability to adjust accordingly is critical. Physical and occupational therapists are good resources for these activities and related education (Sakellariou and Sawada, 2006).

**71. Plan for labor and delivery to accommodate the particular needs of the woman with SCI, and carefully monitor the potential onset of autonomic dysreflexia during labor and delivery.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Women with SCI should discuss with their obstetrician exactly how labor and delivery will be managed. The woman should be checked frequently for effacement and dilation of the cervix beginning at 28 weeks of gestation. In some cases early hospitalization may be necessary (Jackson, 1999). Diminished sensation and absence of pain may result in unrecognized conventional labor symptoms or atypical labor symptomatology, especially in women whose levels are T10 and above (Jackson, 1999). The health-care provider should explain these phenomena to the woman so she can recognize them. For many women with SCI, the most critical complication of labor and delivery is autonomic dysreflexia. Autonomic dysreflexia must be differentiated from preeclampsia (which occurs with the same frequency in both able-bodied women and women with disabilities) so that it is not misdiagnosed. Use of general or epidural anesthetics may assist with reduction of AD risks. Delivery also can be complicated by hip disarticulation, contractures, heterotrophic ossification, and severe spasticity. Because of the potential for complications, the use of forceps, vacuum extraction, and caesarian section is greater among women with SCI than it is in the able-bodied population (Jackson 1999).

## **72. Educate women with SCI about the effects of perimenopause and menopause after SCI.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Studies have demonstrated that there are no significant differences in the menopausal symptoms of women with SCI and those without SCI (Dannels and Charlifue, 2004). Nevertheless, clinical experience shows that within the SCI population, women with incomplete injuries tend to have more night sweats than women with complete injuries and women with paraplegia have reported more bleeding than women with tetraplegia. Other symptoms commonly observed with menopause include depressed mood or fluctuations in mood, headaches, difficulties with sleep, hot flashes, memory problems, bladder changes, dryness of the mucosal surfaces, and changes in skin. For women with SCI, many of the indications of menopause tend to mimic or mask the physical symptoms commonly associated with SCI. As a result, treatment for SCI-related conditions may be delayed if a woman mistakenly believes her symptoms are a result of menopause rather than the injury. For this reason, women with SCI need to be aware of menopausal changes so that their health status may be monitored for secondary complications (Dannels and Charlifue, 2004). Women should be advised to report all menopausal symptoms to a health-care provider.

## **Male Fertility**

### **73. Discuss the prognosis for biological fatherhood and options for assisted fertility.**

(Scientific evidence–I/II/III/IV; Grade of recommendation–A; Strength of panel opinion–Strong)

**Rationale:** Most men with SCI will experience some erectile and ejaculatory difficulties. As a result, assistance with fertility for biological fatherhood is often necessary (Brackett et al., 1998a, Yamamoto et al., 1997; Rutkowski et al., 1999; Salsabili et al., 2006; Shieh et al., 2003, Brackett et al., 2007, Brinsden et al., 1997). For men with incomplete lesions, natural ejaculation and insemination with vaginal intercourse may be possible. For couples considering pregnancy, such factors as semen retrieval (Engin-Uml Stun et al., 2006), quality of semen (Naderi and Safarinejad, 2003)(often decreased after SCI), partner fertility, and availability and affordability of assisted reproductive techniques (ART) need to be considered. The prognosis for biological fatherhood is relatively promising if semen can

be obtained and assisted reproductive technologies are used. Options for semen retrieval include natural ejaculation with masturbation or the use of sympathomimetics drugs and nonvibrostimulatory methods, such as a shower head (Sonksen, 2003). Other methods of sperm retrieval include vibrostimulation (Claydon et al., 2006) and electroejaculation (Heruti et al., 2001). The use of vibrostimulation to retrieve semen has resulted in ejaculation response rates as high as 95 percent and reports have shown pregnancy rates of about 50 percent and live birth rates of 40 percent for partners of men with SCI (Deforge, 2006; Deforge et al., 2004). Electroejaculation is used only in clinical settings when a physician is available to perform the procedure. Note that the vast majority of men with SCI prefer vibrostimulation rather than undergoing electroejaculation for semen retrieval (Ohl et al., 1997). Surgical sperm retrieval can be used if less invasive procedures are not possible or are ineffective (Lochner et al., 1997). ARTs involve processing the retrieved sperm for placement in the uterus (Pryor et al., 2001) or extracting individual sperm (Chen et al., 1999) to combine with extracted eggs for in vitro fertilization (IVF) and/or intracytoplasmic sperm injection (Chen et al., 2005; Chen et al., 1998, Chung et al., 1998). In general, the more sophisticated the ART, the higher the chance per attempt that conception will occur (Deforge, 2005).

### **74. Perform semen analysis for men interested in biological fatherhood in order to provide information and make recommendations for achieving pregnancy.**

(Scientific evidence–I/III/IV; Grade of recommendation–A; Strength of panel opinion–Strong)

**Rationale:** Generally, sperm concentration for men with SCI is within normal limits although motility often is compromised (Das et al., 2006; Ohl et al., 1996). Semen quality is improved in anterograde versus retrograde specimens. In addition, semen quality is typically higher with vibratory stimulation than with electroejaculation. Studies have demonstrated that there is little difference in semen quality with the use of high-versus low-amplitude stimulation via variable-speed vibrators (Basu et al., 2004; Brackett et al., 2000; Brackett et al., 1998b, Brackett et al., 1997).

## **For Men and Women**

### **75. Provide education about adoption as an option for some individuals with SCI.**

(Scientific evidence–II; Grade of recommendation–B; Strength of panel opinion–Strong)

**Rationale:** For women who decide not to become pregnant or couples who cannot conceive, parenthood is still possible with adoption or, in some cases, individuals may meet partners who already have children. Persons with SCI can be positive role models and successful parents following injury regardless of a biological connection to the children with whom they develop a bond (Westgren and Levi, 1994). Health-care providers can be an important support system for persons with SCI who are considering alternatives to biological parenthood.

## Relationship Issues

The occurrence of a spinal cord injury can have a dramatic effect on most relationships. The medical complications associated with the injury as well as mobility and sensory changes can easily affect feelings of self worth and self-esteem. In addition, asking for and receiving assistance from others can be emotionally difficult. As a result, people with SCI initially may find that social interactions are more challenging and intimidating. Relationships with intimate partners, family members, and others may be strained. Open and honest communication can be very difficult during these times. Furthermore, during these times of emotional instability and uncertainty, strong emotional support should be provided to people with SCI and those with whom they have close relationships. In addition to the emotional support, information, education, and counseling related to sexuality, social skills, and interpersonal relationships can help in facilitating a return to the family and the community.

### **76. Encourage individuals with SCI to discuss any concerns that they may have regarding relationships postinjury.**

(Scientific evidence–III/IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Clinical experience has demonstrated that early on after spinal cord injury, many individuals develop concerns regarding the stability of their relationships (Kreuter et al., 1996; Phelps et al., 2001; McAlonan, 1996). These concerns may relate to such issues as dependency, parenting, role in the family, fears of becoming a burden, and sexual ability. Such fears are almost universal and can prevent open and honest communication between the individual with SCI and his or her significant other. Health-care providers should help persons with SCI identify any relationship issues that emerge following the injury. Open communication between a couple and helpful suggestions from providers can begin to alleviate

undue anxiety and stress. In some cases, referrals to counselors, psychologists, psychiatrists, members of the clergy, or family therapists will be warranted.

### **77. Provide opportunities for people with SCI to include their partners in discussions regarding intimacy, sexuality, and fertility.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Although there are many emotional challenges for couples following SCI, open communication, honesty, and trust can assist a couple through difficult times (Phelps et al., 2001; Reitz et al., 2004; Richards et al., 1997). For couples to effectively discuss their relationship and resumption of sexual activity, both partners need to have accurate information about how the injury affects sexual function. Without this information, many partners may be misguided in understanding how sexual function can be maintained and enjoyed following injury. As appropriate, partners of individuals with SCI should be given the opportunity to participate in as many educational and counseling sessions as possible. Health-care providers should always be considerate of the couple's decision as to how much information they want to receive regarding sexuality and fertility.

### **78. Provide opportunities for partners to ask questions and get information about sexuality and fertility whenever possible. In so doing, providers must protect the confidentiality of both parties.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Partners of people with SCI typically need information about sexual function after injury (Westgren et al., 1997). Partners often express fears of further injury, questions regarding sexual responses, and a lack of knowledge as to when it is safe to resume sexual and intimate contact. Partners need opportunities to express their concerns and receive accurate information. If a partner lacks such basic information regarding sexual function, the sexual adjustment of the person with SCI can be negatively affected. In some cases, the partner's lack of information may result in added conflict within the relationship or a termination of the relationship. Providers should allow ample opportunities for partners to ask questions and get information concerning how sexuality, fertility, and relationships are impacted by the injury. Confidentiality for both members of the couple needs to be maintained at all times unless documented otherwise in the medical record.

**79. Assist with education and problem solving for people with SCI who may be interested in a sexual relationship with another person who also has a disability.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** The role of the health-care provider is to be supportive of relationships regardless of disability. There are many reasons why a person with SCI may choose to have an intimate relationship with another person who has a disability. Having a sexual relationship with another person who has a disability is best accomplished when both individuals have information and education about the specific medical and functional issues related to their disabilities. These issues may include positioning, bladder care, pain, mobility, responsiveness, self-care, sensation, and ways to achieve arousal. When both individuals in a relationship have a disability, it will be especially important for them to be able to communicate their needs to each other and seek outside assistance at certain times (Richards et al., 1997).

**80. Discuss the maintenance of healthy interpersonal relationships that existed prior to injury. Assist individuals with developing social skills that will promote healthy interpersonal and sexual relationships.**

(Scientific evidence–IV; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** After an injury, many people experience anxiety around old friends and have difficulties maintaining long-standing relationships. Communication may be strained and important issues often are avoided. For people with SCI, meeting a new person, dating, and developing an intimate relationship pose specific challenges that will need to be addressed, such as medical issues, accessibility, transportation, finances, and personal care. Feelings of depression, negative body image, shame, and anxiety can affect how individuals with SCI relate to other people. People with SCI who were shy and had difficulty forming relationships prior to the SCI may find it even more daunting after the injury. Health-care providers should assist individuals in obtaining the social skills necessary to develop and sustain interpersonal relationships. For single people with SCI, asking for assistance and being able to explain the injury are important skills that will help them develop intimate relationships. The ability to communicate effectively and maintain a positive sense of self-esteem is critical in becoming sexually active. Issues surrounding

meeting potential partners, dating, and feeling attractive should be addressed (Byfield et al., 1999). Peer counselors, members of local independent living programs, and other people with SCI can be important role models for newly injured people.

**81. Offer guidance on using the Internet to meet potential partners for intimate relationships and marriage.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** The Internet offers people with SCI access to others who are looking for love and relationships (Tepper and Owens, 2002). Many websites provide opportunities to develop online profiles highlighting personal qualities, characteristics, likes, dislikes, and the kind of relationship desired. There are some websites specifically for individuals with disabilities. Sometimes people meet potential partners through other online forums, such as discussion groups or gaming sites. Increased access and exposure online can lead to exploitation of anyone, but especially a person with SCI if too much personal information is disclosed, so caution and discretion should be advised. Generally accepted online dating precautions should be taken, including recognizing that information provided online may not be true, not publishing or providing personal identity information, and looking for inconsistencies in information provided. The decision to arrange an in-person meeting with someone presents more serious risks and standard precautions should be observed, including using a public phone or caller identification service, meeting in a public place, bringing a friend, and always informing a trusted friend or family member regarding plans. In general, advise individuals of the dangers of leaving a public place to go to a private location, such as a car or home, until there is reason to feel completely confident about safety (especially on the first meeting).

**82. Encourage individuals with SCI to develop and/or maintain positive relationships with their children.**

(Scientific evidence–II/III/V; Grade of recommendation–B; Strength of panel opinion–Strong)

**Rationale:** Child rearing, as defined by the American Occupational Therapy Association, is “providing the care and supervision to support the developmental needs of a child.” Parents with SCI can provide this level of care, and studies have demonstrated that having a parent with SCI has no detrimental effects on the development of a child (Alexander et al., 2002). Many of the critical

skills of parenting are verbal, supportive, and psychological in nature and can be continued regardless of level of SCI (Westgren and Levi, 1994). For example, providing assistance with homework, attending sports or school activities, and helping children develop self-discipline can all be accomplished by a parent with SCI. Some physical activities may be more challenging, especially with infants and small children. Adaptive techniques for diapering, feeding, dressing, and playing with the child can be implemented. Sometimes the parent with SCI can work with his or her attendant or partner to be the “hands” of the parent while the parent with SCI is directing the activity. Changing traditional gender-related activities also may be helpful. For example, mothers may help with tossing a ball while fathers may read stories (Alexander et al., 2007).

### **83. Support the individual with his or her reintegration into the family.**

(Scientific evidence–V; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** Healthy sexual adjustment is closely related to feeling positive about one’s role as a man or woman (Ducharme, 1999). Initially after an injury, many people are not aware that they will be able to return to their previous roles as wife, husband, or parent. Although roles may be altered, relationships can remain strong and continue to provide a sense of meaning and fulfillment. The person with SCI should be provided with ideas about how to redesign old skills and develop new skills within their desired roles. For example, parents can learn alternative child-rearing activities, such as assistance with reading, tutoring, computer games, or verbally coaching while the child is engaged in physical activity. Frequently, spouses have to assume the role of caregiver, which can interrupt their preinjury role. Integration of new and old roles may be accomplished more easily with education and counseling (Miller and Marini, 2007).

### **84. Ensure that individuals with SCI receive counseling that promotes a positive body image and encourages a respect for one’s body after SCI.**

(Scientific evidence–V; Grade of recommendation–C; Strength of panel opinion–Strong)

**Rationale:** After an injury, one’s body perception may be altered. Sexual function is often negatively impacted by poor body image. Helping individuals with SCI improve their perception of body image should be a regular

part of the clinical interaction (McBride and Rines, 2000). Examples to promote a positive body image after SCI include:

- Encouraging individuals with SCI to choose comfortable clothes that help them express their individuality. With the help of staff members and peers, educate people with SCI about different ways to modify clothing to accommodate any special needs (e.g., bladder or bowel equipment, respiratory equipment, individual wheelchair specifications).
- Reassuring the individual with SCI that if he or she enjoyed activities related to personal grooming before the injury, those activities can still be enjoyed.
- Ensuring that individuals with SCI are as comfortable as possible with equipment, such as leg bags, bladder management systems, respiratory devices, etc.
- Incorporating choices regarding the type of wheelchair, color, and appearance.
- Encouraging exercise depending on the individual’s ability, which can be physically beneficial as well as uplifting for one’s self-esteem.
- Helping individuals with SCI articulate positive aspects about themselves into conversations, for example, encouraging the individual with SCI to articulate his or her interests, activities, likes, and dislikes.

### **85. Discuss options for providing assistance for activities of daily living from someone other than the romantic partner.**

(Scientific evidence–N/A; Grade of recommendation–N/A; Strength of panel opinion–Strong)

**Rationale:** Partners who also provide physical assistance to persons with SCI can develop physical or emotional “burnout” that may negatively affect sexual relationships. An evaluation of relationship priorities and economic resources available to improve this type of situation should be a part of usual care. Both partners must understand and communicate about the physical and emotional demands related to SCI. Often partners of persons with SCI may feel guilty in addressing their own needs and their own mental health. Whenever possible, personal care should be provided by someone other than a romantic partner or significant other to help prevent partner “burnout” and maintain romantic feelings in an intimate relationship.

# Recommendations for Future Research

There has been a paucity of research in the field of sexuality and SCI. Frequently, information about sexuality has been obtained primarily through clinical experience, anecdotal information, and personal communication. Further empirical research in this area is imperative to improve quality of life following SCI. The following areas were identified by panel members as issues requiring further study:

- Determine the optimum time during inpatient rehabilitation or at follow-up to provide information and counseling for issues related to sexuality and reproductive health.
- Evaluate methods to improve the comfort level of staff members in addressing sexual issues for people with SCI.
- Determine characteristics of successful intimate relationships for people with SCI.
- Determine if counseling in the area of self-esteem and body image increases sexual satisfaction.
- Determine if being in a loving, supportive relationship increases the general health of a person with SCI.
- Explore how techniques of sex therapy can be applied to individuals with SCI and their partners.
- Further evaluate the role of SCI on testosterone levels.
- Explore sacral nerve stimulation and functional neuroimaging techniques to improve sexual arousal and orgasm for people with SCI.
- Learn whether the pathways for orgasm in women with SCI differ from men with SCI.
- Develop additional oral medications to improve erections for men with SCI who do not respond to currently available medications.
- Evaluate the effectiveness of a combination of interventions for erectile dysfunction versus single agent treatment.
- Conduct controlled studies that compare the efficacy of erection enhancement methods.
- Explore the potential of stem cell research to alter the function of erectile tissue in men with SCI.
- Conduct studies to develop predictors and best methods of effective sperm retrieval.
- Understand the impact of SCI with concurrent brain injury on the expression of sexual function after SCI.
- Determine variables influencing age-related changes in the sexual health of individuals with SCI.
- Determine what physical abilities (ability to drive a vehicle, ability to transfer independently, ability to dress independently, ability to independently manage bladder or bowel, etc.) may predict high levels of self-efficacy in sexuality.
- Evaluate safety issues for couples who utilize wheelchairs or shower chairs for sexual activity.
- Determine the level of comfort with training for sexual positioning in individuals with SCI among currently practicing physical therapists.
- Investigate what occupational therapy interventions may assist with relationship building.
- Understand the sexual development of young, inexperienced adolescent boys and girls post SCI.
- Explore the sexual health behaviors of gay, lesbian, bisexual, and transgendered individuals following SCI.
- Conduct studies to better understand the issues faced by gay, lesbian, bisexual, and transgendered individuals with SCI in the community.
- Conduct studies to determine obstacles for remaining sexually active after SCI.
- Conduct studies to determine the safest and most effective forms of birth control after SCI.

# References

The following list of references includes all sources used by the guideline development panel to support their recommendations. It provides the level of scientific evidence (I–V or NA) for each graded article. A graded article is one that was evaluated by the methodologists to determine whether it met the inclusion criteria established by the panel. If an article is labeled “Scientific Evidence–NA,” it was evaluated by the methodologists but did not meet the level of evidence criteria. If a citation is not labeled, it was not evaluated by the methodologists. Citations labeled NA or unlabeled were included because the panel believes they enhance understanding of the guideline.

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