

Intimacy and AS

by Michael Mallinson

Let's not hold back on this. You've got Spondyloarthritis and your back and some of your other joints hurt, a lot. You've also noticed that you've lost some flexibility and simply can't get into the positions you used to be able to. Furthermore, what with the fatigue and bouts of depression, you don't feel like doing 'it'. But you are still young and you know it's healthy for couples to have regular sexual intercourse. What's to be done?

At the American College of Rheumatology's annual meeting in November, 2016, Iris Zink in her presentation, 'Sex and Intimacy in Chronic Disease' offered some advice. As a nurse practitioner with a speciality in rheumatology, Ms. Zink noted that sexual dysfunction is often the first manifestation of physical illness. Yet few health care practitioners bring up the subject with their patients, many of whom are also too embarrassed to talk about it.

They shouldn't be. For people with Ankylosing Spondylitis and other rheumatic diseases, not only may their disease cause pain with sexual activity but their medication may be causing sexual impairment. A survey of patients with arthritis showed almost one-fifth said they were unable to engage in sexual intercourse due to limitation from arthritis.

Ms Zink's message is that sexual intimacy doesn't have to involve intercourse, pointing to the fact that the brain and the skin are the largest sexual organs. A lot of intimacy can be enjoyed by hugging and caressing and sexual stimulation that does not involve intercourse. In some cases, people have to overcome cultural or religious taboos to practice forms of intimacy that they may otherwise regard as out of bounds. Everything about sex and intimacy is normal and some patients may need to be taught how to be more creative. Communication between partners is crucial, as is a willingness to experiment.

In the Facebook group of the Canadian Spondylitis Association, there have been discussions on intimacy and finding a position that is not painful. The missionary position (man on top) is painful for both men and women with ankylosing spondylitis, so the cowgirl position (woman on top) may be better. A physical

therapist may be required to provide treatment for functional activities, such as the female AS patient Ms. Zink came across who admitted that she could not open her legs wide enough to allow for sex. Physical therapists can also offer advice on modifications in positioning.

A healthy sexuality, of which there are many forms, is key to a normal, happy relationship. Any sexual dysfunction such as those caused by disease or medications can impact not only people's quality of life, but lead to frustrations and a backing away from intimacy. This is a pity. Everyone suffering from Ankylosing Spondylitis and other rheumatic diseases should be able to discuss their situation openly with their rheumatology health care team. The health care team in turn should be prepared to discuss intimacy and offer advice and treatment options.

Some of the advice can address the top myths about sexuality, such as sex always equals intercourse and the goal of sex is orgasm. Another myth is that there comes a time when sex is not important. In Ms. Zink's view sex is as important at 80 as at 20.

For people living with Ankylosing Spondylitis it is important to not feel that their health and any physical challenges no longer make them sexy. After all this is a young persons' disease and strikes men and women in the prime of their lives, usually before age 35. Who wants to give up on sex and intimacy when there are decades of life left? Key to a continuing healthy sex life is a sense of humour, proper communication and a taste for adventure. Don't give up! As Ms. Zink said to the gentleman who complained his arthritis had made him unable to have an erection and therefore he couldn't keep his wife happy with sex, "What, you don't have a tongue?"!

Michael Mallinson has lived with AS for over 35 years. He developed this content as a consultant to Novartis Pharmaceuticals Canada Inc. No payment was received.

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