

Resource

Sex, drugs and RA

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About the authors

Tanya and her husband Paul, have been living with Tanya's rheumatoid arthritis (RA) for approximately 12 years.? Tanya is a working mother of two, and a patient research partner. She has been involved in setting up and co-organising education for both newly diagnosed patients and medical students. ?

Paul works full time as a manager in a demanding job that involves long hours and travelling.

Julie Taylor is a clinical nurse specialist and Senior Lecturer, her PhD was based around the patients' diagnoses.

"I relied on my husband for both physical and emotional support, which at the time, I found very hard as I had always been so independent and hated asking for help... I was scared about the future, and I felt like a useless wife..."

Introduction

Sex, Drugs and RA: What a combination, and probably not an opening you would expect from a consultation.? Being diagnosed with a long-term condition requires adjustment and acceptance in all areas of life, including the impact that it has on relationships, intimacy and sex.? Whether you are male or female, in a short or long-term partnership or married, intimacy is a way of making us all feel both special and individual and is also an important way of promoting our self-esteem.? In this modern world sex and sexuality is everywhere, from the increasingly explicit sex on television to the easy-access on the internet, through to the articles on how to "wow" your partners and also how frequently you should have sex.? Yet despite all this "sexual freedom" when it comes to the consultation and RA, how often do we acknowledge sex as a problem or even a topic to be explored?

The literature suggests that over half of patients admit to sexual problems, yet as a nurse specialist, I certainly do not talk sex with this many patients in clinic. I see myself as open and strive to give patient-centred care yet tend to talk about relationships when the damage is irreparable or when it is based around pregnancy and fertility issues. Rheumatology teams pride themselves on having a person-centred approach to the services they offer their patients, yet perhaps this is one area that we are still not very good at.

Ideally, in this modern world with the numerous pressures that relationships have to put up with, sex is important, and as healthcare professionals, we should acknowledge that it's part of life and holistic care.? Any long-term condition, such as rheumatoid arthritis, can complicate sexual pleasure by adding more factors into the equation, such as psychological issues, pain, fatigue, and loss of body image, but it should not deter people, both men and women, into thinking that they are not desirable nor have desires. However, these feelings are normal and very real to many people; in fact, they are often more common than we realise. The good news is that many problems can be resolved. The bad news is that we are just not good at talking about sex and relationships without thinking that we have failed in some way.

Psychological effects on sexual relationships

"I remember saying to Paul; I would understand if he left me...He would work so hard, in a demanding job and long hours... He would often come home to find the house a mess, me feeling totally shattered, frustrated and in tears."

Psychological issues may be both short or long term.? They can be as straightforward as fear of hurting during intercourse or more complicated as people begin to come to terms with living with RA.?

Having any long-term condition often involves reevaluating yourself and your identity. There may be fear of the future, fear of bodily change and people need time to work through issues of how the illness may relate to them as a person. There is also a perception from others that will affect how the arthritis fits into your life and may affect your identity.? You are still you.

Psychological problems can have such a profound effect on a sexual relationship.? It is not uncommon for both men and women to have a poor self-image at times, which can have an impact on intimacy and a reluctance to have a physical relationship with someone.? It is vital to keep communicating.? Some people have an open relationship, and therefore discussing problems or issues is easy. In certain cultures or families where sex is a taboo subject, then this is more difficult. Talking is important, whether it is to your partner, your rheumatology team, or to an outside counsellor or a fellow patient. Sometimes the most unlikely person can give the most support.? In fact, Relate (a charity that offers advice and information on relationships) suggest that a breakdown in communication is the most important factor in the decline of a sexual relationship. Remember, your partner may have their own fears or concerns, and it may be a relief for them to discuss this issue.

Sexuality is an integral part of the whole person.?? It is bound by our own illness perceptions, body image and sense of normality, whatever that may be! This is of course reinforced by the overwhelming false portrayal by the media that everyone's relationships and sex lives are better than ours, but in reality, this is not the case, and everyone has their ups and downs. It's like a rollercoaster with emotions attached in fact, just like having a chronic disease.

"The most difficult aspect of Tanya's RA for us to deal with was the unpredictability and my feeling of helplessness when she gets in a flare... My beautiful independent wife struggling."

Physical effects on sexual relationships

There are also physical issues that need to be considered, including pain, fatigue and joint stiffness as well as physical limitations. Following sexual encounters, endorphins (the body's own natural pain killers) are released, and their benefit can last up to a few hours. More intensive sex may not be achievable but gentle, tender loving can actually be soothing and promote well-being. In an ideal world, spontaneity would be great, but unfortunately, we don't work or live in an ideal world, and as I've said before every sex life is a roller coaster, whether you have RA or not. If your RA is not controlled, then sexual activity or sexual desire will not be your priority. With uncontrolled RA, pain and fatigue can be exhausting and emotionally draining.

Fatigue can often be a major issue and can hinder sexual activity; it is also difficult to explain overwhelming exhaustion to people when there is nothing to see. Talk to your health care professional – there may be a reason for your fatigue other than your RA. Try to rest regularly and if you feel too tired for sex, talk to your partner about this, try gentle massage or intimacy at a time when you feel less tired. A warm shower or bath may give you a boost of energy.

There are some practical problems that can be easily solved. Some women experience dryness of the vagina, sometimes related to RA or sometimes related to other situations such as the menopause or Sjögren's syndrome, where the secretory glands that produce vaginal lubrication develop a form of inflammation and therefore causes both dryness and discomfort. Some water-based, over-the-counter lubricants such as KY jelly may be able to relieve this, and even the act of using the gels can become part of the shared intimacy.

Preparation

Some things can be done ahead of time in preparation, and this does not detract from having a fulfilling sex life, in fact, planning can enhance the enjoyment and can be helpful in reducing the pain and making the intimacy and sex more enjoyable. Plan sex for a time when you feel at your best, take medication to allow you to have the peak of your dose to occur in the lead up to sexual intercourse or during it, and wear splints if needed. Take a warm bath if this helps soothe joints or muscles. Try changing the time of the day when you have sex, some people find that early evening may be more beneficial than when your tiredness becomes overwhelming—a bit like getting the medication right – sometimes its trial and error.

A slower approach may be equally as fulfilling, and just as satisfying. Use pillows or bean bags for support, and try experimenting with positions (for example, you could try sex in a chair). Sexual fulfilment does not necessarily have to be just full penetration; using massage can be intimate and equally arousing for both partners. Sex aids or toys can be another way of promoting sexual satisfaction and intimacy. Most toys can be purchased over the internet and delivered discreetly, or even Boots and other local chemists now have a small range of vibrators. The reputation of sex shops has improved so don't discount a visit. It will give you and your partner a chance to have a look before you buy and to ensure that the operating mechanisms are easy for you to use. Take a friend or partner and a sense of humour!!

There is also an emotional side to any long-term illness, and often this is harder to overcome than the practical side, especially when there is a change in body image. Emotions are hard to control yet just as demanding as pain or fatigue. Remember, just being close to someone can make you feel wanted and loved. Enjoy listening to music together whilst sitting close; don't place too much pressure on

you or your partner; there is always tomorrow. Try relaxation techniques together or gentle massage.? Sex is an emotive personal topic.? Try and keep talking and sharing your feelings, even if you feel it is hard; once you start, you may find out things about yourself and your partner that you never knew before.

Remember

- ???Keep Talking, most problems can be sorted.
- ???Be yourself, recognise what you need and want, and what you can achieve, focus on the positive.
- ???Use your rheumatology team for support.
- ???Don't be afraid to acknowledge the problems – we all have them.
- ???Never be ashamed if you need outside help, sometimes it is easier to talk to someone removed than someone we know well.
- ???Remember things can get better:

“Our lives would have been different without Tanya's RA, and in the early days I would, without hesitation, said better, but now I'm not so sure.”

Further reading

[Relate](http://www.relate.org.uk)?: Relate offers advice, relationship counselling, sex therapy, workshops, mediation, consultations and support face-to-face, by phone and through this website.? www.relate.org.uk

[COSRT \(College of Sexual and Relationship Therapists\)](http://www.cosrt.org.uk): Previously known as the British Association for Sexual and Relationship Therapy, this is the national specialist charity for sexual and relationship therapy. This website gives information whether you are an individual needing help or a professional looking for more information. www.cosrt.org.uk

[Brook Advisory Centres](http://www.brook.org.uk): Provides free and confidential help to people under the age of 25 about relationships, sex and family planning.? www.brook.org.uk

[British Sjögren's Syndrome Association](http://www.bssa.uk.net): Provides support and information to individuals affected by Sjögren's, including a helpline, an informative quarterly newsletter and written information. www.bssa.uk.net

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