

Should we say 'Shh' to sex? Here's why Lorraine Grover says NO!



In the Winter edition, and on our Facebook Members' Group, we asked our readers to tell us about their experiences on this topic – and asked whether they were warned that their surgery may have an effect on intimacy with their partners. The response was as mixed as it was overwhelming, with both men and women telling us their stories – our thanks to all of them. Following is therapist Lorraine Grover's thoughts on the subject.

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Sex is a three-letter word that evokes many thoughts and emotions. Perhaps those are good emotions – making us think of intimacy, passion and pleasure. Or, it may be the unspoken part of our lives that is missing. It's a hard word to avoid. The media often uses sex to catch the eye, from selling a product (did you know that the 2005 advert for Pot Noodle had to be shown after 9pm for being too sexually explicit!), to selling us entire lifestyles. Despite this, unfortunately one place that you might find it rare to hear the word sex is in healthcare.

Within many aspects of healthcare sexuality is often silenced and not routinely spoken about. Even when clinicians know there is a high incidence of sexual difficulties associated with conditions such as diabetes, urological disease, colorectal disease, cardiac disease and urostomy formation, it may not be addressed. Discussing sexual issues and function can be shied away from for a variety of reasons, including lack of time, clinician and/or patient fear, embarrassment, or lack of knowledge. None of these should be a reason for sexuality to be silenced or seen as the 'elephant in the room'.

No advice before surgery

I was delighted to see Tracey Emin be so open and honest, raising awareness in the press recently about bladder cancer, and the impact of her diagnosis and subsequent surgery. Reading her outline the impact of her surgery – “my bladder, some of my colon, uterus, ovaries, fallopian tubes, urethra, and part of my vagina had been removed” – and then going on to add “I managed to keep all of my clitoris, not that it's working”, was immensely powerful and really hit me as a woman. It also made me reflect as a nurse and sex therapist, and think, how are patients prepared for this life changing surgery?

Many of my own questions, thoughts and concerns about patient support were reinforced as I read through your responses to Don, who invited people to get in touch about their individual experiences, in preparation for this article. We thank you so much, almost 200 people gave us feedback. Many people with a urostomy said they were incredibly pleased to be given the opportunity to talk openly about a somewhat taboo subject.

An overarching theme was that many of you said there was no advice before surgery, although several men said they were warned of erectile dysfunction (ED), with no mention of what to do about it! There were as many frustrated women as there were men about lack of discussion. Respondents mentioned a general assumption in many cases that older women should not be bothered about it, particularly if they were single. This differed from the treatment of women in their 20s and 30s who seemed to be given more sympathy, as well as those women who had a urostomy in early childhood and were now reaching puberty. A handful of men who had been given 'proper' advice were advised that “nerve sparing would be a priority” and their ability to “perform” adequately would depend on whether their prostate would be removed at the same time as their bladder. Women were told it might be painful depending on which organs were removed. A few women were simply warned against using the stoma for sex. One lady was shocked to find that her bladder, urethra, and womb had all been removed, leaving a much smaller vaginal opening. Two or three people had been offered dilators to overcome this. Men who were prepared to try various erectile dysfunction treatments reported mixed responses and mixed feelings.

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Support from the partner

I was particularly pleased to read 'mixed feelings' separate to 'mixed responses' relating to men and erectile dysfunction treatments. How we feel about ourselves is an important factor woven into our self-worth. There is much more to the picture than simply our sexual organs responding! Whilst sexual function is obviously one part of the sexual response cycle, feelings are important too and should not be underestimated. Sex researchers Masters and Johnson developed a four-stage model of how our body responds during sex: excitement, plateau, orgasm and resolution. Our brain is the biggest sex organ. If we are not relaxed or in the right frame of mind to become sexually excited, whether we are on our own or with a partner, it can be difficult to become aroused, to obtain an erection or have vaginal lubrication. I encourage people to masturbate to see how their body responds following surgery. During the COVID-19 pandemic, solo sex is one of the safest ways to relieve sexual tension! Sex can help reduce stress and anxiety, as well as improving our self-



Should we say 'Shh' to sex? Here's why Lorraine Grover says NO! Cont.

esteem and holistic wellbeing. The responses received highlighted the benefit of a multidisciplinary approach to patient care, including a urologist, psychosexual therapist, oncologist and clinical nurse specialist. Over many years I have seen the advantages of this approach. Pre-operative discussion about sex with a patient (and their partner if in a relationship) is a way of giving back some control in their life, at a time when they may feel out of control. You told us that lack of self-worth was common following a urostomy, though it was encouraging to hear that equally common was having a supportive partner who was not a bit bothered by the bag. At a time when you may find yourself fantasising negative thoughts, open communication and support from a partner can be transformative. There may be pre-existing sexual or relationship issues for a variety of reasons, and therefore receiving individualised care is important. It is not 'one size fits all', and each person's expectations can vary. For some, it may be sitting on the sofa together cuddling or holding hands and feeling an intimate connection. For others, it may be wanting to have vaginal intercourse, others would prefer non-vaginal penetrative sex.

For patients not in a relationship, I would encourage having open communication early on with any potential sexual partners. Connecting with another person about all aspects

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of your life (including your urostomy) is an exciting part of developing new relationships. If you feel nervous about broaching this topic of conversation, you can even 'script it out' to ensure that you feel comfortable and prepared at any time. How great to read about someone who shared with us that they still go to swinging clubs regularly with a urostomy bag, and have a full and active non-vanilla sex life. Pre or post urostomy, having a 'plan' which includes discussion about sex and relationships can be rejuvenating. Sex therapists are trained to help individuals and couples talk in a safe and confidential way about sex and intimacy. This includes helping with communication, talking through exercises that can be done in the privacy of your home to explore sensuality, and bringing together both the emotional and physical aspects of sexuality.

Post-surgery physical changes

Whilst communication can be a game-changer for many, there are significant physical changes brought about by surgery that also need to be addressed. For women, painful sex (dyspareunia) can be helped in a variety of ways, and it is important to give a clear description of what you are experiencing to your HCP to get the best advice. We know that female sexuality is often underestimated in society, and this was further confirmed to us in the responses from many women, that their experience was no exception. Lubrication is key, the wetter the better. There are many types of lubricants on the market: organic, water soluble, hybrid, oil based, silicone, moisturising. I recommend trying out different types of lube to find which one you prefer. If you are using condoms, make sure to use a water-based lubricant as oil-based can damage latex condoms. Beyond lubrication, sex toys have moved on a lot in recent years. You can buy them to meet any budget and even buy them at the supermarket. Vibrators can be made of plastic, silicone, glass – there

are even biodegradable vibrators! They come in all colours, shapes, sizes, and are often whisper-quiet (no need to worry about the neighbours) for either penetrative or non-penetrative sex play. Clitoral stimulators are designed to be held over the clitoris and use air pressure technology to enhance clitoral sensitivity. One option to help with pain during penetration is the Ohnut (ohnut.co), made up of four stretchy rings that link together and provide a buffer at the base of the penis to customise penetration depth.

Sex toys are not just for women - there are a variety of sex toys that can help men with arousal too. A fact that people may not know is that men can orgasm without an erection. If an erection is not seen or felt, it can stop sex play and then arousal such as touching and stroking of the genitalia is inhibited, which can prevent orgasm. Vacuum constriction devices can help men obtain and maintain an erection, with the use of a medically designed constriction ring. Beyond these, there are a variety of drugs available to help obtain an erection, which men often need to use following surgery. For tablets such as sildenafil (more commonly known as Viagra) to work, the nerves necessary for an erection need to remain in good working order. If these nerves have not been 'spared', there are drugs that can be applied directly to the penis instead, such as pellets or injections. This bypasses the need for the nerves to be working to produce an erection. Whilst injections are highly effective, most men do find them daunting. Don't let this put you off. I often find after giving the first injection, patients are usually pleasantly surprised how easy and effective they are. The feeling is often described to me as feeling like a prick in their finger with a rose thorn! After the initial teaching injection, these are then administered yourself as and when you would like to produce an erection. I understand that planning the use of any treatment may seem an obstacle, but I encourage it to be seen

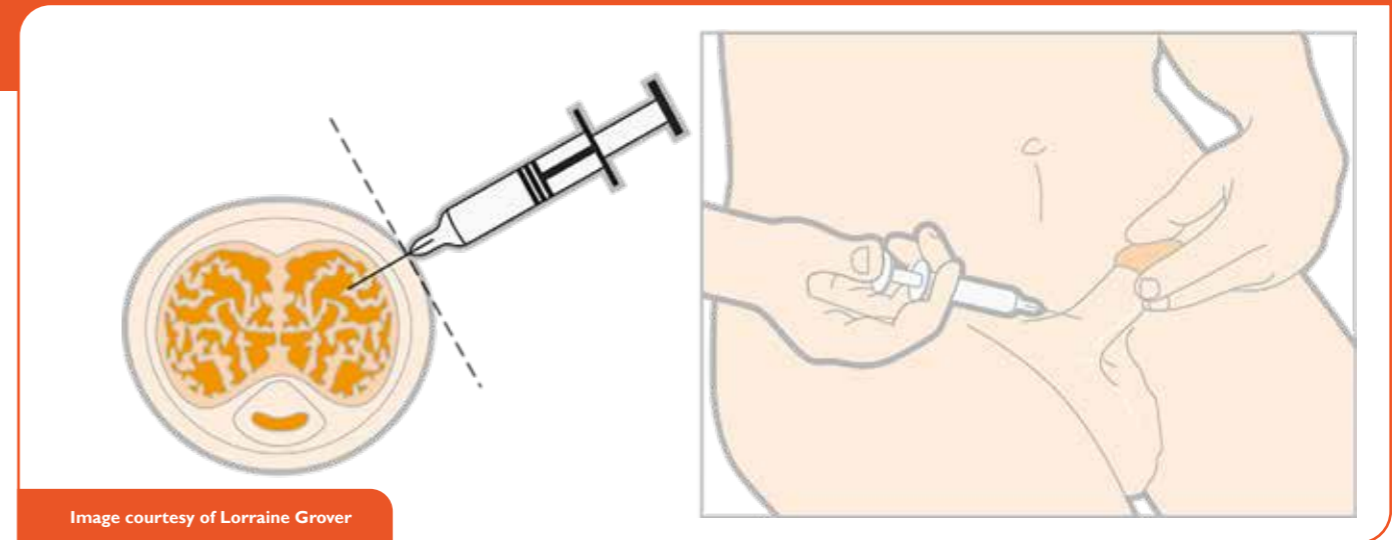


Image courtesy of Lorraine Grover

in the same way that you may plan to use a condom before having sex. A little inconvenient, but worth the effort!

Do not suffer in silence

Healthcare professionals (HCP's) can learn so much from patient's experiences, I encourage you to talk to them to obtain help and advice, if they cannot help you directly, ask who they can refer you to for that help.

The Sexual Advice Association (www.sexualadviceassociation.co.uk) has a variety of free resources, including a confidential SMART questionnaire that gives advice. Do not suffer in silence. Sexuality and intimacy can improve and fulfil your quality-of-life whatever age, relationship status or gender you identify with. Take care and keep safe. Life is what you make it, and now may be a great time to explore the sexual you.

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The Urostomy Association Jubilee Year - Fifty Years of support

A message from Hazel Pixley, Chief Executive Officer



As we start the 50th Anniversary year of our Association, this is an opportunity to look back at what we have achieved, and also to look forward at what the Association needs to do to prepare to continue supporting people for the next 50 years. I would like to thank our first two ‘Gold’ sponsors – Hollister and Salts Healthcare for their support, which is very much appreciated. We are hoping to have other sponsors coming on board during the year.

Jubilee celebration events

Sadly, like everything else, our celebrations are having to change due to COVID-19 restrictions. As I write this, we are still in full lockdown mode,

with no idea when things might change, although the positive thing is that many of our members are reporting having their first vaccination – at last, an advantage to being in the higher age brackets!

We are still hoping to hold 25 celebration Afternoon Tea events around the country, but these will be held in 2022, rather than this year. We plan to hold at least one in each Branch area, along with others in areas where there is no Branch. We will keep you updated via this Journal, Newsletters, website and social media as soon as we have firm dates/venues.

Other events, including the 50 Pier Challenge; Herriott Way Walk and President's Cycle Challenge are also likely to be delayed. However, at present, Dave Simonds' Xtreme Abseil is booked and due to take place in June, so please do support this.

Special Edition of the Journal

The next issue of this magazine, the Summer edition, will be the special 50th Anniversary edition. Editor Don Haines is especially keen to obtain any reminiscences of the early years of the Association, plus any old photos of past branch meetings and other events, such as our annual AGM weekends.

The next fifty years

To help us to take the Urostomy Association forward, we are working with external consultants. We have already started, with the Members' Survey sent out just before Christmas, and we will be bringing you some initial results from this in the next issue of the Journal. Your input, along with that of our volunteers, non-members, healthcare professionals and others, will help to shape the Association of the future.