

When sex lives suffer

What some cancer patients go through, and how oncology teams can help



→ Peter McIntyre

Addressing issues of pain, fatigue and functional impairment such as incontinence is widely accepted as essential to helping cancer patients rebuild their lives. For many people, however, restoring a fulfilling sex life can be at least as important. Patients welcome good information, a listening ear and helpful advice. All too often, they don't get it.

When Dutch clinician Woet Gianotten talks to a group of young doctors or nurses he sometimes asks them to consider whether their parents still have sex. As they stumble backwards away from the question, he asks them something still more toxic. “What about your grandparents? Are they still at it?”

The best and brightest of the next generation of doctors and nurses seem suddenly to be distracted, staring at their shoes or studying something on the ceiling.

“OK,” he reassures them. “We have established that your parents and grandparents never have sex. But let me tell you this – everybody else their age does!” He sees their faces begin to change. “They start to realise that as a professional they have to think about the sex life of people that age.”

Quality of life issues are increasingly important in clinical training for oncologists and specialist cancer nurses, but it is still rare for anyone to talk to them about sexual health. Sex after cancer is considered as a side issue when measured against pain, incontinence and depression.

Yet there is real benefit in helping people to restore their sex lives after cancer – rebuilding self-esteem, confidence and a sense of purpose in life. There are even indications that a good sex life can increase tolerance to pain and prolong life, although there is woefully little hard evidence in this field.

One of the biggest barriers to finding out more about sexual dysfunction after treatment for cancer is the difficulty in opening up lines of communication between doctors and patients. Who is going to mention the sex word and when?

THE EFFECTS OF TREATMENT

Cancer and cancer treatment disrupt and affect people’s sex lives both physically and psychologically. The shock of diagnosis and the trauma of treatment naturally disrupt sexual activity, and it may not become obvious for six months or a year that things are not returning to normal.

Women treated for breast or gynaecological can-

cer may go into early menopause so that the vagina and vulva are no longer naturally lubricated. Radiotherapy to the pelvis can also induce a dry fibrotic vagina that is narrow (vaginal stenosis) and more susceptible to irritation, bleeding and tearing. Women who have a radical hysterectomy for cervical or endometrial cancer can lose a third of vaginal length. It is little wonder that many women end up suffering from dyspareunia (painful sexual intercourse). Apart from the mechanical effects on the body, treatment for breast cancer or gynaecological cancer brings fundamental hormonal changes that induce tiredness and loss of libido, while mastectomy or hysterectomy with loss of the uterus and ovaries often make a woman feel that she has lost her sexual identity.

For men too the effects are mechanical, hormonal and psychological. After surgery for prostate cancer, as many as 80% of men are left impotent, with about 40% of men treated with radiotherapy also losing the ability to have an erection. Those treated with hormone deprivation therapy lose their sex drive and, even where the mechanics of sex can be addressed through Viagra (sildenafil), Cialis (tadalafil) or Levitra (vardenafil), men may experience loss of libido or dry ejaculation and feel they have lost their manhood.

THE BENEFITS OF GOOD SEX

Woet Gianotten has spent half a professional lifetime trying to help people restore their sex lives after stroke, cancer or spinal injury. “Sexuality is much more than only pleasure or fun,” he says. “Sexuality also has positive physical effects. If you get sexually excited and you have an orgasm, your muscle tension goes down. That is why we sleep better after an orgasm. Sexual excitement also gives oxytocin, which is the hormone of pregnancy and delivery and breastfeeding and is also the hormone of trust between people. It is quite common for a man who has an orgasm to be able to talk afterwards. If I say this in a group I see a lot of women suddenly start to smile. They recognise their husband or boyfriend.”

He says that women have a higher pain threshold after having an orgasm, and he sometimes encourages

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“Helping patients restore their sex lives after cancer can help rebuild self-esteem and a sense of purpose in life”

It is not the man with prostate cancer who does not want to talk – it is the physician who finds it difficult

cancer patients with bone metastasis to masturbate to help them with pain relief.

There are no randomised trials in patients treated for cancer to show the effect of sexual activity on survival, but in general Gianotten is convinced that there is a benefit. “We don’t have trials, but we start to have a bit of indication that if you have a better sex life you live longer. In men, the frequency of sex determines how long they live, and in women the quality of the sex life determines how long they live.”

OPENING UP THE DISCUSSION

Luca Incrocci, a radiation oncologist at the Erasmus medical centre, Rotterdam, and a qualified sexologist, is pressing for better communication, better diagnosis and better treatment.

Incrocci is president of the International Society for Sexuality and Cancer, and with colleagues organised the 2nd Rotterdam Symposium on this topic in June 2010, bringing together about 100 clinicians and nurses from across Europe. He says that an inability for patients and doctors to talk about this issue has a hugely negative impact on quality of life.

“Oncological treatments are very complicated and we are getting very aggressive and seeing big differences compared to ten years ago. That is good because more people are cured and overall survival is getting longer and longer, but of course we also see many more side-effects and problems in general and specifically more sexual problems.

“What we are trying to do now is to teach ourselves to try make it easier to talk about this problem. It is not the man with prostate cancer who does not want to talk about this – it is the physician who finds it difficult. The younger doctors ask, ‘How can I talk to a 75-year-old man about this?’ But it is getting easier. All these patients really do appreciate it when we talk to them and they know we are open to it.”

He points out that a lot more men are now treated for prostate cancer in their 50s and 60s while still sexually active. But a proportion of older men are also still sexually active.

“Sex is not only for the young, the beautiful and the healthy. I have an 82-year-old man who uses Cialis just once a month and he says, ‘I am very happy. I am a male again.’ His partner is 65 and they have a great life.”

Incrocci says that the issue has to be raised soon after diagnosis, even if addressing the problem can wait. “If you don’t tell them before treatment that they will get a dry ejaculation because the prostate is not working, they will be frustrated. That is something they need to know before the treatment.

“Patients might have problems due to treatment, urinary incontinence after prostatectomy; proctitis after radiotherapy. At this moment the most important thing is not sex. But after a year they come back and say, ‘You told me there would be a possibility of treating erectile dysfunction. Now I have time to talk about that.’

“We are seeing that in some category of patients, quality of life and sexual functioning is so important that it can really make a difference in the choice of treatment.”

Louis Denis, distinguished Belgian onco-urologist and himself a prostate cancer patient who is now secretary of Europa Uomo, the European patient organisation, goes further. Not only should men be given information about the effect on their sex life as soon as they are diagnosed, but they should be encouraged to keep up sexual activity before they are treated.

He points out that patients generally have a three-month delay before treatment begins, so they can consider how important sexual activity is in their relationship.

“Someone diagnosed with prostate cancer is probably not thinking of having intercourse. We want to reassure them that, up to the moment of treatment, they should maximise erectile potential. There should be some sexual activity, including masturbation, to prevent atrophy of the penis.

“We call that rehabilitation of the penis in advance, in the same way that we do with exercises for incontinence – nobody gets operated on without exercise for these muscles.

“HOW I REBUILT MY SEX LIFE”



Denton Wilson discovered he had prostate cancer at the age of 42, after watching his father die from the disease in Jamaica. When Denton, a champion body builder and fitness expert, returned home to Sheffield in the UK, he was determined not to die the same painful death.

Despite some scepticism from his GP, Denton was tested and found to have a cancer. The following year he had an operation at a Sheffield teaching hospital.

“I was told that I would not be able to have an erection and I would have peeing problems. I was advised to save sperm in case I wanted to have more kids. I saw my father die and saw the pain he went through, so I decided to go for the operation. I was just thinking of surviving really.”

Afterwards he found himself incontinent and impotent. “I was wet all the time and I had to wear these nappies. That was uncomfortable.



I never went out. I was basically housebound.”

He had always been sexually active, but now he felt no sexual urges at all. “I could not feel anything. I felt useless and disheartened. I did not feel like I was a man any more.”

Denton believes in exercise and positive thinking. “I kept doing the exercises and willing myself to get better. I had to get strong by doing pelvic floor exercises to strengthen my bladder.”

His doctor offered him a pump to help him get an erection – but it was painful and undignified, and he rejected the idea of stents to make his penis rigid. Viagra, then a new drug, did help, but his girlfriend thought that sex-on-a-pill made him untrustworthy, and this contributed to them breaking up.

Eventually, Denton found his sexual function restored – he started waking up with an erection in the morning.

“Now I can have an orgasm and it feels much the same but I do not really ejaculate. I feel my sexual performance is better than it was before and I think this is due to my training. I cannot produce sperm but my life is more fulfilled.”

Now at the age of 54, Denton talks to men in Sheffield about the need to watch out for prostate cancer.

“I don’t think the black community in Britain are aware of this. That is why I am doing the work I am doing to show what can be done. If there is something that is going to knock their performances they would rather not do anything about it until it is too late. I tell them I have gone through that and I have got a good sex life, and I am all right.”

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“My sex life is better – because I focus on it more”



At the age of 43, Gabriela was diagnosed with cancer in both breasts. She was the mother of a nine-year-old son, and divorced. Her life was thrown into turmoil. “I was very frightened because at first I thought I would die.”

She had a double mastectomy followed by chemotherapy and the following year had her uterus and ovaries removed. Gabriela, a teacher in Lisbon, Portugal, feared this was the end of her life as a sexual being. “How would I reconstruct my life? Would I ever flirt again or be in love? I felt that this era of my life would be completely erased.”

But she received strong support from friends and from a psychologist attached to her oncology team, and she felt her attitude changing.

“My point of view was, I have survived the worst,

I felt that I had to behave honestly and I was in a rush to tell. I was very anxious and stressed.”

Mostly, after this conversation the man would disappear and she would never hear from him again. “I understood it was too much information, too soon. The next time my reaction was, let’s go to the movies and concerts and take my time get to know the person. This new approach was OK!

“I am now in the stage that every woman has. Sometimes I have a relationship and sometimes I don’t. I am a woman of my age.”

Her view of men has changed. “Women have a prejudice and think men are neurotically emotionally limited. But men are not all narrow minded. They vary a lot. The best reaction from a man is for him to say ‘I am not in love with your breasts; I am in love with you.’”

Gabriela is now more confident and assertive. “My sexual satisfaction is better because I focus better on looking for it. I do things I would never do before. I would say that now I am more secure in myself. I know what I want and I know what I don’t want and I don’t think I will ever be trapped in a relationship again. Naturally, I sometimes have fears for the

future but I have a bit of empowerment. I am the master of myself. It gave me insight about life and love and affection.”

As vice president of the patient association, Viva Mulher Via, Gabriela

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which was the threat to my life. I should adapt myself to the situation and try to do something fun.” She had her breast reconstruction and found “I was in better shape than I was before and that was erotically interesting!” She went back to full time teaching and used social networking Internet sites to start dating.

At first this did not go well. “I felt I had an obligation to disclose my condition. I would do a lot of selection and try to have a lot of conversation and meetings. But when things were starting to get hot,

helps to ensure that other women undergoing treatment for cancer get access to psychological support. “In Portugal we have a culture of some repression in speaking about these issues. I had the opportunity for group therapy after my surgery, when I was really frightened about the future. These conversations with older and experienced women were very important. Many women live with this issue in a very solitary way. I think it should be included in the after care as part of breast cancer survival.”

“Sexologists place more importance on communication between a couple than on pills and plastics”

“If there is a real interest from the patient, it is important that he still uses his penis. The penis is not just hanging there like your ear. It is an organ that goes up and down during sleep even if you don’t have sex to keep vessels intact and the overall physiology active.” Denis says that patients need advice on healthy living. He also encourages patients who want to have a sex life in the future to think about what turns them on.

“You have your body memories, fantasies or recall of actual events. They should not suppress them but can use them as a form of excitement. You need to be relaxed, nice music, pleasant company and massage and a bath and it goes a lot better. When you are tired and stressed and your wife is as well, then trying to have sex does not help too much.”

However, research by Incrocci and colleagues at Erasmus University in Holland suggests that as soon as men have a diagnosis of cancer, their sex life takes a turn for the worse. “The moment the patients have the diagnosis of prostate cancer they already have a decrease in libido. They may have erections and an interest in sex, but they are more thinking about the consequences of prostate cancer. What I found in patients in that particular phase, where patients have not yet had treatment but have had a diagnosis, is that they are more interested in intimacy than in sexual activity.”

THE GENDER DIVIDE

Most experts agree that men and women respond differently to sexual difficulties – men being more concerned about the mechanics and women with the psychosocial and emotional impact. But this difference should not be overstressed. Often the cancer patient – man or woman – is more concerned for their partner than for themselves.

Isabel White, cancer nurse, researcher and a psychosexual therapist from King’s College, University of London, did her PhD on the assessment of women’s sexual difficulties after pelvic radiotherapy. She found that sexual problems started to

become important 6–12 months after treatment.

“Many of these women have had surgery to start with and then a combination of radiotherapy and chemotherapy, and for the first six months they are really still recovering from the onslaught of that, psychologically and physically. Many of them feel very fatigued. It is probably only from the six-month mark onwards that many feel well enough to broach the issue of sexual expression.”

Women were better informed about the bladder and bowel side-effects of radiation than about possible side-effects on their vagina and the subsequent implications for sexual function. “It tends to be not as well discussed and not discussed in as much detail. Bowel and bladder are daily issues and sexual function is usually not.”

Clinicians found it easier to speak to younger women in their 40s and 50s than women over the age of 70. “Some clinicians are superb at this but others find it more difficult to have a conversation about sexual consequences. If the person doing the explanation is embarrassed at discussing sexual issues with an older woman the age of their grandparents or does not know as much about sexual consequences, it tends to be subsumed in all the other information they need to give.”

Incrocci sees a big difference in reactions to sexual problems between a man and a woman. “A woman is not that interested any more in penetration after such a treatment, but they still want to be sexually active. They are interested in caressing, in intimacy, in masturbating and in stimulating. These things are still very, very possible after treatment for gynaecological cancer.

“You have to talk in a very different way to these women because they are shy about coming to the hospital to talk about that. But I have many patients who have accepted not having penetrative sex either because the man cannot get an erection or because the woman cannot be penetrated, and they are still having a great sexual life because they have found other ways.”

OFFERING HOPE

Drugs such as Viagra have been very helpful for many men – but they do not work if there is no erectile function to build on, and while they stimulate blood flow to the genital area, they do not directly affect libido. This is one reason why they have not proved successful for women – a man gets positive feedback from the fact that he has an erection, but a woman does not become excited by increased blood flow to her clitoris and vulva. So far there has been no “pink Viagra” for women, although there are hopes that the selective serotonin uptake drug flibanserin may help women with loss of sexual desire – it had interesting side-effects on women taking it as an anti-depressant.

Women who no longer get wet naturally can use saliva, intimate lubricants or creams (although most doctors warn women treated for breast or endometrial cancer against using vaginal oestrogen creams). A woman whose vagina has narrowed can use vaginal dilators – like a small plastic ‘trainer’ penis – to gradually increase their capacity for penetration. There is anecdotal evidence that women are reluctant to do this once or twice a week. “They certainly don’t find it an enjoyable experience and some find it reminds of them of their illness,” says Isabel White. A Cochrane Review found poor-quality research evidence about whether dilators are helpful.

Therapists and sexologists tend to place more importance on communication between a couple and with the clinician or nurse than on pills and plastics.

Isabel White points out that even where Viagra helps a man it can be problematic for his partner. “How acceptable is it to see someone taking a tablet to become aroused? Unless you explain that he has to take a tablet because the treatment has altered his nerve and vascular function and in his head he is still aroused, you can find communication breakdown



The Challenge. This image, from the Lilly Oncology on CanvasSM collection, was chosen by the International Society for Sexual Medicine to publicise their conference in June next year, as it symbolises barriers and obstacles which must be overcome to address sexual health in cancer survivors

and the partner may be resentful.”

Isabel White always tries to see couples together, since openness to discussing possible solutions and support of the partner are both crucial.

“The more flexible and open the woman is to making changes with her partner the more amenable she is to being helped.

“If it is a relationship with good lines of communication, then the couple are more able to move forward. If one partner has always found sex a bit of a trial and has a rigid repertoire, and the couple cannot communicate with each other, then it is more of a challenge to initiate change.”

Men sometimes find it less acceptable to substitute non-coital sexual expression for intercourse, but Isabel White helps the couple to explore solutions.

“We find out what helps them get aroused, whether that is fantasy, erotic language, erotic literature, visual images, either static or films.” However, she does not recommend becoming over-reliant on porn since it can be a barrier to real sex. “You can almost reach saturation point, where the imagery has to be more explicit to turn you on. You have someone disassociated from the emotion of having sex with a partner and it can become a very lonely and isolating experience.” In almost all cases, she says, couples can be helped to improve their sexual experiences even if they cannot go back to penetrative intercourse.

WHERE ARE THE SERVICES?

The UK and the Netherlands are perhaps more advanced than most European countries in offering sexual support to cancer patients, but even here services are patchy. Even where sexual therapy

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services exist, oncologists and patients may be unaware that they are there.

Throughout Europe, there are pockets of excellence. In Rotterdam, clinicians run outpatient clinics at nil extra cost to the hospital. At the Hospital de São José in Lisbon, the multidisciplinary care team for breast cancer has a clinical psychologist present whenever a woman is given her diagnosis. The head-and-neck cancer service is developing a similar system. Clinical psychologist Luzia Travado says that team work and training are essential to help professionals identify who may be having problems.

“Only when you open the dialogue and ask about their problems and allow space for them to say what is going on and use your listening skills will they open up. You make an environment where the patient feels safe to tell you about their most private issues – and of course sexuality is the most private issue of all.”

Travado recalls having a 65-year-old married man referred to her private practice in a depressed and suicidal state because of erectile dysfunction following prostate surgery. “He was shocked and angry with his surgeon for not keeping him informed. He told me, ‘If I had known this I would have preferred to live less and have my sex life back.’”

Incrocci is campaigning to have sexual issues better recognised in the training of oncologists and in budgets. He points out that no European countries routinely pay for Viagra or for vaginal dilators, even though they may pay for a woman to visit a psychiatrist.

“There is something very contradictory here, because a psychiatrist is much more expensive than getting a set of vaginal trainers and getting help to start using them

from a sexologist or their medical oncologist.

“Governments, ministries and European organisations don’t really see sexual function as a very important side-effect of cancer treatment. They will deal with bowel problems or urinary incontinence, but sexual function is not seen as important.”

Isabel White points out that the evidence base for knowing how to help men and women is very weak – and budgets for psychosocial research are declining. “People like me are competing for smaller and smaller amounts of money. If you have to choose between funding a study on depression and anxiety, or on sexual recovery, you will choose the problem that is perceived as most prevalent.”

Even so, she says that 90% of couples could be helped by existing staff in oncology departments if they knew how to do it. “The problem we have is that the majority of health professionals do not feel they have the expertise to have that conversation. The first thing we need to do is to improve education and development of existing oncology staff for nurses and doctors so they can manage the short-term minor difficulties that people experience – the things that do not really require a sex therapist or long-term work.”

Incrocci says that this year’s Symposium in Rotterdam is a step on the way to raising the profile of sexual issues and cancer in Europe. “I cannot ask every oncologist to become a sexologist as well, but you must remain open. If the radiation oncologist, medical oncologist, urologist or gynaecologist never once asks about sexual function, it is such a frustration and disappointment for the patient. People today expect more from their physician.”

The International Society for Sexuality and Cancer (ISSC) was founded in 2002 to heighten awareness about sexuality in cancer by fostering research, encouraging training and increased service provision, and providing a forum for discussion. Membership is open to cancer clinicians, experts in sexual medicine, social workers, nurses and psychologists. Patient groups are eligible for affiliated membership. The society website is www.issc.nu and Luca Incrocci, president of the ISSC, can be contacted on l.incrocci@erasmusmc.nl

