The ileostomy & internal pouch
Support Group

Pregnancy, contraception, infertility and the ileostomy and the ileo-anal pouch

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Introduction

For many men and women with ileostomies or internal pouches, the establishment of a lasting sexual relationship and the possibility of having a family is a natural desire at the end of a long period of ill-health and it may be seen as the final symbol of new found health and acceptance of any inconvenience or embarrassment associated with their illness. There are many half-truths and, frankly, misleading ideas bandied around in relation to what to expect from sex life, pregnancy, etc, after an ileostomy or ileo anal pouch operation, and this leaflet is intended to dispel some of these.

Sexual Intercourse

The medical condition which has led to the operation may have prevented sexual intercourse taking place for some time, either because of general ill-health or localised pain and soreness around the vagina. Once women with an ileostomy or internal pouch have recovered from their operation, and any surgical wound related to the rectum and anus has healed, they should be able to resume or commence sexual relations.

Sometimes the position of the uterus (womb) is different after rectal surgery and discomfort may be felt in certain positions but it should be possible to overcome this by trying alternative positions.

Similarly for men, there is usually no problem in establishing a normal sex life once recovery from surgery is complete. Just occasionally a man may have difficulty in maintaining an erection if the surgery or disease has damaged the nerves to the genital organs. If this is the case, he should not be afraid to consult his doctor because there are effective treatments for this condition now. Occasionally either men or women may develop psychological “hang-ups” about sex, perhaps because of a feeling of loss of attractiveness due to the ileostomy.

Specialised psycho-sexual counsellors who understand these problems can be most helpful.

Pregnancy

Before embarking on a pregnancy it is important to check with your doctor or surgeon as to whether you are now fit to go ahead. You may be asked to visit a gynaecologist for pre-pregnancy counselling to discuss any possible difficulties before pregnancy occurs.

Most women with ileostomies and internal pouches sail through their pregnancies with no particular problems, but some commonly asked questions and less common problems will be discussed.

Will my ileostomy or internal pouch work normally during pregnancy and will I be able to manage it when my tummy gets bigger?

Usually the ileostomy works perfectly normally but you may need to increase fluid intake because the developing pregnancy and the changes in your body require extra fluid. Occasionally during pregnancy, women get episodes of intestinal obstruction when the enlarging uterus causes a hold up in the passage of

intestinal contents. The stoma ceases working and the abdomen may become distended and colicky pain is felt. Restricting the diet to fluids only and resting may resolve the problem but on rare occasions, hospital admission and an intravenous drip will be needed to 'rest' the intestine.

During pregnancy, changing of the ileostomy bags is not usually difficult but when the abdomen gets very big in the later stages of pregnancy, it may be more difficult to see the stoma and it may be necessary to use a mirror.

Sometimes the stoma enlarges due to stretching of the skin and muscle and there may be some prolapse of the intestine into the bag. That is more of an inconvenience than a danger to health. Normally there is minimal alteration to the function of a pouch.

What about diet during pregnancy?

Nobody needs to eat for two in pregnancy but some increase in certain foods may be desirable. Plenty of protein and vitamins are needed so it may be sensible to eat more meat, eggs or cheese and some vegetables or salad. Avoid raw egg and all unpasteurised milk products. Liver is no longer advised. Iron tables will usually be prescribed and possibly some vitamin tablets.

Pregnant women should avoid all but small quantities of alcohol and, of course, smoking can be very harmful for the developing baby. Folic acid is recommended for the first three months of pregnancy. It is advisable to start this before getting pregnant.

Is Caesarean section necessary for women who have an ileostomy or internal pouch?

Caesarean section is certainly not the rule for ileostomy patients; indeed most obstetricians will try to avoid this because previous surgical scars may make the operation slightly more difficult. The vast majority of people with an ileostomy can have a vaginal birth but there are a few factors which can affect details of the birth.

Women with an internal pouch may be advised to have a caesarean section to avoid anal incontinence and they should be guided by their own consultant.

If the rectum has been removed and there is scar tissue in the perineum (the area between the vagina and the original site of the anus), it may be necessary to do an episiotomy (a small 'cut' to enlarge the vaginal entrance) in order to make the birth easier and prevent an ugly tear. If there has been a lot of damage to the nerve supply, the woman may not get the urge to push her baby out and so may require a forceps delivery.

None of this matters because local anaesthetics are used, or an epidural (a special injection near the spine which takes away all the pain of childbirth). If the midwife or doctor are not familiar with ileostomies or internal pouches, do not worry, they will listen to your knowledge!

Will I be able to breast-feed?

There is no reason at all why ileostomists or women with an internal pouch should not breast-feed. Remember that a breast-fed baby may drink several pints of milk a day and so fluids must be taken in greater quantities. There is no evidence that beer is better than any other fluid for breast-feeding mothers!

Infertility

There has been much discussion and disagreement as to whether infertility is more common in people who have had bowel surgery. Approximately 10% of the population have a problem in getting pregnant and it is possible that some of the causes of infertility are a little more common in people who have had one of the conditions leading to an ileostomy or internal pouch.

If women are in a very poor state of health and grossly underweight, as sometimes happens to people before their surgery, their periods may stop and they will not ovulate (make an egg). Once health is restored and the weight reaches normal levels, the periods and ovulation resume. Occasionally a drug is required to stimulate ovulation.

Sometimes the underlying condition, or the operations for it, cause damage to the Fallopian tubes, either by causing kinking and adhesions, or rarely by blocking the tubes. Where this is suspected, tests will be done by X-ray to check the tubes and it may be necessary to have an operation to improve the tubes. If this is not successful, or if the tubes are very badly affected, test-tube baby treatment, *in vitro* fertilisation (IVF) may be considered. This treatment is perfectly possible for people with an ileostomy nowadays because the eggs are usually collected through the vagina and so there is no danger of interfering with the ileostomy. It is, however, important to remember that IVF is still a relatively unsuccessful form of treatment and not everybody gets their 'miracle' baby.

Contraception

Clearly family planning is sensible for all couples but some methods may not be suitable.

Condoms are the 'go anywhere' contraceptive and particularly appropriate for those having casual sexual encounters but also very reliable for stable couples, provided they are consistently used.

Diaphragms or **caps** are not always suitable for women with an ileostomy or internal pouch because the altered anatomy of the vagina and uterus may make insertion and retention difficult. Nevertheless they are suitable for some women.

The pill may be suitable depending upon how much intestine is remaining. A higher than average dosage pill may be necessary if absorption is not very good and, in some individuals with Crohn's disease, absorption is so unreliable as to make the pill unsuitable as a form of contraceptive. A temporary upset of the digestive system resulting in fast throughput of the intestinal contents may make absorption unreliable.

Another form of contraceptive which might be suitable is the three-monthly depot injection of progesterone. Check-ups and supervision are necessary for women on the pill. A new injectable contraceptive – Norplant – is available and can be removed if not suitable.

The IUCD (coil) is not advisable for women who have not had children and if there is a history of damage to the Fallopian tubes or infection, the IUCD should not be used. If the uterus is fixed in an unusual position following surgery, it can be very difficult for an IUCD to be inserted.

Sterilisation is perfectly possible but will usually need a laparotomy (i.e. opening of the abdomen) rather than a laparoscopy (looking into the abdomen with a telescope) because of the danger of damage to the intestine when there has been extensive surgery. For this reason it is often best to persuade the male partner to have a vasectomy, just as simple for a man with an ileostomy or internal pouch as any other male!

Conclusions

I hope that people with an ileostomy or internal pouch who were worried about their ability to fulfil their sexual and reproductive functions are reassured by this leaflet. They certainly may need some additional help and advice but this should be readily available. If your local doctor is not familiar with any problems, the surgeon or specialist is likely to know of a hospital gynaecologist who understands ileostomies or pouches or IA can put you in touch with an appropriate person.

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