Living with a Kock Pouch

- Providing support and advice
- Helping you with your concerns
- Local organisations
- Contact information

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IA
Ileostomy & Internal Pouch
Association

Contents

This booklet has been written by IA (Ileostomy and Internal Pouch Association) to give you information and advice which you may find useful before and after Kock Pouch Surgery (Continent Ileostomy).

It has been designed to answer some of the questions you may have and to provide constructive solutions to some of the problems you may experience. This is a generic booklet and is not specific to any hospital.

This booklet is to be used as a guideline and as your confidence grows with your Kock pouch you will find that different things affect you in different ways at different times. Adaptation to the Kock pouch is individual and can take up to two years following initial surgery. Therefore, take each day as it comes and live life to your fullest ability. You will still be susceptible to coughs, colds and upset stomachs and shouldn't necessarily blame the Kock pouch. If your symptoms persist then you should contact your GP, consultant or stoma care nurse specialist.

You may find that the information provided by your hospital differs from what is provided in this booklet. Please check with your consultant or specialist stoma care nurse if you have any queries.

What is a Kock Pouch?

A Kock pouch (or continent ileostomy) is an internal reservoir constructed out of the patient's small bowel. This reservoir is attached to the abdominal wall and leakage of bowel contents is prevented by a one-way valve, also constructed from small bowel. In order to empty this reservoir or pouch, a catheter (tube) is inserted through an entrance on the abdominal wall.

Is a Kock Pouch suitable for me?

Patients who have their large bowel removed may have an ileostomy. There are different types of ileostomy and include; loop, incontinent and continent (Kock Pouch). Certain conditions of the large bowel require surgical removal of the large bowel and rectum.

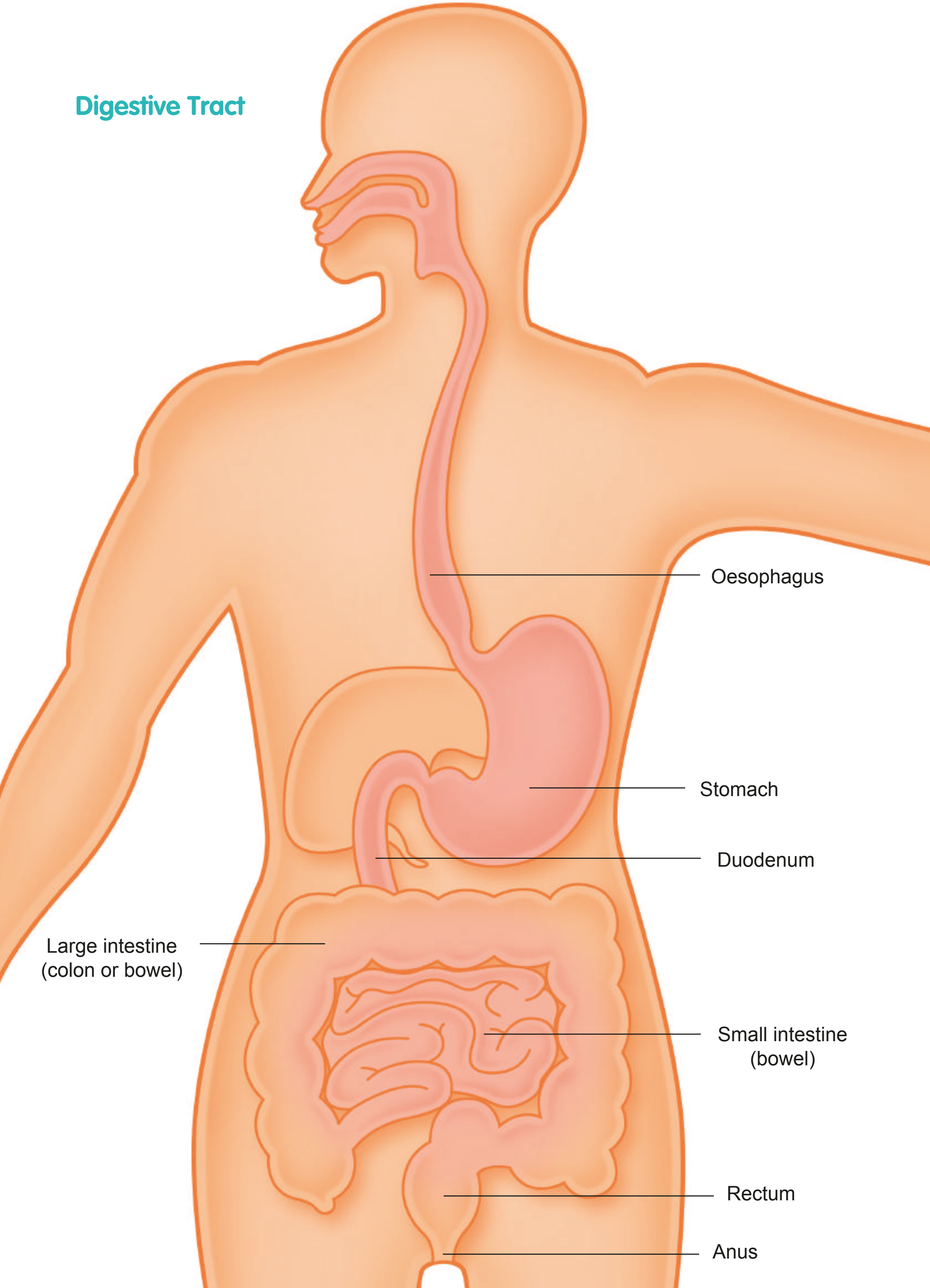
Patients diagnosed with ulcerative colitis, Familial Adenomatous Polyposis, low rectal cancer or anal sphincter damage may be considered for this surgery. It can also replace a conventional ileostomy for those who experience severe parastomal skin conditions, psychosocial difficulties and/or sexual problems due to their ileostomy. It is also an alternative for those whose ileal-anal pouch has failed or for those who are unsuitable for an ileal-anal pouch procedure which may be due to poor sphincter control or because they have had their anal canal removed.

Before your operation you will be thoroughly assessed by the colorectal surgeon and specialist stoma care nurse to make sure that this operation is the best option for you. A Kock pouch is not suitable for everyone and it is strongly recommended that you have a consultation with your specialist stoma care nurse at the colorectal outpatient appointment to discuss your options further.

Contraindications

Patients who have undergone a previous resection of a significant amount of small bowel are not able to consider this surgery. Other contraindications are Crohns disease, obesity, mental health problems, age over 60 years and frailty.

Digestive Tract



Normal Anatomy

From the stomach food enters into a passage known as the duodenum. The duodenum empties into the small bowel (small intestine) which is about 400 cms in length. In the small intestine digestive juices are added to the food, allowing some of it to be absorbed into the bloodstream. The small intestine empties into the large bowel (large intestine or colon). The large bowel is much wider and measures about 100 cms in length. It begins in the lower right side of the abdomen across and down the left side to join the rectum. The rectum is the lower 15 cms of the large bowel and it is the storage area for waste matter (stool).

Awareness of the presence of waste matter in the rectum gives rise to the urge to empty it. The waste comes out via the anus which lies between the buttocks. The anus is surrounded by sphincter muscles which are able to tighten so that it is possible to control the passage of wind and waste matter at will. This act of emptying the rectum is called defaecation.

How is the Kock Pouch constructed?

The continent ileostomy can be made in conjunction with removal of the rectum and large bowel, or later on in people who already have a conventional ileostomy. The continent ileostomy may be placed lower down than a conventional ileostomy. About 45 centimeters (18 inches) of the lower part of the small bowel are used for construction of the continent ileostomy.

The bowel is opened; turned up and sewn together so as to create a reservoir. A non-return valve is also made out of the small bowel so as to prevent leakage of stool through the flush outlet. The outlet is led to the surface of the skin and the reservoir is sewn to the inside of the wall of the abdomen.

Once the pouch has healed the pouch is emptied by inserting a special catheter through the valve 2-4 times per day. This will be after a few weeks. There should therefore be no need to wear a stoma bag. A stoma cap or gauze square worn over the stoma should be all that is required.

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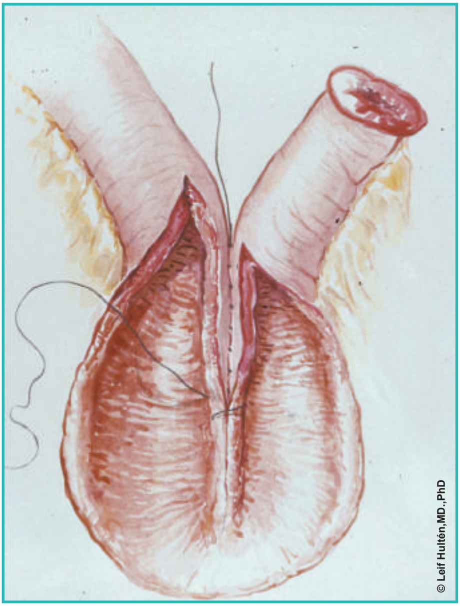
Approx 45cm of bowel is used



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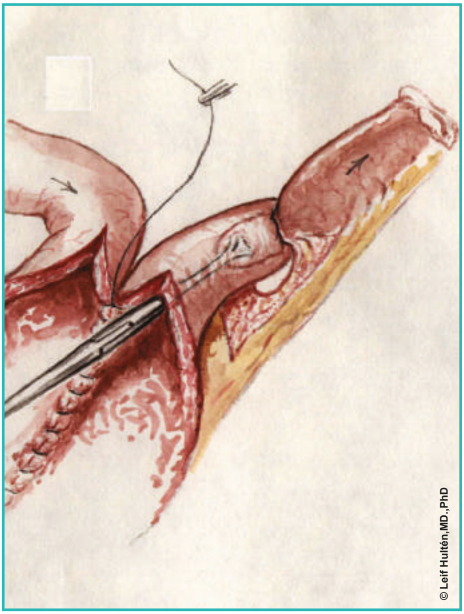
Loop is opened and stitched to form reservoir



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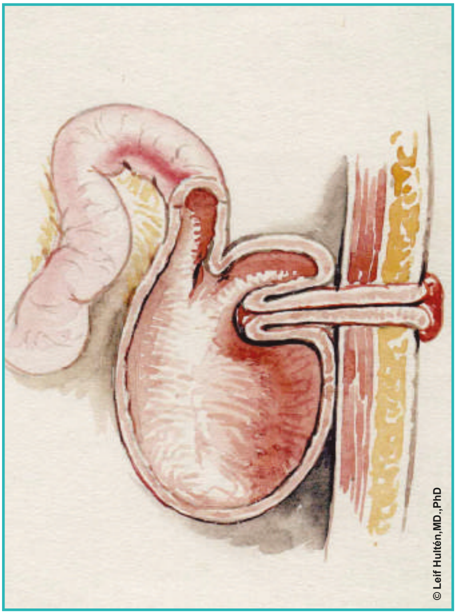
A non-return valve (nipple valve) is created



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Pouch positioned - outlet through abdominal wall

What does the operation involve?

Returning from theatre you will have a ‘drip’ (giving you intravenous fluids) and a separate urinary catheter which empties the urine from your bladder. You may also have several wound drains. These are usually removed approximately 3 - 5 days post-operatively.

The nurses will regularly check your stoma and gauze dressing and make sure that the pouch catheter is draining freely. The catheter will need to stay in place for approximately 14-21 days after the operation. It is therefore likely that you will go home with this catheter in place and return 2-3 weeks post-operatively for its removal by the stoma care nurse specialist. The catheter will have been marked in theatre so that you have an indication of how far into the pouch the catheter is inserted.

The catheter will probably be held in place with a vertical drain tube attachment device which will be changed as required. You will be instructed in how to use this and be provided with some for use once discharged as these are not available on prescription obtain via your stoma care nurse specialist.

After Surgery

The day after surgery, the nurses will help you to get out of bed for a short period in order for your bedding to be changed and to help you with your personal needs. You will feel very tired. You will also see a physiotherapist, who will guide you on how to move and also encourage you with some breathing exercises to help clear your lungs after the anaesthetic.

The nurses will be monitoring your blood pressure, pulse and temperature regularly. They will also be checking your wound and ensuring that the stoma catheter into the pouch is well secured and draining freely. They will start to flush this pouch catheter with 20mls saline (salt water) at least twice a day to keep it draining. This is usually started 1-2 days after the operation. After 3 – 4 weeks, warm tap water is used to flush the pouch rather than saline.

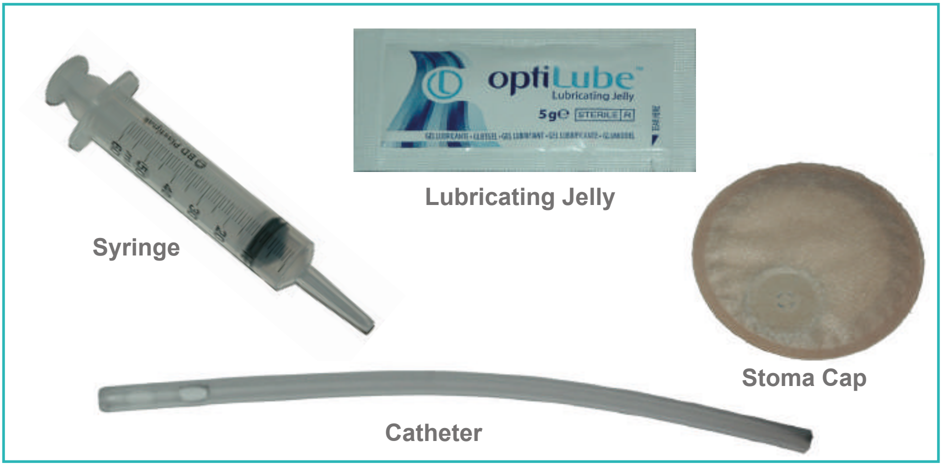
Whilst you are in hospital, your stoma care nurse specialist will visit you most week days to make sure that everything is satisfactory with the pouch catheter and to answer any questions that you may have. When you are feeling well enough, the nursing staff

will teach you how to flush the catheter which involves a syringe with a nozzle and 20 mls salt water (saline). It is very easy to do. You may wish to do this each time you intubate or only when your output is thick.
By the time you are discharged you must be able to do this yourself at least twice a day. You will be given plenty of time to master the technique.

Approximately 2-4 weeks after the operation you will be taught how to catheterise the Kock pouch with the wide bore catheter. In the early weeks, it will need to be catheterised approximately 8 times in a 24hr period, so that it never gets too full whilst it is healing.

Female patient catheterising her Koch Pouch - ready to empty into the toilet

It is recommended that you leave the catheter in situ over night until you feel confident with inserting it. When the pouch is healed, it is anticipated that you will need to catheterise approximately 2 – 4 times a day.



Living with a Kock Pouch

Once you have gained confidence with your Kock pouch there is no reason why your normal lifestyle cannot be resumed in a similar way as to before your surgery. However, it is recommended that you wear a Medic-alert bracelet outlining the details of your condition and surgery (www.medicalert.org.uk).

Information should include:

- Condition – Ulcerative Colitis, FAP
- Surgery – Internal pouch/ continent ileostomy (Kock Pouch)
- Insert Medina/ileostomy straight catheter 4 – 6 hourly (M8730)
- Do not irrigate
- In case of profuse diarrhoea; treat with oral fluids and salt (Dioralyte), and antibiotics. Consider draining pouch continuously by means of a catheter. Avoid milk and alcohol.
- Inability to intubate; seek medical advice at hospital, intubate with children's proctoscope or cystoscope under direct vision and introduce catheter.

Some people with Kock pouches make use of the RADAR scheme (www.disabilityrightsuk.org.uk/radarkey). After paying a nominal fee, a key is provided allowing access to all disabled toilets within the UK. A directory is provided or a smart phone app is available.

Dietary considerations

Diet is an important aspect of pouch formation and although there may be some dietary restrictions it is important to maintain a healthy diet but above all enjoy your food.

All foods should be chewed well and taken in small amounts. Daily grape or prune juice can thin the output aiding intubation and drainage time. The amount taken is individual, however, one small glass is recommended. A low residual diet is advised. Low-residue relates to foods low in fibre and includes foods that are easy to chew and easy to digest so that your output can pass easily through the catheter.

The table opposite will provide some guidance of foods to consider.

	Low Residue Foods	High Residue Foods (avoid)
Starchy foods	White bread/flour White pasta White rice Couscous Pastry (white flour)	Wholemeal or Granary bread/flour Wholemeal pasta Brown rice Pearl Barley Quinoa
Breakfast cereal	Cornflakes Rice krispies Frosted flakes	Whole wheat cereal (e.g. Weetabix, Branflakes, Shredded Wheat) Porridge, Muesli and Granola
Dairy	Milk Yoghurts (smooth) Cheese Cream	Yoghurts or cheeses containing fruit or nut pieces
Meat, fish and eggs	All tender meat, fish and poultry All eggs	Tough gristly meat
Vegetables	Peeled, well-cooked, soft/mashable vegetables Potatoes (not skin) Crisps	Raw vegetables/salad Baked beans Split peas/lentils Peas, sweetcorn, celery All seeds, pips, tough skins
Fruit	Soft, ripe fruit without pips or seeds	All dried fruit Citrus fruit Berries Prunes Smoothies/fruit juices with bits
Nuts	None	Avoid all
Desserts and sweets	Plain sponge cake Custard Ice-cream Jelly Semolina, rice pudding Chocolate Seedless Jam Plain biscuits	Popcorn Biscuits with nuts or fruit Chocolate with nuts or fruit Cake with nuts or fruit
Fats	All	None
Other	Clear soups Spices, pepper Stock cubes Tea, coffee, squash	Pickles, chutneys Horseradish Relish

Drugs

You should ***not*** stop taking any prescribed medicines without consulting your doctor.

Some medicines may alter your pouch function or change the colour of the output. Some medicines may not be absorbed effectively such as enteric coated or slow-release tablets. Diuretics (water tablets) may lead to dehydration.

You should consult your Consultant, GP or stoma care nurse specialist with any concerns you might have.

Drug	Colour of faeces
Iron	Black
Antibiotics	Green
Anticoagulants	Red
Aspirin	Red

Daily Living

Household chores

Initially following surgery and for up to 8 weeks you should avoid household activities such as vacuuming, mowing the lawn, cleaning the windows, picking up and/or carrying children and carrying heavy shopping. Gentle exercise can be increased slowly over this period of time. Short walks are the best way to start. The physiotherapist will be able to offer further advice.

Work

You should be aiming to return back to work 6-8 weeks following surgery. Depending on how strenuous your occupation, you may be advised to return part-time initially and then build your hours back up to full time. Everyone is individual, so speak to your Consultant or stoma care nurse specialist. You may also need to discuss your surgery with your Occupational Health Nurse.

Driving

Following any major surgical operation it is advised not to drive for 4-6 weeks. Seek advice from your GP and check your motor insurance policy prior to re-commencing driving.

Sport/Hobbies

Most sports can be enjoyed, however anything strenuous may put pressure on the valve of your Kock pouch and over time may lead to seepage/leakage of mucous and/or faeces. If concerned you should seek advice from your Consultant, stoma care nurse specialist or physiotherapist with regards to when best to recommence any sporting activity.

Travelling

When ready to travel, travelling is quite safe but may need a little more thought and consideration. When travelling abroad you might consider the following:

- A change in environment may alter your pouch output
- Hot climates increase your risk of dehydration, consider increasing your fluid and salt intake
- Where unsafe to drink tap water only drink bottled.
- As a precaution always take a supply of anti-diarrhoea tablets and rehydration sachets.
- Avoid ice-cubes, ice-cream and salads washed in local water
- Carry catheters, medication etc in your hand luggage
- Have good travel insurance
- If you need to irrigate use bottled water.

Sex and Pregnancy

Your usual sex life can resume when you and your partner are ready. With pelvic surgery there is a risk of sexual difficulties following surgery.

For men, they may experience failure to get an erection or ejaculation or both. For women, they may find sexual intercourse painful due to change within the pelvic anatomy or vaginal dryness. Any sexual difficulties should be discussed with your Consultant and stoma care nurse specialist.

The method of contraception for family planning should be discussed with your stoma care nurse specialist. The contraceptive pill absorbs effectively in the small intestine as long as the pouch output remains a porridge-like consistency.

It is important to note that some patient’s fertility may be considerably reduced after surgery for inflammatory bowel disease. Pregnancy following Kock Pouch is possible, however if planned then this should be discussed with your Consultant. Once pregnant, the pelvic location of the pouch may change as the baby grows within the womb. This pressure can cause the valve to slide and therefore lead to intubation difficulties. There is also a small risk of bowel obstruction. Pregnancy should go to full term and a vaginal delivery is recommended.

Problem solving and concerns

Difficulty intubating

Relax and change position. Sometimes stretching your abdomen and inserting the catheter at a different angle can help. Also twisting the catheter slightly as you insert it and instilling a small amount of water as you intubate can help prevent the mucosa getting stuck in the drainage holes on the catheter. Do not keep trying and trying as this can make the mucosa in the valve swell and make intubation more difficult. Leave it for an hour or so and then try again. If you have not been able to intubate for 12 hours then seek medical advice.

Leakage

Leakage/seepage of mucous is normal and this should be able to be contained in a stoma cap or gauze dressing. This mucous may be faecally stained or have a small amount of blood in it - do not be concerned. If the leakage is profuse then you may need to wear a stoma appliance. If this continues you should consult with your Consultant.

Bleeding

The mucosa leading to your Kock pouch may bleed slightly with the passage of your catheter - this is normal. If bleeding is profuse and continuous then you should consult your Consultant.

Pain

Intubating the pouch should not be painful but if you have difficulty intubating and have persevered trying then you may experience discomfort. This should pass quite quickly. If you have pain within your pouch you may have pouchitis which is treated with antibiotics. Please consult your Consultant, Stoma care nurse specialist or GP.

Summary

This is only a guideline and as your confidence grows with your Kock pouch you will find that different things affect you in different ways at different times. Adaptation to the Kock pouch is individual and can take up to 2 years following the initial surgery.

Therefore, take each day as it comes and live life to your fullest ability. You will still be susceptible to coughs and colds and upset stomachs and shouldn't necessarily blame the Kock pouch. If your symptoms persist then you should contact your GP, Consultant or stoma care nurse specialist.

References

Available upon request. Please contact IA for further information.

About IA

IA (Ileostomy and Internal Pouch Association) is a support group which has the primary aim of helping people who are living with an ileostomy or an internal pouch; their family, friends and carers.

It was started in 1956 by ileostomy patients and members of the medical profession. It was the first ostomy association in the UK and is a registered charity.

Certain inflammatory bowel diseases, such as ulcerative colitis and Crohn's disease sometimes cause such damage to the patient's large intestine (colon) that it is necessary for the surgeon to remove it entirely.

With a Brooke ileostomy, the lower end of the small intestine (ileum) is brought out through the abdominal wall and the body's waste matter is collected in an externally attached bag. Alternatively, the patient, depending on the reason for surgery, may be able to choose to have an internal pouch, which involves the construction of a reservoir from a section of the ileum. Someone who has an internal pouch does not need an external bag.

It is estimated that there are more than 9,000 new ileostomy operations carried out in England alone each year (source: NHS 2018) and around 400 internal pouch surgeries (source: Ileoanal Pouch Registry 2017). This means that you will almost certainly have met someone who has an ileostomy or internal pouch, as they lead perfectly normal lives.

What are IA's aims?

Any serious illness will disrupt a person's normal lifestyle, especially if it has lasted many years and has led to major surgery resulting in a change of body function and body image.

IA aims to help anyone living with, or supporting somebody with, an ileostomy or an internal pouch to return to a fully active and normal life as soon as possible.

IA aims to help them with all aspects of their rehabilitation including social activities, and relationships with their families, friends, employers, colleagues and members of the general public.

IA aims to work in close co-operation with the medical authorities as part of a team whose primary aim is the complete rehabilitation of every ileostomy or internal pouch patient.

IA aims to promote and co-ordinate research – not only into ways of improving the quality of life with an ileostomy or internal pouch, but also into the illnesses which lead to these operations.

IA aims to improve knowledge about the management of ileostomies or internal pouches and encourage development of new stoma equipment and skin care preparations.

IA Activities

Hospital and home visiting to give confidence and encouragement, by example, and practical help in living with an ileostomy or an internal pouch.

Members' meetings are arranged throughout the country by IA's local member organisations. A medical adviser or stoma care nurse may be present to give advice if necessary and there may be a guest speaker, either on a medical subject or one of general interest.

Equipment exhibitions are often held at members' meetings, with manufacturers' representatives present to give advice and answer questions. Members have the opportunity to examine and compare all the alternative brands to find the ones best suited to their individual needs.

The **IA Journal** is published quarterly and is sent to every member free of charge. It is full of articles of interest, news and views, exchanges of correspondence, and advertisements by equipment manufacturers of their latest products. Other literature is also available from national office.

Medical research is carried out into the illnesses which lead to ileostomy or pouch operations, and into many aspects of life without a colon.

Lectures and demonstrations are often given by IA members to groups of doctors, surgeons and nurses, to assist them in gaining more knowledge about ileostomies or internal pouches for the benefit of future patients who need such operations.

IA Organisation

IA is represented by a network of local member organisations across the UK and Ireland.

Each group offers support to its members, prospective members and other interested parties on a local level.

IA Membership

IA membership is open to anyone living with, or due to have, an ileostomy or an internal pouch; to family, friends and carers or anyone who may be living with any other type of stoma or is interested in the work of IA.

To join IA visit www.iasupport.org or contact us for an application form using our contact details on the back of this booklet.

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