



Ileostomy & Internal Pouch  
Association

Because we know, we care

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# Families and Carers

**IA is the national support group specialising in the support of people with an ileostomy or internal pouch.**



Having major surgery can be stressful and difficult for the patient, their partner and other family members. When the surgery is to form an ileostomy or internal pouch, a person may also feel alone and struggle to come to terms with their altered body image. Partners and other family members might feel pushed away by the person going through surgery, while they too are struggling and need time to understand what is happening to their loved one. IA is here to support everyone; the patient, their partner, carers, and other family members.

When surgery is done as an emergency, it can be frightening for the patient, their partner and family members - although possibly more so for their partner/family members as the patient is often too ill to fully understand the situation. It is important to try and understand what is happening and what will happen to your loved one after surgery. Talking to the surgeon, and stoma care nurses may help so you can offer support after the operation. The stoma care nurses will have literature available to read, and IA can also provide you with easy to understand information about living with an ileostomy or an internal pouch.

Where surgery is scheduled in advance and is not being done as an emergency, there is often more opportunity for family and carers to offer support, and get support themselves. If the patient agrees, then attending hospital appointments with both the surgeon and stoma care nurse can be beneficial for everyone. The family member or carer can learn more about what is going to happen and how they can support their loved one. This can also help the patient who may not be taking in everything that is being said during the appointment because of their fears and concerns about having surgery.

IA offers a visiting service to people who are due to undergo, or have undergone surgery. The trained visitor who has been through a similar experience is closely matched to the patient in terms of age, gender and lifestyle and is a great opportunity to talk to someone who understands what they are going through. Your loved one may want you to be part of this, whether it happens by phone or face to face. Additionally IA can put you, the family member or carer, in touch with others who have supported those they care for through surgery.

After surgery, you may find the biggest challenges come once your loved one is discharged home. Leaving the security of the hospital nursing staff can be very daunting, and it is common for the patient to feel anxious as they return home. You can help by offering practical and emotional support, whilst also respecting that he/she may wish to be independent and come to terms with surgery in their own way. Offering encouragement to help them to get back to everyday activities is a helpful and practical way to support someone after surgery; for example, going with them on a walk everyday helping them to gradually build their strength and confidence.

IA has a range of literature available for both patient and partner/carer to help them understand more about living with an ileostomy or an internal pouch. IA's local groups are also there to offer guidance and support; many partners and carers come along to group meetings, with or without the family member with the ileostomy/internal pouch, and find it beneficial to be able to chat informally with others in a similar situation. The forums on IA's website also contain a section for family and carers to ask questions or you can connect with others via social media or through IA's Journal.

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