

When someone in your family has IBD

Introduction

It is common for people living with Inflammatory Bowel Disease (IBD) to feel that those around them don't understand their condition, or the effects this can have on their daily lives. This leaflet is written to help you to recognise the physical and psychological effects of the disease, and answer questions often expressed by those supporting someone with IBD.

There is no right or wrong way to deal with difficult situations – everyone has their own way of coping and you may not want to deal with things in the ways suggested below.

What is IBD?

IBD is a term used to describe Ulcerative Colitis and Crohn's Disease. In Ulcerative Colitis the lining of the colon (large bowel/intestine) becomes inflamed and ulcerated. Crohn's Disease is inflammation of the digestive tract which can occur anywhere between the mouth and the anus, but most commonly affects the small bowel (intestine) or the colon. Crohn's Disease causes ulceration and damage to both the lining and the wall of the intestine.

Symptoms can include abdominal pain, weight loss, urgent or bloody diarrhoea (or constipation for some people) and extreme tiredness. Some people may also experience nausea, vomiting, swollen and painful joints, back pain, mouth ulcers, inflamed eyes, rashes on their body, red lumps on their legs, or painful abscesses around the anus. The symptoms will vary in severity from person to person and may flare up or improve at different times. Many, but not all people with IBD will experience some periods of remission, when they are free of symptoms.

It is estimated that about 180,000 people in the UK have Ulcerative Colitis or Crohn's Disease. The illness can occur at any age but most frequently starts between the ages of 10 and 40 years. There is no cure at present.

What causes IBD?

The cause or causes are not yet known. Researchers believe IBD may be caused by an abnormal reaction of the immune system to intestinal bacteria, sometimes combined with genetic factors and environmental triggers.

Is IBD like IBS?

IBD is often confused with IBS (Irritable Bowel Syndrome). IBS is a separate condition, needing different treatment, although some of the symptoms may be similar.

How is IBD treated?

Treatment will depend on the severity of the disease, and which part and how much of the gut is affected.

➤ Medication

This is usually prescribed to reduce the swelling and pain of inflammation, either in tablet form taken by mouth or in the form of enemas or suppositories inserted into the anus. Sometimes drugs are given directly into a vein (in hospital).

➤ Diet

Some foods may aggravate the symptoms, but generally people should eat as varied and nutritionally sound a diet as possible. In Crohn's Disease it may help to eat food which is easily digested such as a low residue diet. Treatment for Crohn's is sometimes in

the form of a special liquid diet prescribed by a specialist doctor or dietitian.

➤ **Surgery**

If drug therapy is ineffective surgery may be needed to remove some of the bowel. In Ulcerative Colitis this may involve removal of the colon. In Crohn's Disease the most severely affected parts of the bowel may require widening or removal.

➤ **Rest**

It is also very important for people with IBD to get enough rest, particularly during a flare-up of their disease.

What is it like to live with IBD?

It can be hard to live with IBD, especially during a flare-up when symptoms can be acute. People can feel very unwell and can suffer from lack of appetite and nausea, diarrhoea, severe abdominal pain, weight loss and extreme tiredness, as well as sometimes bleeding from the rectum.

IBD can be a very embarrassing illness to live with. Some people suffer from bloating and wind, which they are unable to control, and they may worry about making noises and smells that might offend other people.

People may need to go to the toilet urgently and often, with very little warning, and can be devastated when they have an 'accident' with uncontrollable diarrhoea. This can be very distressing and can limit a person's lifestyle – they may feel too afraid to leave their home in case they have an accident in public, or may restrict themselves to visiting places where they are familiar with the toilets. Travelling and holidays may become difficult or even impossible.

It may be difficult to maintain a normal social life, which can lead to isolation - even meeting friends for a meal may seem daunting when someone is continually worrying about the possible effects of eating. Certain jobs may no longer be possible, or they may not be able to work at all, which in turn can lead to

financial hardship, loss of self-esteem, frustration and despair.

People with IBD can suffer from very low self-esteem when it comes to intimate relationships – they can worry that they are no longer attractive, especially if they have had surgery resulting in their body waste being collected in a bag on their lower abdomen. Their feelings about sex can also be affected by tiredness or pain, or by just feeling unwell, as well as by the fear of an 'accident' at an intimate moment.

Other concerns may include the risk of cancer, the need for surgery or the side effects from medication. The possibility of developing cancer understandably creates apprehension for everyone. NACC has an Information Sheet about the slightly increased risk of bowel cancer for a small number of people with IBD. (See *Further help* below.)

Side effects from medication

People with IBD can suffer with adverse side effects from their medication, particularly if they are taking steroids. Although often temporary, these may include changes to physical appearance and emotional well being. These can be very distressing and hard to come to terms with.

➤ **Physical appearance**

Side effects may include weight gain, rounding of the face, a fatty lump in the middle of the upper back, facial hair, hair loss and acne.

➤ **Emotional well being**

Side effects may include difficulty in sleeping, irritability, depression, anxiety, panic attacks or mood swings from highs to deep lows.

➤ **Other side effects**

People may also experience night sweats or headaches due to raised blood pressure. They may be concerned about developing longer-term side effects such as diabetes, osteoporosis, or, more rarely,

glaucoma or cataracts.

➤ **Withdrawal symptoms**

Reducing or coming off steroids can also be particularly unpleasant. Withdrawal symptoms may include extreme fatigue, severe pain in the muscles, bones and joints (especially in the legs and feet), changes in appetite, and mood swings. On some days people may become tearful or anxious, and find everything too much for them.

What is it like to live with someone who has IBD?

At times you may find it hard to live with someone who is tired or in pain, doesn't feel like eating properly, is continually rushing to the toilet, or experiencing distressing side effects from their medication. They may not be able to take on their fair share of the responsibilities in the home or family, go out to work, lead an active social life, or even venture out of their home. On some days even the simplest task may be too much for them. They may feel angry that they have got this illness, or they may feel bad about themselves, and take out their anger and frustrations on you. Or you may feel frustrated if you can't get through to them because they have become quiet, withdrawn or distant.

What can I do to help?

Most people with IBD show great courage and determination in dealing with their symptoms, but sometimes they can feel overwhelmed by their illness. It may be difficult for them to talk about their feelings or to ask you for help. Your positive support, patience and understanding can make a big difference to their lives.

Ways that you can help may include:

➤ **Practical help**

Offer practical help when needed, such as shopping, cooking or caring for dependants, or give lifts if driving or using public transport is difficult.

➤ **Being there**

It is important for them to have someone they can trust to talk to, who will really listen to them and try to understand how difficult life has become for them. Try to build up their self-esteem by offering them encouragement and telling them that you think they cope well with their symptoms.

➤ **Reassurance**

Try to keep it low-key if they cannot get to a toilet in time and have an 'accident'. Reassure them that it doesn't matter, but without denying the distress they feel.

If you are in a sexual relationship, it is important that you reassure your partner that you love them and that they are still attractive to you.

➤ **Sensitivity**

Try to avoid making insensitive comments about smells, noise, the length of time they spend on the toilet or the fact that they may need to use the toilet a lot, and the inconvenience of having to stop or find toilets when you are travelling or are away from home.

➤ **Humour**

Although it is important for you to be sensitive and caring, keeping a sense of humour is also important, and sometimes the most trying situations can be alleviated by seeing the funny side and having a good laugh together about it.

Financial support

Having a long-term illness can cause financial problems because of additional expenses due to the illness or living on a reduced income – the sufferer themselves may have had to take time off work or have stopped working altogether, or you may have given up work to care for them.

Both you as a carer, and the person you are supporting, may be eligible for welfare benefits. Claiming the benefits you are entitled to is a sensible step to take and can help by reducing the stress caused by money worries. However, the welfare benefit system is complex, and making a claim can be a difficult and distressing experience, particularly for someone with bowel disease. You may find it useful to get information and support from someone with experience of welfare benefits. For example, you could contact a Citizens Advice Bureau (CAB) and ask for an appointment with a welfare benefits adviser, who can do a benefits check and help with any claims. Some CABs also have debt advisers who may be able to help with financial difficulties or budgeting to meet ongoing financial commitments. Look under Citizens' Advice Bureau in your phone book for details of your nearest one. You can also find details of your nearest bureau at: www.citizensadvice.org.uk.

NACC has some written information on welfare benefits for people with IBD, and runs a telephone appointment system to help people with IBD talk through any practical questions relating to Disability Living Allowance and Attendance Allowance. NACC also provides personal grants to help people suffering from IBD to meet special needs which have arisen as a direct result of their illness.

Look after yourself

Living with, or being close to, someone with IBD can be stressful and can contribute to difficulties in any relationship. When you are doing your best to support your loved one it is easy to neglect your own needs. It is simply not possible to remain cheerful and caring all the time. Remember that you, too, need consideration, support, and listening to with understanding when you feel down. It is important that you too can share your feelings honestly with someone when you feel frustrated or disappointed, without feeling guilty about it, but at the same time without blaming the person who is ill.

The opportunity to air some of your frustration or disappointment with the person you are trying to support may help the relationship if done with a sensitive and caring dialogue. Try not to 'blow your top' as this would only end in distress for both yourself and the other person. If you feel at the end of your tether perhaps you could talk through your feelings with someone outside of the relationship, such as a trusted relative or friend, or try contacting a counsellor, for support. NACC has a service called NACC-in-Contact where people who have a personal experience of IBD offer a confidential, supportive listening service by telephone to sufferers, their relatives or carers.

Remember that you may need time for yourself, to do something that you want to do, such as going out with friends, even if your partner or relative cannot go out themselves. It is important to keep your friends and social contacts, to avoid isolation, and also to give yourself treats sometimes, to feel all right about this and not to feel guilty about meeting your own needs.

The person you are supporting may not be able to be gracious, loving or supportive to you sometimes – try not to take this personally but to remember that they are unwell, that they are not always like this, and that it is not your fault. Remember that you are doing the best you can in what may be very difficult circumstances, and that is the most that anybody can do.

Further help

If you have any further queries please call the **NACC Information line** on **0845 130 2233** or email: nacc@nacc.org.uk.

The line is open weekdays from 10am-1pm (excluding Bank Holidays). There is an Answerphone service outside of these hours.

To speak to a NACC Contact please call **NACC-in-Contact** on **0845 130 3344**. Open weekday afternoons 1-3.30pm and evenings 6.30-9pm (excluding Bank Holidays).

Parent-to-Parent support

Volunteers who are parents of children with IBD have been trained to give confidential support and information by phone to other parents. Call the NACC Information Line for an appointment.

IBD and Me

NACC also provides a website discussion forum for 16-29 year olds with IBD:

www.ibdandme.org.uk

NACC has a comprehensive range of **Booklets** and **Information Sheets** including:

Understanding Colitis and Crohn's Disease;
Living with IBD
Food and IBD
Drugs used in IBD
Surgery for Crohn's Disease
Surgery for Ulcerative Colitis
How can counselling help you?
IBD in children
Caring for a child with IBD:
 a Parent's Guide
Sexual relationships and IBD
Is there a risk of cancer in IBD?
Managing Bloating and Wind
Managing Diarrhoea
Travel and IBD

Phone the NACC Information Line for a full list of publications, or for details on how to join NACC. Information sheets and FAQs can be downloaded from the NACC website: www.nacc.org.uk. You can also join NACC online.

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We hope that you have found the information helpful and relevant. We welcome any comments from readers, or suggestions for improvements. Please send your comments to Helen Terry at NACC, 4 Beaumont House, St Albans, Herts AL1 5HH – or email h.terry@nacc.org.uk

The National Association for Colitis and Crohn's Disease (NACC) is a voluntary Association, established in 1979, which has 30,000 members and 70 Groups throughout the United Kingdom. Membership of the Association costs £12 for the first year and £10 subsequently. Additional donations to help the work of the Association are always welcomed.