

# Helping patients own their IBD

## Information for patients on self-management for IBD relapse and how to extinguish a flare

Always remember Crohn's disease and ulcerative colitis are chronic conditions and currently there is no cure. Both conditions alternate between remission (no symptoms) and relapse (where symptoms return). It can be months or years between them but it is important to report symptoms as soon as possible so they don't get out of control.

### What you can do if you think IBD symptoms are returning or uncontrolled

**A relapse or exacerbation of IBD is often called a 'flare'. If your bowel habits begin to change, it may be that IBD has become active.**

#### Points to notice

- Has your bowel frequency/stoma output changed significantly?
- Are stools loose or have you had diarrhoea with blood or a slimy substance for more than three days?
- Have you had abdominal pain?
- Are you waking at night with symptoms?

If yes, you should contact your GP or IBD nurse as soon as possible.

#### Step 1 – Is this an emergency?

If you have any of the following symptoms, please contact NHS 111 or attend your local emergency department:

- fever (a temperature above 37.5 °C)
- severe abdominal pain
- vomiting
- no bowel motions/stoma output for 3 days or more

#### Step 2 – Easy tests

##### Blood tests

Contact your GP or IBD nurse specialist to organise bloods tests for full blood count, liver function, urea and electrolytes, and inflammatory markers (ESR &

C-RP). Blood tests are used to determine an IBD relapse and help to decide on best treatment options.

### Stool tests

Stool tests for bacteria (MC&S) and faecal calprotectin. Did you know having IBD increase the risk of developing infections in your gut? A stool sample for MC&S can help detect this. In some cases there may be other causes for your symptoms than IBD. Calprotectin is a protein released in your gut during a relapse/flare.

### Step 3 – Current medicines

The dose for mesalazine based medicines can be increased during a flare.

**Do not increase other agents, eg azathioprine, mercaptopurine, methotrexate, adalimumab, infliximab, vedolizumab, ustekinumab.**

There are a number of brands of mesalazine, each has a different dose as they are released differently in the bowel.

|                                       | <b>Maintenance dose</b>             | <b>Flare dose</b>                   |
|---------------------------------------|-------------------------------------|-------------------------------------|
| <b>Octasa &amp; Asacol MR</b>         | Up to 2.4g OD (or in divided doses) | 2.4-4.8g in divided doses           |
| <b>Mesavant XL</b>                    | 2.4g OD                             | 2.4-4.8g OD                         |
| <b>Pentasa tablets &amp; granules</b> | 2g OD                               | 4g OD (or in divided doses)         |
| <b>Salofalk Tablets</b>               | 500mg TDS                           | 0.5-1g TDS                          |
| <b>Salofalk Granules</b>              | 500mg TDS                           | 1.5-3g OD preferably in the morning |

Key:

OD – once daily

BD – twice daily

TDS – three times daily

g – grams

mg – milligram

If symptoms settle using 'flare dose' then after six to eight weeks reduce back to 'maintenance dose'.

### Rectal therapy – mesalazine suppositories and enemas

If you are familiar with using these, it is safe to start every night for two weeks

to help improve symptoms. If symptoms do not improve within one to two weeks, please contact your IBD nurse.

### **Steroids (prednisolone/budesonide/beclomethasone)**

Please note these medications are not recommended as long term treatment, these are mostly used when IBD symptoms have not responded to current therapy. If you are prescribed this by the GP, please inform your IBD team.

Current treatments for IBD are designed to prevent the requirement of steroid treatment and side effects associated with this medication. Steroid treatment must not be stopped abruptly.

### **Step 4 – Call the IBD advice line**

#### **Barnet Hospital and Chase Farm Hospital:**

**Tel:** 020 7216 4761 (line open Mon-Fri, 9am-5pm)

**Email:** [rf.bcfh-ibdurses@nhs.net](mailto:rf.bcfh-ibdurses@nhs.net)

#### **Royal Free Hospital:**

**Tel:** 020 7830 2283 (line open Mon-Fri, 9am-5pm)

**Email:** [rfh.ibdnurse@nhs.net](mailto:rfh.ibdnurse@nhs.net)

Please provide your full name, date of birth, contact number, and hospital (MRN) number if known with a brief message. We aim to respond within one working day, please note this should not be used in an emergency.

### **More information**

For more information about the IBD service at the Royal Free London, please visit our website: [www.royalfree.nhs.uk/services/services-a-z/gastroenterology/inflammatory-bowel-disease-ibd-treatment/](http://www.royalfree.nhs.uk/services/services-a-z/gastroenterology/inflammatory-bowel-disease-ibd-treatment/)

### **Your feedback**

If you have any feedback on this leaflet or for a list of references for it, please email: [rf.communications@nhs.net](mailto:rf.communications@nhs.net)

### **Alternative formats**

This leaflet is also available in large print. If you need this leaflet in another format – for example Braille, a language other than English or audio – please speak to a member of staff.

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