The energy draining out of you?
The Big Sink Hole everlasting treadmill running on a flat battery?
Sledgehammer Hill knocked for six?
Feeling stuck in a rut?
Zombie Land landed on you?
Brain Fog fighting your way through the fog?
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INTRODUCTION

In 2009, Crohn’s and Colitis UK were awarded a £481,242 research grant for Improving Fatigue in People with Inflammatory Bowel Disease. The project was managed by Crohn’s and Colitis UK and delivered in conjunction with our Research Partners at King’s College London, University College London and Addenbrookes’ NHS Trust.

Steering Group
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And thanks to all the Crohn’s and Colitis UK members and healthcare professionals who gave their time to this project.

For the purposes of this report, all participants names have been replaced by pseudonyms.
**FATIGUE – AN UNDER-RESEARCHED PROBLEM**

Inflammatory Bowel Disease (IBD) affects the quality of life of 300,000 people in the UK. Severe fatigue is a commonly reported symptom; during remission 40% of people report it as the primary symptom. It is estimated that 100,000 people may benefit from improved awareness and treatment of IBD-related fatigue.

Fatigue is more common and often worse when IBD is active. Many people find that this improves as their IBD improves but, for some, there can be a time lag of weeks or even months before they regain their normal energy levels. Sometimes the fatigue does not go away even when the IBD seems to be completely under control.

In 2008 Crohn’s and Colitis UK conducted focus group interviews with 46 participants. The research found that fatigue had a severe effect on the social and emotional well-being of participants and limited their employment opportunities. People reported that their fatigue-related issues seemed to be poorly understood by clinicians and were not addressed in medical consultations.

Fatigue in IBD has been a very under-researched area – in a preliminary search of the medical journal database Medline in 2009, 5 references were retrieved for fatigue in IBD. Similar searches for cancer and fatigue gave 898 references and for multiple sclerosis and fatigue gave 353 references. A systematic review of fatigue in inflammatory bowel disease conducted in 2010 found ten studies that included data on IBD patients, but only one study (conducted in children) measured fatigue in IBD patients as a primary outcome.

Although there is a strong correlation between fatigue and poor quality of life in patients with IBD in remission, there has been little research either about the experience of patients with IBD-related fatigue or on what impact fatigue has on overall quality of life.

What is IBD fatigue?
Fatigue has been defined as an overwhelming sense of unremitting tiredness, lack of energy, or feeling of exhaustion not relieved following rest or sleep. However, the subjective individual nature of fatigue makes it difficult to define, assess and measure.

In our 2008 focus groups we found that participants described fatigue as affecting their physical and cognitive (‘thinking’) abilities and impacting on their everyday functioning. It is clear that IBD fatigue affects many areas of life.

What causes fatigue in IBD?
There are many factors which may combine together to cause fatigue in IBD.

- Diet and alcohol
- Being overweight or underweight
- Other health problems
- IBD medication, in particular steroids
- Sleeping problems
- Pain
- Extremes of weather
- Stress
- Emotions such as depression and anxiety
- Lack of support and understanding

Any, or a combination of these factors may lead to fatigue. However, some people have no explanation for their fatigue.

The key findings are:

### Key Finding: The review confirmed that there is little evidence to support interventions which result in IBD fatigue being poorly managed. There is also a need for greater awareness of the issue among healthcare professionals.

### Key Finding: There were no studies identified reporting exclusively on experience of fatigue as experienced by people diagnosed with IBD.

The literature review concluded that IBD fatigue has a negative impact on individuals’ physical and cognitive performance, resulting in a reduced quality of life. Inconsistent use of terminology and definitions of IBD fatigue indicated that future research should explore experience of IBD fatigue from the individual’s perspective. The long-term consequences of IBD fatigue and its prevention and management have not been studied and no questionnaire was validated to measure IBD fatigue.

Although there are many research articles describing the physical impact and treatment of IBD, they did not report on people’s experience of living with IBD and how symptoms such as fatigue affect their quality of life. Reference to the full literature review paper can be found in the Appendices on page 18.
LIVING WITH IBD FATIGUE

6

(Roger, aged 64)

‘It’s very strange to put your finger on it’ and out of the blue, like hitting a brick wall. hour by hour and can come on suddenly unpredictable, varying day by day or even to different people. It can also be very difficult to describe and put into words what fatigue is like, and it feels different with IBD in a number of different ways:

1. The experience of IBD fatigue
2. The impact of IBD fatigue on people’s lives
3. The coping mechanisms used by people with IBD fatigue

What did patients tell us?

1. The experience of IBD fatigue
Many participants in our research had difficulty to describe and put into words what fatigue is like, and it feels different to different people. It can also be very unpredictable, varying day by day or even hour by hour and can come on suddenly and out of the blue, like hitting a brick wall. It’s very strange to put your finger on it’ (Roger, aged 64)

‘physical heaviness … just a general lassitude and can’t-be-bothered-ness. It’s like a kind of physical depression … feeling under the weather’ (Julie, aged 47)

2. The impact of IBD fatigue on people’s lives
We found that fatigue can have an effect on all aspects of life. Some people find it difficult to function at all when their IBD is active, both because of bowel symptoms but also fatigue. Our interviews suggest that fatigue may affect the lives of people with IBD in a number of different ways:

• Physical Activities
The low energy levels caused by fatigue can make it very hard to take part in physical activities such as sport. Some people find that they do not even have the energy to carry out everyday tasks such as driving, housework or collecting the children from school.

• Memory and concentration
Some people find that fatigue can make it difficult to think logically and had difficulty with concentration and memory. Some people reported that when they are very fatigued, they have trouble speaking and may stumble over their words. Some people call this ‘brain fog’.

• Emotions
Fatigue had an impact on people’s emotions. Participants reported that they cannot do as much as they would like, and often feel frustrated and angry. Some people may feel isolated and lonely if they find it difficult to get out and socialise with friends. This can lead to depression and low confidence.

• Social activities
Because of its unpredictable nature fatigue can make it very difficult to take part in social activities. This may mean that people with IBD fatigue find it difficult to go on holiday, travel, socialise, or even take part in hobbies or interests.

• Relationships
Some people find that fatigue has a negative effect on their relationships with friends and family. For example, some may feel that because their condition cannot be seen, people do not believe them and think that they are being anti-social. People living with IBD fatigue report feeling guilty if their partner or family have to do extra things to help or if their family miss out on doing things together.

We also found that people found it difficult to talk about fatigue or for others to understand it, and that having a conversation about fatigue with a healthcare professional or a family member can be the first step towards recognising the problem and dealing with it.

Several of our research participants found that even taking part in the study had helped them to realise the impact that fatigue had on their lives.
Our focus group research in 2008 found that people rarely talked with their doctor (either GP or hospital consultants) about fatigue. During consultations, the focus was on the functioning of the bowel and not on the impact of the condition on their life. One respondent stated that ‘fatigue isn’t one that they would mention, definitely not, even if you keep saying it every time.’ Participants were made to feel that fatigue had to be accepted as an inevitable part of their condition and that nothing could be done about it.

In order to help us understand the level of awareness and information needs of fatigue in IBD among healthcare professionals, we handed out questionnaires at the British Society of Gastroenterology conference in March 2011, and sent the same questionnaire to IBD nurses as an online survey.

The survey indicates a need for greater information on fatigue and IBD, however it is noted that the survey has several limitations, particularly the self-selected and relatively small sample (94 healthcare professionals).

Despite 55.3% of respondents indicating that their patients often or very often report fatigue, and 92.6% of respondents indicating that patients report fatigue as a problem more frequently than ‘rarely’, the level of self-rated knowledge among healthcare professionals was low –

- 27% indicated that they had poor knowledge of the likely causes of fatigue in IBD
- 59.2% rated their knowledge as ‘fair’
- only 13.8% rated their level of knowledge as good or excellent [Fig 3].

In all the pie charts the percentages have been rounded up or down to the nearest decimal point.

Most respondents’ usual course of action, when faced with a patient presenting with fatigue with IBD in remission, would be to check the haemoglobin level and treat if low (92.5%). Other frequent responses chosen were referral for other diagnostic tests (41.9%), advice on diet (36.6%), advice to take more exercise (33.3%) and advice to get more rest or sleep (31.2%). Actions mentioned by respondents in the open ended response section of this question, included:

- Check disease activity and inflammatory markers
- Holistic interview identifying stressors
- Referral to IBD nurse, dietician or psychologist (the need for psychological support or referral was mentioned by many respondents)
- Check drug side effects
- Assess for depression

A high percentage (68.9%) of healthcare professionals surveyed consider that IBD fatigue can be adequately treated in most or some patients. However, given the perception of it being a treatable condition, the comparative reluctance to ask about fatigue in clinics is more troubling.

The survey results indicate that 40.4% healthcare professionals who responded actively raise the topic with their patients (often, very often or always). However, 33% only raise the topic ‘sometimes’, 18.1% only ‘rarely’ raised the topic and 8.5% stated that they never raise fatigue with their patients [Fig 4]. As the survey was filled out by a self-selected group of respondents who are likely to have above average interest in fatigue, the results suggest that there is a need to increase the profile of IBD fatigue.

The general comments included:

“Fatigue is common and I think approach should be multidisciplinary including dietician, psychologist, and gastroenterologists”

“It is the single most difficult symptom to manage as those who experience don’t seem to get any benefit from current strategies.”

“I believe that fatigue is a major issue but unfortunately still poorly recognised as a problem to IBD patients.”

“Very undertreated in primary care.”

The survey results indicated that healthcare professionals, as well as patients, would welcome greater understanding of fatigue.

At the end of our first year of research, we extended the remit of our research to conduct some in-depth interviews with healthcare professionals to further explore their understanding of IBD fatigue.

We advertised for healthcare professionals to come forward via the Crohn’s and Colitis UK newsletter and an IBD specialist nurses’ newsletter and used a snowballing method to identify other healthcare professionals. Twenty semi structured interviews were conducted with a range of practitioners (gastroenterologists, IBD nurses, general practitioners, dieticians, psychologists and pharmacists).

Key findings of this research were that:

- Healthcare professionals mentioned a variety of blood tests that could be done to assess reasons for fatigue but there was no systematic checklist or pathway for referral. There was a sense of healthcare professionals referring patients to each other with no clear objective or idea of what can be offered to the patient.
- Some felt that a fatigue rating scale would be very useful; others felt it would be another piece of paper that would not be used.
- Many healthcare professionals expressed a desire for better education and information sources on IBD fatigue.
- There was a sense of healthcare professionals’ perceptions of fatigue see the Appendices section on page 18.
WHAT CAN WE DO TO HELP IBD FATIGUE?

Up to this point we found that very little research had been conducted on IBD fatigue and that it has a significant impact on the lives of a large percentage of IBD patients even when the disease is in remission. Healthcare professionals were often unsure how to treat fatigue, and patients were reluctant to raise the issue.

The next phase of our research was aimed at producing some practical outcomes to help healthcare professionals and patients measure their fatigue and suggest ways that the fatigue can be managed.

Developing a new Fatigue Rating Scale

Our interviews with patients confirmed that fatigue was a big issue that had a severe impact on many areas of life. It also confirmed a need for a way of measuring fatigue to enable people with IBD to discuss fatigue with their healthcare professionals and test interventions. Fatigue scales had been used in many other conditions, to help patients and doctors measure levels of fatigue, however there was no scale that had been developed and validated specifically for IBD.

A draft of our new fatigue scale was rigorously developed and tested with 70 of our volunteers for the study. We then contacted 2,132 Crohn’s and Colitis members at random in October 2012 asking for volunteers to test the questionnaire, 605 people offered their help, and were then posted a booklet of questionnaires including our new IBD Fatigue rating scale (IBD-F), 469 questionnaires were returned (a response rate of 77.5%).

In testing the IBD-F scale performed well against two other fatigue scales widely used in other chronic conditions (MFI and MAF), however our study participants had a clear preference for our new scale.

Our fatigue scale, which can be accessed and scored online, or printed from our website as a PDF, will enable:

- Patients to self-assess their fatigue and the impact it has on their functioning
- Patients to more easily raise their fatigue symptoms with healthcare professionals
- Healthcare professionals to assess measure and monitor patients’ fatigue over time.

For a more in-depth analysis of the methodology of the fatigue rating scale development see the appendicies on Page 18.

Checking the reversible causes of IBD fatigue

There is a lack of strong evidence on the causes of fatigue in IBD. Previous research has identified anaemia, sleep disturbances and biochemical imbalance as possible clinical causes of IBD fatigue. It is also potentially related to a number of other non-IBD factors such as thyroid function, depression and social support. However, there is no consensus on what potential contributory factors should be assessed in a patient with IBD. In our interviews with healthcare professionals they mentioned a variety of blood tests that could be done to assess reasons for fatigue but there was no systematic checklist or pathway for referral.

We gathered together a number of healthcare professionals and people with IBD to generate a consensus checklist of possible reversible medical causes of fatigue. We then piloted this checklist with a small group of patients at an outpatient clinic. Patients were tested for active inflammation via blood, endoscopic, or faecal calprotectin markers. Once active inflammation was excluded as a cause of IBD fatigue, the other possible causes of fatigue were assessed by blood sample results.

Fifty two IBD patients thought to be in remission participated in the pilot testing of the checklist. From these, 36 (69%) were in remission and 16 had evidence of active IBD. Of the 16 with active IBD, 13 (81%) had fatigue. Of the 36 patients in remission, 18 (50%) were fatigued and 18 (50%) were in remission and not fatigued. The study found that even in remission, blood tests can reveal potentially reversible abnormalities that could be treated.

Blood tests in respect of possible causes of fatigue were not routinely requested for all patients. In addition, if tests were performed the reported abnormal blood test results were frequently not followed up and in some cases these were not acted upon as follow-up appointments.

Of the 16 with active IBD, 13 (81%) had fatigue. Of the 36 patients in remission, 18 (50%) were fatigued and 18 (50%) were in remission and not fatigued. The study found that even in remission, blood tests can reveal potentially reversible abnormalities that could be treated.

Blood tests in respect of possible causes of fatigue were not routinely requested for all patients. In addition, if tests were performed the reported abnormal blood test results were frequently not followed up and in some cases these were not acted upon as follow-up appointments.

This work has resulted in a checklist for professionals to consider what further tests might be useful for each individual patient with fatigue. This is made available as an online checklist which prompts a doctor or nurse to review recent test results and consider what else might be needed. The checklist is available on the Crohn’s and Colitis UK Fatigue in IBD website at www.fatigueinibd.co.uk/checklist.

See Appendicies on page 18 for references to further information on this study.

To view the full fatigue rating scale, visit www.fatigueinibd.co.uk/questionnaire

CROHN’S AND COLITIS UK: TACKLING CHALLENGS IN IBD FATIGUE REPORT 2014
As part of our initial research application we set out to identify two interventions to see if they made any difference to IBD fatigue. Our review of the literature identified the areas of exercise and diet as being important areas for further research (these were also areas that patients had told us they wanted more guidance).

**Exercise**

Exercise has been shown to be effective in other conditions.

We looked at the literature on fatigue interventions for cancer, multiple sclerosis (MS), and rheumatoid arthritis (RA). In total, there were 1600 papers for cancer, 400 for MS, and 200 for RA. The interventions that had been successful in treating fatigue in cancer and MS have often been exercise-related, and it was considered likely that exercise would be an effective intervention for IBD given the similarity of the description of IBD fatigue with cancer fatigue, in particular.

Our second researcher at University College Hospital spoke with patients in clinic about their experience of exercise, and found that they were very eager to talk about this issue. Many patients are physically active, even during flare-ups, but considered they could do with further guidance.

For individuals with cancer there has been a reversal of advice regarding exercise. Patients were previously advised to rest (advice we also found was often given to IBD patients in our 2008 focus groups), however, individually prescribed exercise is now acknowledged by medical experts as a treatment for cancer fatigue. Our focus group participants (2008) were frequently advised by health professionals to control their fatigue by taking rest and sleep. We wanted to answer the question – is this also outdated advice for IBD patients?

Exercise for individuals with IBD has received little attention from researchers, and because of the lack of evidence clinicians are often cautious about advising exercise. The few studies of exercise in inflammatory bowel disease have focused on low-grade walking programmes. The current research literature provides some indication that exercise is beneficial for individuals with inflammatory bowel disease, but there are currently no evidence-based guidelines for exercise and IBD.

Our review of the literature found some recent studies that have shown the following:

- Exercise is well tolerated in individuals with IBD.
- Improvements in quality of life were found in Crohn’s disease patients following a 3-month low-grade walking programme, which required walking three times a week at 60% of maximum heart rate.
- Recent studies have suggested that low to moderate activity is safe, and in general individuals with IBD should benefit from and increase exercise.
- Resistance training may particularly benefit the IBD population in whom corticosteroid use and intermittent periods of inactivity may impair muscle mass and bone health.
- There are no studies in IBD patients that support the idea that low-intensity exercise makes IBD symptoms any worse.
- Some individuals do present with gastrointestinal symptoms during high-intensity exercise, but symptoms are not common in low-intensity exercise.

In addition to the literature review, our researcher sampled eleven patients from an IBD clinic who reported themselves as ‘exercising’.

- Three of the 11 patients we questioned reported doing exercise often, to work up a sweat.
- Aerobic exercise was the most common undertaken (by all eleven patients) but only two did resistance exercise regularly.
- Four of the patients felt that exercise helped them with fatigue; the effect of exercise was described as ‘a good kind of tiredness’.
- Six patients out of the 11 questioned reported having received no advice from healthcare professionals regarding exercise.
- All of the exercising patients felt that exercise was beneficial and that ‘both children and adults with IBD should be encouraged to exercise’.
- Patients felt there was a need for hospitals to offer exercise classes for people with mobility difficulties.

Our preliminary research concluded that for patients to vary exercise levels according to their disease activity, effects of medication and severity of symptoms, there is a need to test individually prescribed exercise for the patient.

See the appendixes on page 18 for reference to publication on exercise in individuals with IBD.

**Diet**

An intervention based on diet was also considered. It was hoped this would enable an individual with IBD to reduce their fatigue by making suggested dietary changes. A number of options were considered, but the literature pointed towards a study to assess reduction of fatigue by increasing intake of omega 3 fatty acids (found in fish oil).

There have been studies in IBD focusing on effects of omega 3 on disease activity and the immune system, but none on fatigue. Although benefits of increasing dietary omega 3 fatty acids in relation to fatigue in other diseases have been reported, more research in this area is required with IBD patients.

Our focus group had indicated that patients experienced both physical and cognitive fatigue, and randomised controlled studies using omega 3 supplements have found positive effects on mood, depression, cognitive function and mental fatigue. It has been suggested that the anti-depressive effects of omega 3 fatty acids may relate to anti-inflammatory gut-brain mechanism, and that these fatty acids could therefore improve mood and quality of life in individuals with IBD.

It has been found that omega 3 fatty acids may improve physical performance by increasing blood flow to active muscles and reducing muscle soreness and inflammation after exercise. Other reported effects include a reduction in heart rate and oxygen consumption during exercise.

There are also indications that omega 3 has been useful for fatigue in other long-term medical conditions – for example in breast and lung cancer survivors.

We designed a study which combined omega 3 fatty acids and exercise. There has been recent research to study the mechanism by which exercise acts on the brain and it appears to enhance the effects of omega 3 fatty acids (DHA). The evidence would suggest that the combined effects of increasing omega 3 and exercise on fatigue could be more effective than exercise or omega 3 alone.

**THE INTERVENTION STUDY**

- Some individuals do present with gastrointestinal symptoms during high-intensity exercise, but symptoms are not common in low-intensity exercise.
- Resistance training may particularly benefit the IBD population in whom corticosteroid use and intermittent periods of inactivity may impair muscle mass and bone health.
- There are no studies in IBD patients that support the idea that low-intensity exercise makes IBD symptoms any worse.
- Some individuals do present with gastrointestinal symptoms during high-intensity exercise, but symptoms are not common in low-intensity exercise.
- There have been studies in IBD focusing on effects of omega 3 on disease activity and the immune system, but none on fatigue. Although benefits of increasing dietary omega 3 fatty acids in relation to fatigue in other diseases have been reported, more research in this area is required with IBD patients.
Methods
IBD patients attending the clinics at University College Hospital London were screened for their suitability to participate in a clinical study testing the change in fatigue following a 12-week programme of four possible treatments: individually-tailored exercise plus an inactive supplement (placebo), or an omega 3 fish oil supplement, compared with no exercise with fish oil supplement, or placebo.

Screening Requirements
Participants were required to have:
• no active disease;
• to eat less than 2 portions of oily fish per week on average;
• to undergo moderate-vigorous exercise less than twice per week on average; and
• to have no other diseases which could contribute to fatigue, eg, anaemia.

Interventions
Exercise: A 15-minute consultation enabled the personal trainer and participant to devise and record a goal-based, individually-tailored exercise programme, which fitted with the patient’s lifestyle, time restrained, and current level of fitness/activity. The trainer was able to help individuals who, to a certain degree, were already exercising to generate a more formal exercise plan. For participants with little experience of regular exercise, the trainer suggested ways of incorporating more activity into their daily lives, either by extending current activities or by trying new ones within their capabilities.

Omega 3: All participants received bottles of apparently identical supplement (some were omega 3 and some were placebo) with instructions on how and when to take them, a supplement record sheet, and a simple diet diary to uncover the level of oily fish intake.

Follow-Up
All subjects were telephoned one week after starting their intervention, and were contacted subsequently by email or telephone at fortnightly intervals to see how they were progressing and whether they had any issues or problems with the treatment. Further support was provided by the trainer if requested.

Any change in fatigue resulting from the interventions was assessed by comparing the results of questionnaires patients completed and data from activity monitors used for a week, before and after the 12-week study period.

We used several different questionnaires to measure fatigue, including the FACT-F questionnaire (the main way we wished to measure fatigue), and our new IBD Fatigue Scale (IBD-F).

Results
60 participants commenced their allotted intervention; 52 patients completed the study intervention and attended for the final fatigue assessments.

Study Outcomes
i) The effects of exercise and fish oil on fatigue
Statistical comparisons showed no significant interaction between the effects of exercise and fish oil on fatigue (using one did not enhance or detract from the effect of the other). Fatigue appeared to worsen in the omega 3 groups, for reasons it is difficult to explain. Fatigue was however significantly reduced in the exercise groups, as measured by our new IBD-F score.

ii) Adverse effects resulting from exercise and fish oil
Very low numbers of adverse events were reported (less than 1%), and only 1 treatment-related adverse event (in one individual undertaking exercise) was experienced by the 52 individuals undertaking the intervention. The main effects of both treatments suggested that neither exercise nor fish oil were associated with the likelihood of a patient experiencing side effects, including gastrointestinal symptoms.

Conclusions and pointers for further research
There was some evidence of improvement in fatigue with exercise. We found exercise and fish oil, either singly or in combination, to be safe and well-tolerated. In particular, there was no evidence for any impact of exercise on gut-related symptoms; this is significant since our previous focus groups studies with IBD patients and their physicians, showed this to be a major concern. That this was not found suggests that IBD patients and their physicians can feel confident that patients can follow the Department of Health recommendations for 150 minutes of moderate-vigorous exercise per week, enabling them to enjoy the proven health-related benefits of this level of exercise.

On an anecdotal level, reports from a few of the exercise group patients indicated life-enhancing benefits following adherence to the exercise plan suggested by the trainer. These included improved relationships with friends and family, and a greater feeling of well-being.

Limitations of the study
The need for relatively low baseline levels of physical activity excluded a significant proportion of the UCLH patient population, who were in their thirties on average and relatively active (whilst in remission). In addition, the study protocol did not formally assess the degree to which participants increased their exercise levels, or how well they met their planned exercise goals.

Future studies
The results of this intervention study suggest that further investigation would be warranted of an exercise intervention, including a greater level of supervision of those individuals undertaking the exercise programme, hence enabling the degree of compliance with the regime to be assessed.
OVERALL OUTCOMES OF THE IBD FATIGUE PROJECT

The project set out to enable people with IBD fatigue, carers, family, and healthcare professionals to benefit from:

- Increased self-awareness of the problem
- A new method of measuring fatigue
- Evidence about reversible undiagnosed medical causes of fatigue
- Design and test of new approaches to improving symptoms

Increased self-awareness and a new method of measuring fatigue

In January 2013, as part of the development of a fatigue rating scale, we contacted members of Crohn’s and Colitis UK to assess their level of awareness of the IBD fatigue project and their views on the usefulness of the newly developed IBD fatigue assessment scale.

We randomly selected and approached over 2100 Crohn’s and Colitis UK members, 605 agreed to take part in the study, and 464 returned the completed questionnaire. From those who responded 51% were aware of the project and 90% were aware that IBD could cause fatigue. Despite the high level of awareness only 54% of patients had discussed fatigue with a healthcare professional and only 38% had asked for help. Of those patients who had asked for help only 27% (48 patients) were offered treatment and 5% were referred to sources of further information.

We anticipate that the IBD fatigue assessment scale will encourage a greater number of patients to discuss fatigue with their healthcare professionals.

Conclusions

This project has confirmed that fatigue is common and troublesome for people with IBD. We have worked with these people to develop a new way to assess and measure fatigue and its impact, which will in future allow the effect of any treatment for IBD fatigue to be measured.

We have found that health professionals need more information and training on IBD fatigue. We have completed initial testing of a checklist and an exercise intervention which looks promising and which should enable us to develop larger scale studies to test interventions for fatigue in IBD.

We have raised awareness among both members and healthcare professionals that more attention needs to be given to fatigue to end the “don’t ask don’t tell” approach to IBD fatigue.

We have developed a new website and materials and promoted fatigue awareness via our 2014 Crohn’s and Colitis UK awareness campaign.

The findings and learning from the project have been widely communicated to patients and healthcare professionals through publications and local, national and international presentations.

‘The brain fog feeling’
Appendices

List of publications:


19. Presentations to groups of IBD nurses in London, Manchester, Birmingham.


Crohn’s and Colitis UK is the working name for the National Association for Colitis and Crohn’s Disease. Charity registered in England and Wales Number 1117148, Scotland Number SC038632. A company limited by guarantee in England: Company number 5973370. 4 Beaumont House | Sutton Road | St Albans | AL1 5HH | General enquiries 01727 830 038.