



# The Voice of Inflammatory Bowel Disease

A Manifesto  
for Young People



## INTRODUCTION

Welcome to The Voice of Inflammatory Bowel Disease – A Manifesto for Young People. This manifesto came about through a number of workshops of young Irish people who either have Crohn’s disease or ulcerative colitis.

These four workshops, which were facilitated by an independent company in late 2008 and in early 2009, were the first time ever that young people with Inflammatory Bowel Disease (IBD) got together to share our experiences.

We worked together on what we believe are the key issues facing young people with IBD and what we would like to see change – that’s what is presented in this booklet.

The patient manifesto gives young people a voice in what is decided about their condition, how we are treated and how others respond to us.

This manifesto explains who we are and what we want, then it outlines 12 calls to action that arose from the workshops. Some of these changes are practical in nature, such as making IBD a long-term illness, having better access to toilet facilities and having control and respite from symptoms.

Some of the changes are more aspirational but still have a real impact on how young people deal with the condition e.g. not letting IBD define our identity and learning to accept the condition.

Throughout this manifesto, there are quotes from some of the participants in the workshops. This will hopefully give you a sense of how we feel about our condition and help you understand that there are personal experiences behind all of the calls to action in the patient manifesto.

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## WHO WE ARE

Before we explain a little bit more about the manifesto, let's talk a bit about who we are. We're young people – we're mostly in our early to late 20s.

We're a group of guys and girls – some of us are married, some of us have kids (or kids on the way!), some of us are in relationships, some of us are single.

We're from right across the country – some of us live in cities, some in towns or villages and some of us live in rural Ireland.

We vary a lot in our working lives – some of us are self-employed, some work in the public sector and some in the private sector.

Some of us are studying at the moment and some are taking a break from working life. Many of us are hoping to do some further study or progress our careers.

We're different in a lot of ways – some of us like to go out often; some of us are more home birds. Some of us are into sport; some prefer music or the arts. Some of us are extroverts and some of us are introverts.

But one thing that collectively brings us together is that we are young people living with Inflammatory Bowel Disease – whether it's Crohn's disease or ulcerative colitis (or in a couple of cases, both forms of disease).

We may be at different stages of our disease – some people are newly diagnosed while others have had it for years. Some of us are currently feeling well while others are stuck in the middle of a flare- up.

But we can all relate to having experienced the same thing – life was travelling along fine until one day we started to feel unwell.

We thought it would clear up and go away but it didn't. Then we started having to see doctors and undergo tests. We waited to get a diagnosis and all the time we were physically feeling terrible and worrying about what was going on. In many cases, we literally thought we were going to die.

Then eventually we were told what was wrong with us. Great – a diagnosis. But that was only the start of our journey and since then, we've had to learn a lot about the disease and how to manage it so that we can still live a relatively normal life.

Inflammatory Bowel Disease isn't an easy thing to talk about. Let's face it; it can be quite embarrassing to talk about toilet habits. It's tough to explain it to friends, to give reasons why you can't go out that night or to broach the subject with your employer or work colleagues.

Some people aren't sympathetic. Some people don't understand but we feel that if they were given more information, they would respond better.

We're not going to be able to fix every aspect of our condition but there are things that could improve our lives.



## WHAT WE WANT

For most of us, the workshops were the first time we'd talked about our condition in depth with people outside of our immediate family or our partners.

It was also the first time we'd talked about it with people going through the same experience.

Inflammatory Bowel Disease can be a very isolating disease – we know there are other people out there with it but we don't usually get to share experiences, swap tips, talk about it together or figure out strategies to live our lives with the conditions.

This manifesto is a document for change – things that we would like to achieve and what we would like to see change for the better.

The manifesto brings together our concerns, our wishes and what we feel are our rights. We want to have a voice in decisions that are made concerning Crohn's and colitis.

This document will give you an insight into what it is like to be a young person living with Crohn's or colitis and will make you more aware of our needs and hopes when faced with this illness. We don't want compassion or pity – we just want a little understanding.

"I've never actually met anybody else with Crohn's until today and just the thoughts of meeting somebody or being able to actually put out your hand and help somebody and make someone's life better, I'd love that." Sarah (28)

"If someone said to me before, 'This is going to happen to you, how are you going to deal with it?', I'd be like, 'I won't be able to'..."

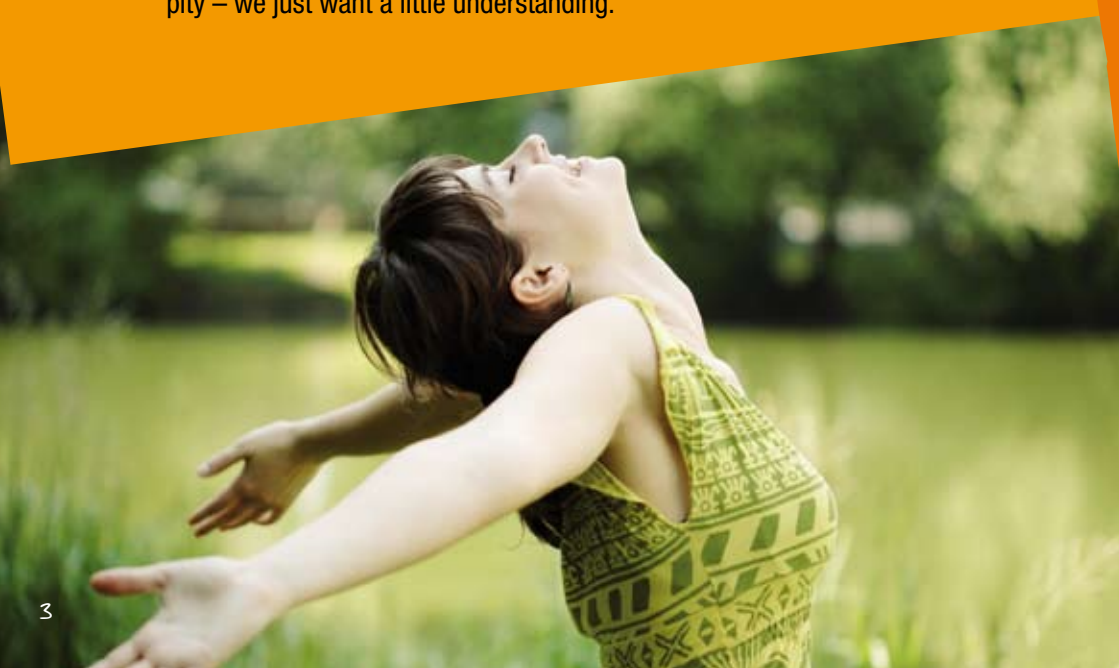
...It would be the same if you said to someone, 'You're going to lose a leg in an accident, how are you going to handle that?'...

...They might think they wouldn't be able to live but they always are and they come back stronger. It's like whatever doesn't kill you makes you stronger...

...It's so true and you only realise it when you actually come up against a big wall; it's like climbing Everest and then coming down the other side. You kind of think, 'Wow, I'm impressed with myself now for being able to do it. If I can do that, I can do anything'...

...You don't want colitis to happen but...I've got a lot from this. It's not a bed of roses and it takes a long time initially to deal with it." Colm (30)

Note – All names in the patient manifesto have been changed to ensure the privacy of participants in the forum meeting



## A LITTLE BIT MORE... ABOUT CROHN'S AND COLITIS

In Inflammatory Bowel Disease (IBD) the digestive system is impaired and the gut becomes inflamed and swollen. There are two very similar forms of IBD which can be hard to tell apart: Crohn's disease and ulcerative colitis.

Crohn's disease can affect any part of the digestive tract. Ulcerative colitis, in contrast, is restricted to the colon.

In both diseases, there is inflammation and damage to the intestine wall in the form of lesions or sores that often bleed easily. The symptoms of Crohn's disease and ulcerative colitis may be mild or severe. Common symptoms include:

- Persistent diarrhoea (which can sometimes be bloody)
- Severe pain or cramps in your abdomen
- Fever
- Weight loss
- Loss of appetite
- Fatigue

The complications of IBD can be severe. The more severe the disease, the more likely it is to develop complications.

The most common complication is where the intestine becomes blocked or much narrower, forming a stricture. Swelling narrows the space for food to pass. This space can then clog up and may be very painful.

Fissures or tears in the intestinal tissue are also common. A fissure in the anus can be very painful when you go to the toilet. Fissures can become infected so they need to be treated.

An abscess or ulcer caused by an infected fissure can form anywhere in the intestinal tract. Deep ulcers can puncture the wall of the bowel and infection can spread into nearby organs and the abdominal cavity. A deep ulcer or abscess can go on to form an abnormal tunnel or channel called a fistula.

While the symptoms of Crohn's and colitis can sometimes settle for periods of time, there are usually flare-ups (a recurrence of symptoms) every so often.

There is no cure for IBD but treatments can help to reduce the frequency and length of flare-ups.

Surgery is usually reserved for cases that are not responding well to other medical treatments. People with ulcerative colitis usually find that surgery that removes the large intestine can eliminate their condition.

With Crohn's disease, however, surgery can help to relieve symptoms but isn't a guarantee that the condition will completely disappear e.g. inflammation can occur in a previously unaffected part of the intestine.

The exact causes of Crohn's and colitis have not yet been identified but it's believed that both genetic factors and environmental triggers have a role to play.

Stress has been ruled out as a cause of developing IBD but it is thought to be a contributing factor to flare-ups.

It's estimated that 15,000 Irish people have IBD and the most common age for symptoms/presentation of IBD is between 15 and 25.

While it has a similar sounding name to irritable bowel syndrome, IBD is a very different condition that affects the muscle contractions of the bowel. There is no inflammation with irritable bowel syndrome.





## 12 CALLS TO ACTION

### 1. IBD DOES NOT DEFINE US

While we have to deal with the reality of having IBD, we don't want to simply be labelled as 'The guy with Crohn's' or 'The girl who has ulcerative colitis'.

IBD is part of our lives but it isn't the sum total of our lives. It doesn't describe who we are as people.

#### Teen years

Many of us first developed symptoms and were diagnosed when we were in our late teens. This was a time when we were still trying to figure out who we were and what we were going to do in life.

Suddenly we were slapped with this label of IBD and we didn't even know what it meant.

#### Where we are now

Now, we're young people who are either starting off on our first job or college course or else we are settling nicely into careers and thinking about starting a family in the near future.

We're still in a period of transition and we want to know that the opportunities that other young people have are also open to us.

Many of us are still finding out about ourselves – what makes us who we are, what we want to achieve in life and what our priorities are.

#### The future

It's hard to come to terms with the fact that you have a chronic illness and that you'll have it for the rest of your life. When you're in your early 20s, you're not thinking about life in your 40s or 50s.

But we have to think about the fact that we'll be living with this condition when we're that age and we wonder how we will cope with it.

#### Our lives

While living with IBD may mean that there are certain things we have to be aware of or avoid doing, that doesn't mean we can't still live fulfilled lives.

We still want to travel, play sports, attend social events, have a family and be part of a community. We want to be able to work and do well in our careers.

#### Telling others

If we need to tell others about having the condition, we'll tackle that in a way that's right for us. But we don't want that to mean that others will treat us differently.

We want people to accept that IBD is part of our lives. Knowing about the condition will explain why we sometimes can't make social nights out or have to take extended toilet breaks!

We don't want other people to think that IBD is some form of excuse or a cover for laziness (misconceptions that some of us have encountered).

#### Living with flare-ups

Of course, how we feel about our identity and IBD is influenced by whether we're feeling good or whether we're going through a flare-up.

When our symptoms are under control, our energy levels are good and we get to enjoy the freedom of being well. We don't have to spend any time thinking about IBD because it isn't a part of our daily lives.

*"When you're well, you forget all about it, you block it out."* Kate (28).

*"I'd forgotten what it was like to live like this,"* says Patrick (23) who has been free of flare-ups for the past year. *"It's a whole new lease of life – going out socialising, going anywhere you want. You can do anything you want. You don't have to worry about toilets, you don't have to worry about anything."*

When we are going through a flare-up, we're back to defining ourselves as having IBD. If we have to take to our bed because of the symptoms and if we're in pain, everything else has to temporarily be put to one side. If we're feeling well, we're not that concerned by our condition.

If we're feeling bad, we focus more on the fact that we have IBD but we want to move out of that stage and get better again.

Work might have to wait and we can't go out to meet friends. Even simple activities like being able to walk to the shop suddenly seem like mammoth tasks.

There's no doubt that IBD can impact on our lives. In some cases, it has stopped us doing what we want to do. Having IBD affects the pathway we take in life. But we are determined not to let it take over our lives completely.

We want to take ownership of our disease. We want to feel that we have control over it and over our lives.

*"It's not the end of the world. You have it and you're going to have it probably for the rest of your life but you can get on with your life."*

Michelle (25)

*"The one thing that's always in my head is that I can't let this be my life. I'm Adam, that's who I am first and foremost and what I do is what I do. This part of me, it's something I have in the background if you like. I can't let this be my rudder and let it steer me through life. I have to pick my own thing and go for it as best I can."*

Adam (25).

## 2. AWARENESS LEADS TO EARLIER DIAGNOSIS

### How the condition starts

The stages before you are diagnosed with IBD are probably the hardest time. Life is normal and then, suddenly, you start to get these symptoms.

You don't understand what's happening and you start to worry. You tend not to talk about it with others because it's embarrassing and because you don't want to face up to what's happening.

Then one day you notice blood in your stools and you think it might be cancer.

*"For weeks and weeks I couldn't go to the toilet and every time I thought I needed to go to the toilet and got there, it was just full of blood. I didn't tell anyone. I was afraid, I kind of thought 'Oh, I've got bowel cancer or something like that'. But then I ended up going to the hospital."* Fiona (29).

Or you feel so weak and in so much pain that you know this isn't just a tummy bug or that it's because you've been overdoing things lately. You know there's something seriously wrong and you go to see the doctor.

*"I spent two weeks pretty much in bed, I just got very sick. I started to feel weak but I kind of ignored it and I took something for the diarrhoea. It just wouldn't stop..."*

*... After about two months, I was losing a lot of weight and people around me were going, 'What's wrong with you?' And I was like, 'Oh it's grand, it's grand, I'm fine'. But I went to the doctor and he sent me to a specialist."* Adam (25)

### Getting diagnosed

Some of us put up with our symptoms for weeks or months because we didn't know they were connected with a medical disease. Some of us just thought we felt this way because we were run down and that it would clear up eventually.

If there was a public awareness campaign that highlighted the symptoms of IBD, people would know to seek help from their doctor and they could be diagnosed much earlier.

It would also help reassure people that although they have scary symptoms, such as blood in their stools, it doesn't mean that they have cancer.

We'd like to see some advertising of the symptoms – whether it's a television ad or a billboard campaign. We see TV campaigns for lots of other conditions and their symptoms, so why not one for Crohn's and colitis?

### Greater awareness of IBD symptoms

It can take weeks or months to be officially diagnosed with IBD. You might have to undergo a barrage of tests (some of which aren't that pleasant!) but then, finally, you're told what's wrong with you.

Your first reaction is usually relief.

*"I was happy to know what it was and that it was treatable – at least I won't be in this pain forever."* Aisling (25).

*"Once I was diagnosed, I almost felt a sense of relief, which might seem very strange but I kind of felt that this isn't all in my head, there is actually something wrong with me."* Seamus (28).

Finally, there is a name for this illness. There's a reason why you've been feeling sick and spending half your waking day on the toilet. But what happens next?

### Information on diagnosis

We feel there is a need to provide more comprehensive information when somebody is diagnosed with the condition.

When some of us were diagnosed, we weren't told very much and were left to find out ourselves.

*"I was just told I had ulcerative colitis and I wasn't given any leaflets."* Adam (25).

We have a lot of questions at this stage – will our condition improve, will it get worse, what do I need to know about looking after myself? And even if I'm not on them at the moment, what are the treatments that are available?

If we're given the correct information when we're diagnosed, it means we won't worry so much. It also means we'd be less likely to go off and find information on the web that presents the worst-case scenarios. These can scare you even more.

We think that everyone newly diagnosed with Crohn's or colitis should be given an information pack that brings together all the essential information.

*"Instead of me looking on the Internet and Googling everywhere and seeing everything that I shouldn't see, it would be better to have some booklet with step by step on your diagnosis. Where the condition might go and where's it at now."* Cormac (24).

### Talk to us

Alongside the information, we'd like someone to talk to us in detail about our condition. In some cases, our consultant did this and it helped us enormously. But not everyone gets the same level of consideration.

*"At the start, you just want someone to sit down with you and talk you through it."* Mark (26).

We also think that newly diagnosed people should be referred to a support group. There may also be a need for some form of counselling service so that they can have some help in coming to terms with their diagnosis.

Above all else, we believe that a diagnosis should be delivered with sensitivity. We all remember how we were told that we had Crohn's or colitis.

In some cases, we were given the news with compassion and further explanation.

But some of us were told rather bluntly and were left confused and apprehensive about the future. How we are told about our condition sets the tone for how we deal with it in the future.



"If the general public know that if you're passing blood, you've diarrhoea and you're not eating, these are the symptoms of IBD, well then, they might just get off their horse to go to the hospital quicker instead of thinking it will pass..."

...There is definitely not enough information - not just for the people who have it but for the general public. Like when I went in to hospital, there were people - the nurses and doctors - who said I was lucky I'd come in. I'd been sick for a month but they said there are people who leave it for six months. But then I started to think, 'Well what if I'd gone in a week or two earlier, I mightn't have been as bad'."

Liam (27).



### 3. WE NEED TO MOBILISE YOUNG PEOPLE

We all want a support group for young people with IBD - doing these manifesto workshops has shown us that we can gain a lot from talking to each other and sharing experiences. Alongside that, we also see the need for a youth advocacy group to campaign on things that need to be changed.

#### Talking is good

The majority of us want to talk about our condition but we carefully choose who we talk to about it - we talk to our parents, siblings, close friends and partners.

But we don't talk about it to everyone because we're not sure how they will respond or how they will cope with what we tell them. Some of us talk about it often with our trusted friends and family. Some of us talk about it rarely.

*"You get so emotional when you talk about it because you very rarely do. It's something that I'm starting to do more of because, you know, with family, I would have blocked them out completely..."*

*...It's because you just want to do it on your own. You think you can deal with everything that's thrown at you but you can't."* Ruth (23).

#### Support from family and friends

We feel incredibly lucky to have supportive family and friends. They listen to us when we're feeling down, they try to make us feel better and they accompany us when we're going to appointments.

They're an amazing support system but ultimately they can only understand it to a certain level.

And sometimes we feel we can't talk about it with complete honesty to them because we don't want to worry them.

#### Peer support

That's why we feel it is important that we have peer support - so that we can talk to other people our own age about our condition. Even doing these manifesto workshops has shown us how beneficial that kind of interaction can be and we want to keep it going.

*“Talking to anybody else who is going through something similar to what you’re going through is a help. It’s one thing having your family there being supportive and all but, at the end of the day, they’re not going through it.”*  
Fintan (25).

### *So what about the practicalities of the peer support group?*

While we’re all very internet savvy, we feel that the web isn’t the best way to stay connected to each other. We can use it to organise meetings but we actually want to meet up with others face to face.

We want to get together to talk about how we’re doing with Crohn’s or colitis. We think it’s best to meet up regularly – perhaps every three months or every six months. Nobody has to commit to meeting up but it’s a group where anyone who wants to come along is welcome.

We think it is also worthwhile to organise these groups in different regions so that people around the country can get together regularly.

We think it’s important that these groups are people of similar age.

When these groups are up and running, we think it would be hugely beneficial if people newly diagnosed with Crohn’s and colitis are told that the groups exist and are given contact details.

We also think there is a need for a group for parents and partners of those with IBD so that they can get support and access information.

### *Youth advocacy group*

The Irish Society for Colitis and Crohn’s disease (ISCC) is a voluntary group and doing the best it can with limited resources. Not everyone with IBD, however, is aware of the ISCC.

We think it is time that young people partner with the ISCC to create an advocacy group for those under the age of 30 who are living with IBD. The ISCC is a perfect starting point. This group would allow younger people with IBD to get fully involved and to pursue campaigns such as classifying IBD as a long-term illness.





#### 4. IBD CAN BE INVISIBLE

In our experience, people find it hard to believe that someone who looks healthy on the outside has an illness. This can sometimes mean that others doubt that we're actually ill or think that we are sometimes exaggerating how bad we're feeling. We get the feeling sometimes that people believe we're using IBD as an excuse to get out of doing things or because we're lazy. And that's far from the reality of who we are as people.

If people see that something is physically wrong with someone, like a broken leg or a skin complaint, they are more likely to take it seriously and to empathise with that person.

With Crohn's and colitis, we often don't have outward signs that we're not well. And when there are outward signs like weight loss, they can lead to a whole other scenario of misunderstandings! Some of us have lost weight so rapidly that we've heard back that people thought we were on a crash diet or on drugs. It would be laughable if it weren't so bizarre.

But generally people tend to underestimate the condition's effect. If they understood how it physically affects us, we feel they would be more considerate towards us.

They would take us seriously when we explain how we need to use the toilet right now and how we can't just wait a few minutes. They'd understand that our condition isn't just a case of having a dodgy tummy and that symptoms can actually be severe.

People would also understand that IBD is so bad sometimes that it can affect our mood. We can't help but feeling down when our symptoms are severe and are impacting on our lives.

Some people might assume that it's 'all in people's heads' and that they should 'pull themselves together' but it's not as simple as that. It is a physical condition and should be taken seriously.

*"You can get up, you get dressed, you put your make up on, whatever, and you look fine to people. No one knows that you're sick but you're actually very sick."*

Aisling (25)

## 5. BETTER ACCESS TO TOILET FACILITIES

If a stranger were to stop one of us on the street in our local area and ask us did we know where the nearest toilet facilities are, we'd have the answer at the tip of our tongue.

That's because, quite simply, we've developed mental maps of where the toilets are in our cities, towns and villages. We've had to because it's information that we need to know. When we're in the midst of a flare-up, we need to be able to access toilets in a hurry.

*"When I used to come to Dublin to go to the hospital for my check up, from the train station to the hospital, I used to have my locations for each toilet for every shopping centre, everything." Yvonne (30).*

*"Even to do my shopping on a Friday, I won't go anywhere that I don't know where there is a toilet two minutes away from me." Fiona (29).*

Lack of public toilets means that sometimes we have to miss out on social events because we know there aren't any toilets close by. Travelling overseas can throw us in a loop because suddenly our mental map of our surroundings is totally gone.

### *More public toilets*

There should be more public toilets in our towns and cities and there should also be more toilets provided either on or adjacent to public transport.

Many of us feel we have no choice but to drive to get to places as at least then we can stop the car and take a toilet break. If you're stuck on a bus, train or the Luas, then your options are limited.

And even if we know where a public toilet is, there isn't any guarantee that it's going to be in a cleanly state.

### *Access to toilets*

We would like to raise awareness amongst certain groups, such as publicans, as to the importance of making their toilet facilities available free of charge to people with Crohn's or colitis.

Some of us have had bad experiences when trying to access toilets in venues.



*"I found before when I needed to go to the bathroom, I'd go in wherever I saw a pub, a restaurant, whatever and I'd go in and I'd head straight for the bathroom. Sometimes people would grab you and say, 'Where do you think you're going, you're not a customer', and I'd say, 'I have to use the bathroom'. Then I'd be told, 'No, you can't use it here'." Liam (27)*

*"The only time I was actually stopped using a toilet in a hotel, I actually did say to her, 'Listen I have a condition and I need to use the toilet' and she just went really red and got embarrassed. She said, 'Oh right, it's up on the left'. But other than that, I've never had any problems." Declan (28)*

Most of the time we literally don't have time to buy a drink or a snack in a venue before we need to use the facilities. And if we had to spend money every time we needed to use the loo, it would soon add up.

We should be able to use the facilities without paying and without having to have an awkward conversation with the staff.

### Toilet Card

Some of us have heard of the Toilet Card, which sets out that we have a medical condition and need access to the toilet facilities.

Some of us feel we'd be too embarrassed to use the card but some of us think we would use it.

*"It's a bit embarrassing but if I needed to use it, I would." Fintan (25).*

*"If it came to it, I would pull out the card. It's a bit embarrassing but if there is somebody who is being completely belligerent, it's them who should be embarrassed if you show the card to them." Ed (28).*

Some of us had never heard of the Toilet Card and were unsure how to get access to it.

Greater awareness of its existence would help and it would also be beneficial if people who work in pubs, clubs, restaurants, shops etc. knew what it was so they would be familiar with it if someone showed it to them.

## 6. CLASSIFICATION OF CROHN'S AND COLITIS AS LONG-TERM ILLNESSES

One of the changes that we feel most strongly about is including Crohn's disease and ulcerative colitis on the list of illnesses designated as long-term illnesses.

It's a change that we feel would have a real impact on our lives – it would help relieve the financial burden on us and would also give our conditions more recognition as being serious and life long illnesses.

### Long Term Illness Scheme

At the moment, people suffering from certain conditions (who are not already medical card holders) can get free drugs, medicines and medical and surgical appliances for the treatment of their condition. The scheme, which is run by the Health Service Executive, is known as the Long Term Illness Scheme.

The scheme doesn't cover GP fees or hospital co-payments. The list of long-term illnesses covered by the scheme includes diabetes, epilepsy, Parkinson's disease and several others.

Crohn's disease and ulcerative colitis are not on the Long Term Illness Scheme and the Government has indicated that it doesn't plan to extend the list of eligible conditions.

But we think that our conditions should be included on this list and we think there should be a campaign to achieve this.

### Drugs Payment Scheme

Most of us are on some form of medical treatment – whether it is prescribed tablets, infusions or regular injections. All of these things cost money and while the Drugs Payment Scheme is a help, it still means that we are paying €100 a month for our treatment.

*"If the drugs payment scheme wasn't there, we'd all be goosed because the drugs are very expensive. But there still is a financial burden on us." Ed (28).*

*"It's an extra worry you could do without." Mark (26)."*

If Crohn's and colitis were recognised as long-term illnesses, it would help somewhat with this financial burden.

It would also create more awareness amongst the medical community and society at large that IBD is a chronic condition that isn't going to magically clear up one day.

### *Financial burden*

Aside from these costs, people with Crohn's or colitis have a lot of other financial costs – going to see their GP regularly, getting blood tests done and sometimes having to buy certain foods.

These financial costs soon build up and are life-long limitations for us.

Some people are being treated through the public system but still have to pay out for these costs. Others have private health insurance but there's obviously another cost involved there.

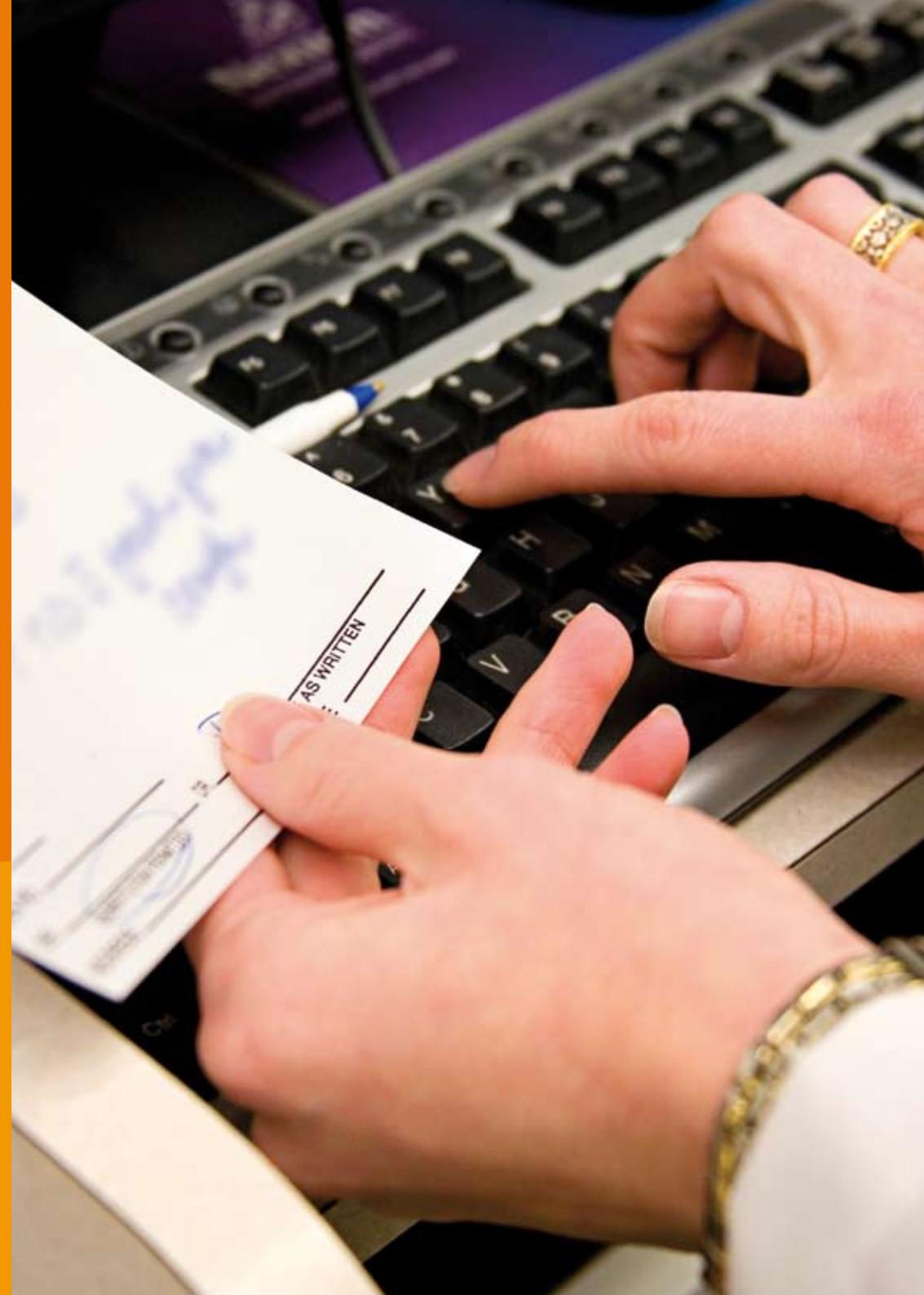
### *Medical card/Illness benefit*

Another concern is the fact that some of us who are on lower pay scales are finding it a huge struggle to try and get a medical card. They're not earning enough to be able to pay for GP visits or treatments but they're being told that they're earning too much to qualify for a medical card.

Some of us have had difficulty accessing the Department of Social and Family Affairs illness benefit (previously called disability benefit). Flare-ups can mean we're out of work for extended periods and we feel that there should be more support and help for us.

*"We're not recognised as a long term illness so we're not as important as people with diabetes and it's awful because we take medicine everyday. I take medicine twice a day. It costs a fortune and like I'm not recognised as being as sick as somebody with diabetes."*

Yvonne (30)



## 7. DON'T JUDGE US

Fortunately, most Irish people don't need to know about IBD because they're never going to experience it.

But that doesn't mean they shouldn't be more informed about it. One day they might become friends with, work with or fall in love with someone who has IBD!

If people knew a little bit more about Crohn's and colitis, they'd respond better when we raise the subject with them.

If they read something or saw something about IBD in the media, they'd get what it's about.

### Getting it wrong

There are a lot of misconceptions about Crohn's and colitis.

*"One half of people think you're dying – they look at you and say, 'God, you've Crohn's disease, can you stand up?' Then the other half of people really haven't a clue what it involves."* Sarah (28)

A lot of people underestimate just how much IBD can impact on a person's sense of well being and on their life.

*"If you explain to someone that you have Crohn's and they ask what it is, you might say, 'Well, I have to go to the toilet a lot, I get back cramps and I'm tired all the time'. It doesn't sound that bad to them."* Ruth (23).

*"Personally, I think a lot of people think we're making it up. I had a boyfriend who said, 'Why don't you just get on with it?'"* Kate (28).

### It's not IBS!

Another thing that really frustrates us is when people think that Inflammatory Bowel Disease is the same thing as Irritable Bowel Syndrome. For the record, it's not!

*"I know a few people who have IBS and when they hear about your condition, they kind of go, 'Oh right, you'll be grand, just take your medication'. I don't think they actually realise what it's like – if they could live with it for a week, they'd soon realise."* Colm (30).

### Re-labelling Crohn's

We think that it might help people be a bit more understanding of Crohn's if the name was changed.

At the moment, it's called Crohn's **disease** and we feel that the 'disease' part of the word might give off the wrong impression of the condition.

Even for us, it sparks up images of being unclean and contagious. And we're the ones who know exactly what the reality of the condition is!

In fact, many of us already choose to call it Crohn's - we think it should either be shortened to Crohn's or else called something like Crohn's Condition.

### Awareness

To sum up, we'd like to let people know that even though we look healthy outside, it doesn't always match the inside.



## B. ACCEPTING IBD IN OUR LIVES

When you're diagnosed with Crohn's or colitis, it takes time to realise that it is not going to go away.

### Phases

Some of us go through a denial phase and some of us fight against it in the initial stages. We live life exactly the way we did before and we fit in with our group of friends because we don't want to be seen as different.

But we find that our lifestyle and IBD aren't compatible and something has to give. We can't do the late nights at the pub in the same way that our other friends can and we can't eat everything we want because some things don't agree with us. You don't want IBD to get the better of you but eventually, with time and experience, you start to realise that with that course of action, you're actually struggling against yourself.

### Acceptance

You start to accept that IBD is part of your life but that you can manage your condition and still do things that you want to do.

You understand that IBD might actually have changed the course of your life – the career that you've taken, the activities that you do and your relationships with others.

*"Before diagnosis, I had a path set out for me. Now I have to think more about things – work, family, relationships."* Kate (28).

*"My first reaction to getting diagnosed was relief – okay, they know what it is after all this messing around. But the relief turned into, 'God, I've actually got something, I'm like one of those people you hear about who's got something and there is a name for it'. And this wasn't in my plan for life. My life is changed now, in terms of what is in front of me."* Ed (28).

### Choices

We may not have the exact same choices that we would have had if we hadn't developed IBD. But we have other choices and we still have control over what we decide to do.

*"When things are taken away from you, you value being able to make choices."* Tina (21).

We may pick another career; we may decide to go travelling now while we're feeling well. We may have to think more about planning a family. This is a particular concern for women as they wonder about the impact of drugs on their fertility and when is the best time to have a baby.

Both men and women think about how they would be able to look after children while they deal with their IBD symptoms. Tiredness is a particular concern.

### Looking after ourselves

We learn to take time for ourselves and learn that we shouldn't feel obliged to always put others first.

If we're not feeling well and can't do something, we tell people that so that they don't think we're not interested. It's not that we don't want to do it, it's because we physically can't.

*"I've learnt to try not to do everything – there are some limitations and I have to take care of myself."* Yvonne (30).

*"You start saying no to people – this takes time to do – but you realise you can't do everything and you make time for yourself."* Rachel (25).

### Growing stronger

In a lot of ways, the changed path that we might have had to take has deepened our understanding of who we are and what we want in life. It's something that we can draw strength from.

*"It's taught me a lot about who I am, what I want to do."* Patrick (23).

*"I've become so mentally tough from dealing with everything I've had to deal with. Like last year, my best friend killed himself and some of my friends are really struggling with it. I am too but I just think from everything I've had to cope with, I've managed to deal with it a lot better..."*

*...Everything else that comes my way is not as big as it probably would have been beforehand... I'm very philosophical about everything. I have this illness – bottom line, it's not going to kill me. I'm not saying it's great but I appreciate a lot of things better in life."* Declan (28).

### Making the most of feeling well

We appreciate it more when we're feeling well and don't take things for granted.

*"You know that when you feel well, that's the time to step things up a gear and get to do the things you can't otherwise do." Fintan (25).*

*"I appreciate life so much more now when I'm well. I just know when I wake up and I feel good, it's time to get my daughter down to the playground and go for walks. I appreciate being able to do those things." Kate (28).*

*"I suppose I'm more accepting of it and I'm trying to kind of overcome it but kind of incorporate it into my life..."*

*...I know my limitations because of it and I do as much as I can within my limits." Aisling (25).*

### 9. WE WANT TO BE PARTNERS WITH OUR MEDICAL TEAMS

Some of us are fortunate enough to have a great relationship with our consultant or GP and we feel like we're really on the same side in treating this disease. But most of us have felt frustrated at times with the medical world – whether it was in getting a diagnosis or in managing our disease now.

#### The whole person

Sometimes doctors can think of us almost like case studies and we need to remind them that we're people too! For us, it's not just about the medical side of what's happening in our bodies.

It's also about how we're dealing with the condition, how we're getting through the working day and relating to others. We want to talk about things like diet and holistic therapies. We don't just want to discuss the medical side of things.

#### GPs

We understand that GPs have to deal with lots of different conditions and that requires a lot of knowledge. But we would like them to have a greater understanding of IBD symptoms so that they can recognise that people might have it and refer them on to consultants quicker.

Some of us initially went to our GP but we felt that our symptoms either weren't taken seriously or the diagnosis was delayed.

*"My first point of call was my GP and this was an ongoing thing for about a year..."*

*...Then it got to the point where I was in bed and I couldn't move and we had to get the doctor out to me because I couldn't move, I was having pains obviously... I went back to him a number of times and he told me it was an ulcer, he told me it was appendicitis, all these different things...*

*...Eventually I found out that I had both Crohn's and colitis. I think GPs should be aware of the symptoms but they should also know when they're out of their depth and send you to a specialist." Patrick (23).*

*“I went up to my GP a few months ago and explained that my colitis was kicking up again. He said, ‘What do you want me to do for it?...*

*...I had to tell him what to give me – a dose of steroids – and that’s exactly what he did. Sometimes it feels like you’re educating them. It’s like a conveyor belt – you go in, they give you the drugs and you’re back out again. You’re only inside for two minutes...*

*...I suppose the GP has a full waiting room and he has to get through a certain amount of people. But it’s just that doctors won’t take the time to actually sit down and listen to you. I mean it’s their job to make those kinds of decisions – not mine.” Liam (27).*

### Consultants

Those of us who were diagnosed a while back get the sense that how consultants interact with their patients has improved in the last few years. But there are still things that we’d like to see change.

We’ve already talked about how the diagnosis of Crohn’s or colitis should be delivered with sensitivity.

When we meet with our consultants, we sometimes feel like we need to know the right questions to ask and if we don’t ask them, we won’t find out the answers.

Consultants don’t always guide us through the process or arm us with the right information. We’re also conscious that we shouldn’t waste consultants’ time, which means we can feel under pressure about asking questions.

*“I’ve actually gone in with a list of things to ask. I just say, ‘I have to ask you all this stuff’. It’s gone to the point where you know otherwise you’ll walk out and realise, ‘Oh I forgot to say that’ and then you won’t see your consultant again for a while.” Aisling (25).*

We’d like to be able to talk more about how to manage the disease and ways to cope with it. But we also recognise that these things might need to be addressed by other people, not just consultants.

The further along we get with our condition, the more we feel that we are able to have some say in our treatment. If we feel like the consultant isn’t on our wavelength or dealing with our concerns, we know we can change to another specialist.

But, overall, we want to build relationships with our consultants.

### Other medical professionals

Many of us feel that while we can build a relationship with our consultant, it is more difficult to do this with registrars or junior doctors in hospitals.

While we will get to know our consultant, a registrar might only be there for a few months and mightn’t have the same knowledge about our condition.

We realise that junior doctors are rotated and that’s part of the system but we would like them to have more knowledge about our conditions and listen to us more.

*“It’s like your chart gets put in the list and whoever is next, whoever picks your chart up is the one you see.” Yvonne (30).*

*“You can get a young doctor just out of college and they don’t know – they know it all theoretically – but they’re kind of asking you about the condition.” Orla (21).*

If we do go into hospital as an emergency case, we’d like doctors to listen to us when we tell them about the nature of our condition and what treatments we are on.

We don’t want to have to sit around while they try to get up to date on the condition – ask us, call our consultant or find someone who knows more about it.

We find that specialist nurses are a great source of information and support. They know a lot about the condition and are interested in how we’re feeling. Our only gripe about specialist nurses is that we wish there were more of them!

## 10. FREEDOM TO LIVE A NORMAL LIFE

IBD can impact on our lives – what we want to do, where we want to go and what we're going to plan for the future.

But despite this, we feel that we should still have the freedom to live a normal life.

We don't want to feel that we're being held back from all the things that other people get to enjoy. There are a few different ways that we feel we can be helped to lead a normal life.

### Control of symptoms/respite from symptoms

When our symptoms are under control or in remission, we feel like we finally have some freedom again. We can go out at night and not worry about making a mad dash to the toilets and we can get involved in activities that we might previously have had to cut back on.

This freedom only comes about because we aren't experiencing symptoms. We want to have control over our symptoms and be able to have respite from symptoms. This can happen because of medication, surgery or lifestyle changes.

We want to know what works for the condition so that we can regain some control over how it impacts on our lives.

### Travel

*"My friends went to Thailand last summer and I couldn't go because I was just terrified..."*

*... They only went for five weeks and I'd love to have gone but I haven't had a clear period of being well. I'd just be terrified to go with them and for me to be sick and for them to have to look after me. It's their holiday too." Orla (21).*

*"I'm in a comfort zone with my job and maybe my colitis stopped me going for other jobs. I'm in the same job for the last six or seven years. I can dictate when I go on a break or when I go on lunch. There have been jobs where if I didn't have the colitis, I probably would have gone for them. I probably wouldn't have got them anyway but I would have gone for them." Colm (30).*

Like most young Irish people, we like to get away to see new places – whether it's a two-week holiday or a round-the-world trip.

Some of us have still managed to travel while dealing with our condition and some of us have felt it just wasn't worth taking the risk of going away and still having symptoms.

We'd like to have the freedom to travel where and when we want and a large part of that is having some control over our symptoms and having practical help like better access to toilet facilities.

### Careers

We want to be able to go to work, to be a part of a team and to develop our careers. When we're feeling unwell, we might have to call in sick and we don't like that feeling of not being able to do our job or letting our employer down.

Some of us feel that having IBD has meant we haven't progressed as much at work as we otherwise might have. In some cases, we've had to go part-time at work or we've stayed in jobs that fit in with our condition. Who knows where our careers might have progressed to if we didn't have this condition?

On a practical level, we'd like employers to be more aware of what IBD is and how it might affect workers who have it. Equally, we'd like college lecturers to know a little bit more about how it might affect students.

It would mean they would understand better if we can't come into work or college and that there is a genuine reason why we need time off to get better.

### Relationships

Some of us have been in relationships prior to being diagnosed and some of us have met our partners since then.

Our partners are often a huge source of support for us.

*"I'm with my girlfriend for four years and her grandmother had colitis so I think she's well informed about it. She's been fine over the situation. She understands when I have to rush to the toilets when we're out somewhere like a shopping centre." Cormac (24).*



In some cases, the stress of having IBD hasn't been easy for a relationship. Our partner mightn't understand what it's like for us or mightn't be very sympathetic. In some cases, the relationship has broken up and that can be a hard thing to deal with.

When it comes to dating, we find that it isn't the easiest subject to broach.

*"When I was diagnosed with Crohn's, I had a boyfriend and he was like the perfect guy. But when I was diagnosed, he broke up with me and I haven't really had a proper relationship with anyone since. It's like three years ago so it's been hard. My sister is like, 'Oh you're just so fussy' but it's not – it's because telling people is hard..."*

*...I'm always kind of assessing guys – would he understand about my illness? You don't know when to say you have it. I'm very cautious and I haven't really seen anyone for long enough to be able to say it to them."*  
Aisling (25).

### Family

Some of us are young enough that we're not planning to have a family straight away. For others, we're just getting into that life stage where thoughts of having children are becoming more of a reality.

We'd like to know that having a family is an option open to us. When we have children and our symptoms are particularly bad, we might need a bit more support from our partners or other family members. But we want to feel that having a family is something that is definitely on our horizon.

### Socialising

When our symptoms are under control, we want to make the most of that time and get out and about to meet up with friends.

To help us have social lives, we think it's important that there are practical measures like having access to public toilets.

And when it comes to socialising, it's vital to us that our friends understand if we might have to head home early or can't make it out for the night. It's not that we don't want to meet them – sometimes we just physically can't do it.

## II. KNOWLEDGE IS POWER

When it comes to IBD, knowledge is power. The more you know about it, the better you can tackle your condition and the better you feel about it.

We believe there are still gaps in the information available to people with IBD – we often feel that information is out of date and isn't specific to Ireland.

*"Any leaflets that the hospitals give out are out of date and just tell you the symptoms – you already know that. They're not practical – they don't give you advice on how to deal with Crohn's."* Joanna (29).

We've already mentioned providing information to people when they're initially diagnosed but the communication shouldn't stop there. We want to be kept informed of all the latest developments with IBD and new strategies to cope with it.

### HOW

We're all up to speed when it comes to the internet and we use it to find out information about IBD. The Internet is a key source of information but it is both a blessing and a curse.

Sometimes we come across extreme cases on the web – some things scare us and go into way more detail than we need.

*"I've read stories on an American website about people dying and being bedridden for eight or nine months. I read that just after being diagnosed so I was starting to think, 'Is that what I'm going to be like?'"* Ruth (23).

In general, we're looking for websites that draw you in, have a range of information, are updated often and look attractive. Websites with forums are good because you can read about other people's experiences and ask questions.

### WHAT

We'd like to have a one-stop shop Internet site that gives us a range of information on how to live with IBD. These topics would include treatment options, tips on how to financially deal with IBD and would give lifestyle changes that might help manage symptoms.

We'd also like to see links on this website to support services and a list of questions to ask our consultant or GP. Starting out with this disease, we often don't know what are the right questions to ask of medical professionals so this would help us enormously.

We seem to be getting mixed messages about the role of diet in managing IBD. Many of us have been told by medical professionals that changing your diet doesn't make any difference to the condition but we've heard from others and found ourselves that it does.

It may be the case that there are no hard and fast rules for what foods are good and bad for people with Crohn's or colitis. Perhaps it's a case of trial and error with certain foods. But we would like to be told about that because, in some cases, it just might make us feel better.

*"The information that the doctors gave me was, 'You know, you can pretty well eat anything and drink anything. You can do what you want, it has no effect..."*

*...I kept telling them, 'But if I stick to this diet here, I seem to feel a lot better'. You're telling me to eat whatever I want and go for a few drinks whenever I want but every time I do that, I get sick. If I stick to this plan, I feel way better."* Cormac (24)

*"There's no information on nutrition, lifestyle, what we should be doing for our disease and how to get support."*

Aisling (25)

## 12. WHERE ARE THE ROLE MODELS?

### Role Models

Most of us know of famous people who have either Crohn's or ulcerative colitis. Some of the names that regularly crop up include the singer Anastacia (Crohn's), John F Kennedy (colitis), voice coach Carrie Grant (Crohn's) and Marilyn Monroe (colitis).

*"It helps to see there are some people who have had success in their lives and have Crohn's."* John (22).

*"I was in shock when I read that Marilyn Monroe had ulcerative colitis – that someone so famous, who worked so hard and achieved so much had the same condition as me."* Orla (21).

We think it would be good to have a famous Irish person who could talk about their experience and raise awareness of IBD.

### Spokespeople

We'd like to see somebody young talk about how they deal with the condition.

We'd like them to be successful and getting on with their lives. We'd like them to inspire us and boost our morale.

*"To see someone who works hard and has the illness, it's really inspiring."* Rachel (25).

Some of us would prefer not to go forward as spokespeople – we may not be comfortable yet with our disease or we mightn't want others to know.

But some of us would be happy to be spokespeople and to share our experiences.

While we'd like to hear about young people who live with IBD, we also think it's helpful to hear about older people who are managing their condition well.

It gives us hope for the future and reassures us that while IBD is part of our life, it doesn't have to be the whole of our life.

*"I know someone who has had colitis for the last 35 years - he's 52 now and he's going okay..."*

*...I look at people like that and say, 'They're managing, they're 52 and they're flying along. They're married with kids and they've a normal life'."* Colm (30).



# The voice of Inflammatory Bowel Disease

A manifesto  
for young people

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