



# Atlantis Healthcare

Inflammatory Bowel Disease

NZ Patient Journey

Janssen-Cilag

July 2014

Building unique support  
solutions for individual  
person needs

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What is it like to live with  
Inflammatory Bowel Disease in  
New Zealand?

# Patient Journey Research

Atlantis Healthcare were asked by Janssen-Cilag (a pharmaceutical company) to talk to people living with IBD about their experiences.

Atlantis Healthcare talked to people living with IBD and the people who care for them – carers; gastroenterologists; nurses; a surgeon; a dietitian; and people from Crohn's and Colitis New Zealand and the Ostomy Society

From this we tried to capture what it's like to live with IBD from a medical; physical; psychological and social perspective

This is called a **Patient Journey**

# Our People living with IBD

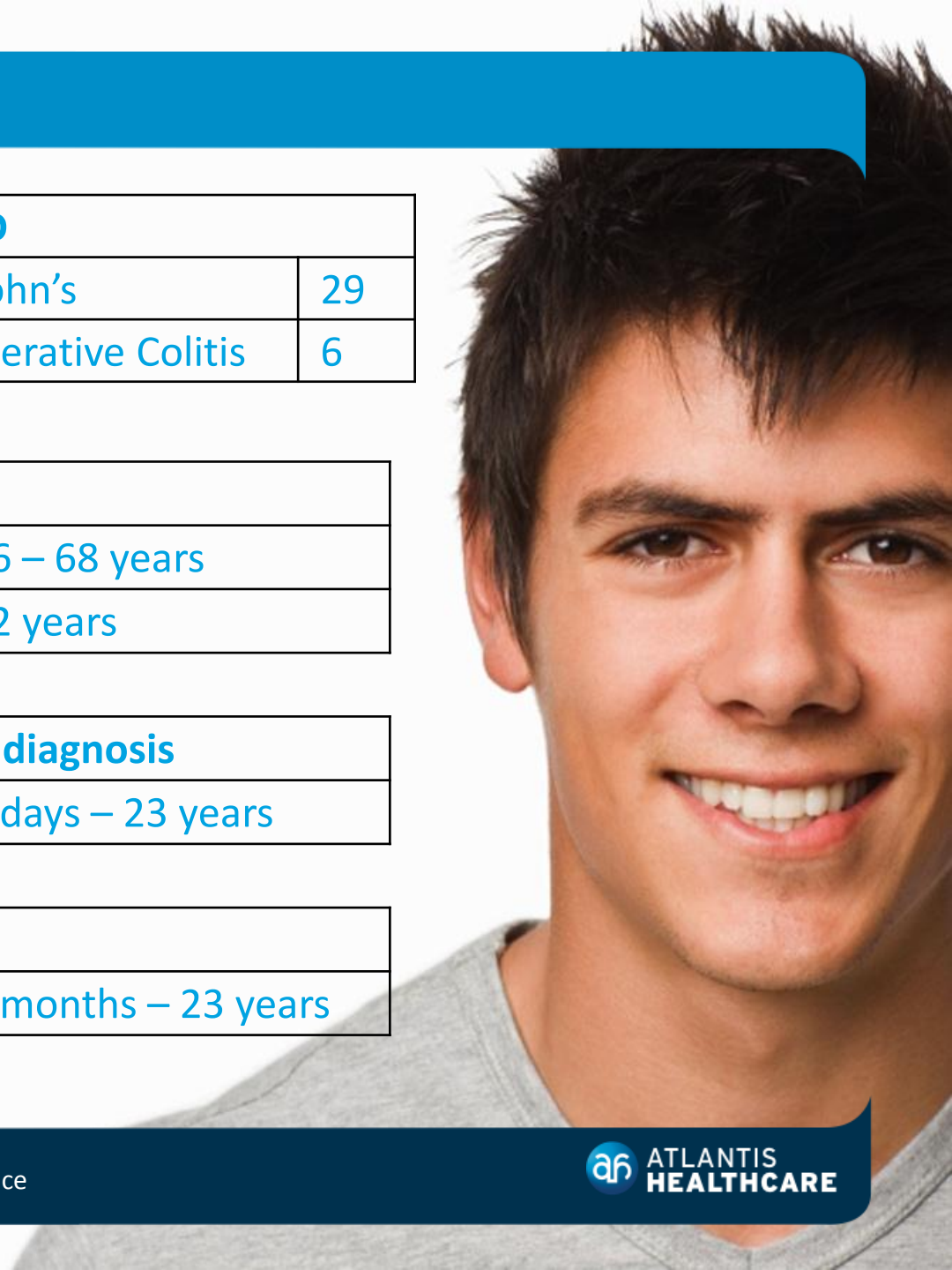
Gender	
Male	13
Female	22

IBD	
Crohn's	29
Ulcerative Colitis	6

Age of Participants	
Age Range	16 – 68 years
Mean	32 years

Time from first symptom to IBD diagnosis	
Range	2 days – 23 years

Time since IBD diagnosis	
Range	7 months – 23 years



# What symptoms did people talk about **before** being diagnosed?

- **Crohns:**

- Abdominal pain
- Weight loss
- Diarrhoea
- Urgency
- *Less so:* mouth ulcers; anaemia; perianal problems; constipation

- **Colitis:**

- Urgency
- Diarrhoea
- Blood in stools
- Abdominal pain
- Weight loss

## How old were people when they were diagnosed?

- **Symptoms** typically began in adolescence [range 5 – 35 years]
- Some persons were **diagnosed** as young as 5 years old
- Others not **diagnosed** until their 50's
- Most felt 'something was wrong' most of their lives

"I was annoyed it had never been picked up though. Because I had the classic signs. *I didn't know about Crohn's way back then.*" [CFOC1]

# What does the person do?

## Thinks symptoms are due to something else

- Virus
- Food intolerance
- Gynaecological problems

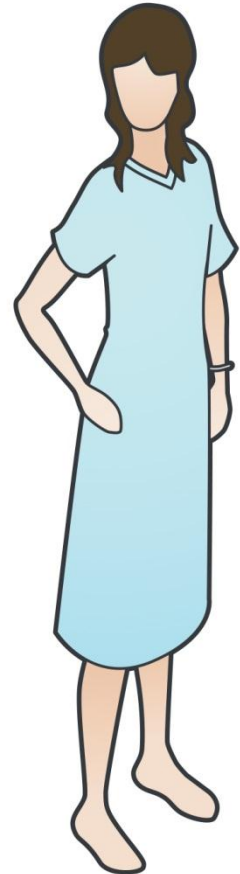
Isolated  
Confused  
Embarrassed  
Disgusted

## Normalises abnormal symptoms

- Loses sight of what 'normal' bathroom habits are

## Avoids seeking help because they are:

- Embarrassed
- Worried it might be cancer
- Unaware of IBD, so don't know what to tell their doctor



## To get a diagnosis, the person:

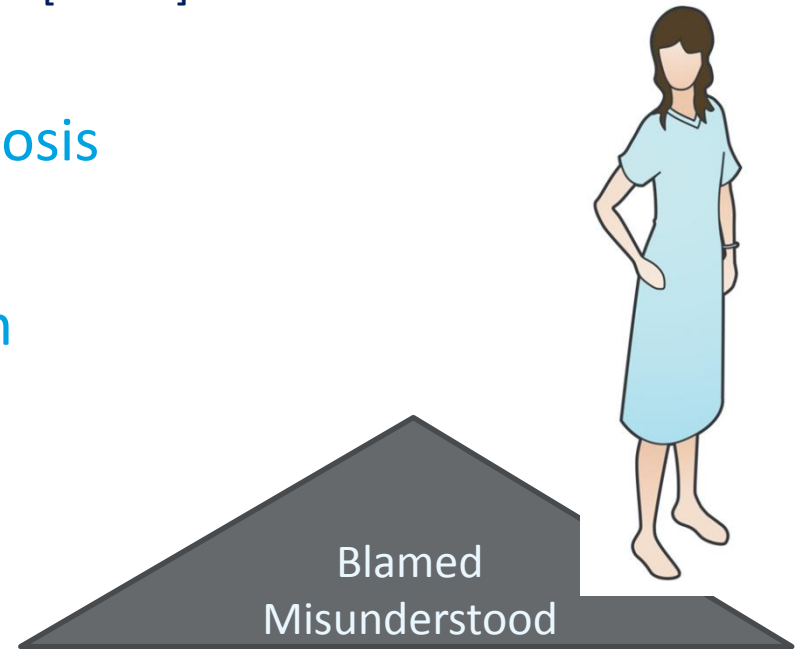
- **Goes to see their GP**
  - But can find it difficult telling their doctor about their symptoms:
    - How often they get them
    - How bad they are
    - The impact the symptoms are having on their lives
  - Feeling that GP's are overworked and don't know enough about IBD, which holds up the diagnosis
- **But, the person has to see a GP to be referred to a Specialist ... and get the right tests:**
  - Bloods + faecal calprotectin
- **Bleeding:**
  - 'gets you through quicker'
  - Prompts referral to colonoscopy - essential for diagnosis



# Getting the wrong diagnosis is very common

- Irritable Bowel Syndrome
- Coeliac disease
- Diverticulitis
- Endometriosis
- Symptomatic relief with no diagnosis
- Suggestion of bowel cancer
- Small bowel bacterial overgrowth
- Anorexia
- Bulimia
- Attention Seeking Disorder
- Stress

"You kind of *feel like you are going a bit crazy*, cause you are like, '*I know my body, this isn't right*'" [CFYA3]



## Getting that diagnosis

- Lots of tests, but not followed in sequence. Decisions typically made person-by-person:
  - Biomedical markers
  - **Faecal calprotectin** – not always done by GP
  - Bloods
  - Endoscopy
  - **Colonoscopy**
  - Capsule endoscopy
  - MRI
  - CT scan

"You have to have a biopsy to make a diagnosis so colonoscopy is often the one ..." [SA2]



# Diagnosis



# Diagnosis: What the Healthcare Professionals do

- **Healthcare professionals (HCPs) like to establish a relationship with the person**
  - First few months seen as 'critical'. People are getting to know their disease; symptoms; and their specialist
- **Introduce them to the healthcare team**
  - Focus mainly on IBD nurse (if available)
  - Few referrals to a psychologist; physiotherapist; social work
  - Dietitian not offered routinely, unless requested by the person or if there is a nutritional deficiency
- **Give the person information about their disease**
  - CCNZ Booklet
  - Websites
  - Mention of support from Non-Government Organisations (NGO's)
    - Crohns and Colitis New Zealand (CCNZ)
    - Ostomates Society

## How do people feel when they hear their diagnosis?

- Many people say they felt shocked:
  - Never heard of IBD before
  - Took some time to come to terms with IBD being a lifelong condition

***"The doctor said here, take these pills. I said "for how long?" ... It might be more than a year... "that long?!". I had no idea what chronic illness is like, so it took a long time to sink in." [UMYW1]***

## How do people feel when they hear their diagnosis?

- Many people went through a stage of 'denying' their diagnosis
  - Wanting to be 'normal'
    - Choosing not to take medication
    - Drinking, partying (mainly during adolescence)
    - Feeling 'in control'

"To a certain extent ***I wouldn't accept that I was sick***, so in a way I was sabotaging myself ***because I wanted to go out and feel normal.***" [CMYC6]

- Other people relieved to receive a diagnosis they can do something about

"It was a real relief to have a diagnosis of Crohn's, ***you could put a pin in it and know what it was.***" [CMYA1]

## What causes IBD?

- People had a number of ideas about what had caused their IBD:
  - Food and diet
  - Genetics
  - Virus
  - Stress
  - Unknown

"I got diagnosed when I had just graduated. I think ***all the stress of exams*** set it off."  
[CFYC3]

"I don't think it is necessarily any of these [food, antibiotics, stress] things that cause it...there must be ***some element of genetics***, as well as some environmental or physical triggers, that then releases that genetic expression." [UMYA1]

# Consequences:

## IBD has lots of consequences:

- Physical health
- Relationships
- Sense of normality
- Sense of loss
- Attitudes of society
- Reduced ability to engage in community and leisure activities
- Gains
- Emotional vulnerability
- Impact on working life



## Consequences:

- **Physical health:**
  - Ongoing effects of fatigue and pain have the biggest impact
- **Relationships:**
  - Forming new relationships can feel daunting
  - Communicating to partners about IBD difficult
- **Sense of normality:**
  - People want to be treated ‘normally’
  - Caregivers sometimes unsure of how to talk to people about IBD and how they are feeling

# Consequences

- **Living situation**
  - People changed their living situation – selling homes to ‘downsize’ their lifestyle
- **Family Planning**
  - Affects ability to plan for a family, with some people unsure if they could ever have a child
- **Quality of Life**
  - People gave up hobbies, or reduced community activities
- **Ability to engage in fulltime work limited**
  - Has a big impact on personal finances
  - Creates stress

# Consequences

- Socially
  - difficult living with an invisible disease
    - Hard to communicate symptoms when people “don’t look sick”
- Emotionally
  - People reported feeling vulnerable, powerless and humbled
- Coping: people focus on what they can control

**Healthy:** "Yeah, diet's been a big one for me, realising *diet is something that I can control*. Even though my specialist says it has got nothing to do with Crohn's, which many of them do." [CFYA3]

**Unhealthy:** "I started drinking, I started smoking. I abused my body because then *I felt like I was in control* and just ignored the fact that I'd just had this operation and been given this life-changing diagnosis." [CFYC8]

# Consequences

- Gains: “Bugger the consequences!”
  - Some people become determined to not let IBD stand in their way

"No matter how bad my Crohn's has been, I've always tried to keep on top of it and so *I've lived a pretty normal life*, I went *bungee jumping with my ileostomy*." [CMYA1]



Impact

## Impact on Relationships

- People reported a significant impact on their relationships
  - School
  - Friends
  - Family
  - Intimate relationships
  - Parenting
  - Socialising
  - Transitioning from paediatric to adult services
  - Work

## Impact on Life Transitions

- IBD impacts on ability to stay at school and attend university

"My education suffered quite a lot....***I never really stayed at school...*** yeah its cause I was in hospital, and if I wasn't in hospital I was acting up because of it." [CMYC7]

- School life disrupted due to treatment, a lack of understanding, and bullying

***"I was bullied at primary....*** I go there with a ***nasogastric tube*** and everyone was like 'oh ok', everyone was fine with it. But then there was this one girl uh, who said ***'disease boy'***, they called me ***'disease face'***... so everyone was like disease face, disease face....then I got like depressed after that. ***I got depression at 10 years old and I was depressed for 2 years"*** [CMYW1]

- Educating others helped with acceptance and coping

"[teacher] thought it would be a good idea to do a massive poster on what was actually wrong. Because all I got was 'why are you fat now, you used to be skinny, now you're fat'..... so I did this big poster..... [when I went to school], ***it was so much easier, like they understood.***" [CFYW1]

## Transition

- People largely had difficulties with their transition from paediatric to adult services, some dropping out of treatment altogether
- HCPs passionate about making this transition easier in the future

“I suppose one of the areas I work in and I see a big need is adolescent services... ***this is gonna be a very formative time of their life.*** Particularly, I think they are at risk of being left ***isolated*** or ***not supported*** or ***not understood***, so, one of the big areas that we are missing is adolescent wards, for example, in-persons, and adolescent-appropriate support as an out person.” [S1]



# Intimate Relationships

- Forming new relationships can be difficult
  - Anxieties about telling new partners
  - Concerns about acceptance
  - Most prefer to give small amounts of information at a time

"It's pretty hard going on a date when you're in the middle of a flare." [UMYC1]

"It was hard finding someone who would **accept you** for being sick." [CMYC6]

"She doesn't know the full story. I've only told her what I want her to know so ***I'm dreading when I do tell her the rest of it*** ... that can play a little bit on your mind in a relationship." [CMYC6]

# Socialising

- Many people feel they become socially isolated
  - Losing friends
  - Not going out
  - Feeling like they are missing out

"I mean I didn't go out, I stopped drinking, ***I stopped socialising.*** It was work, home, the hospital. ***Socialising was talking to the nurses at the hospital.***" [CFYA1]

"We don't have many friends or ***we lost our friends..***" [CFYA1]

"About every six months all the guys go away for a big fishing trip.. they went to Aussie for New Years and since I couldn't work I couldn't go. ***I was the only one of all my mates staying [at home].***" [CMYC6]

## Impact on Work

- The impact on working life was one of the biggest issues faced by people living with IBD
  - Lack of understanding
  - Perceived discrimination
  - Difficulties with communication
  - Stress created when taking time off work
  - Affects career choices and career progression
  - People feel discrimination is rife

"Employers are not very supportive... they were so cruel, and I wish I had the power to take them to someone and say, look, ***this is discrimination.***" [CFYW3]

## Impact on Work

- People unsure of whether to tell their employers about IBD

"When you are going for a job, it's hard to say 'I've got Crohn's disease, anything could happen'. Of course you're not going to get the job, so **you're better not to tell them** wait till you've got the job and tell them...." [CMYC7]

- People want greater awareness and accommodation of IBD in the workplace

"We want to talk to Unions. When they do collective bargaining agreements we want Inflammatory Bowel Disease to be on those agreements. Because it has all those other things like sexual orientation, race and all that stuff... and **we're wanting to add stigma surrounding bowel disease as well.**" [UMYC1]

- People would like education about IBD to be available for employers
  - Online
  - Booklets or information sheets

Treatment



## Treatment: Healthcare Professionals Perspective

- Treatment approached in step-wise fashion:
  - i. GP prescription
  - ii. Colonoscopy (key to diagnosis)
  - iii. 5-ASA's
  - iv. Steroids
  - v. Blood tests
  - vi. Immunisations
  - vii. Immunosuppressants
  - viii. Biologicals - subcut
  - ix. Biologicals - infusion
- Surgery may occur at any time



## Treatment: Peoples' Perspective

- Most began with a 'softly softly' approach instigated by medical team, starting from the more 'gentle' pills, then to steroids and lastly biologics
- People feel that they 'have' to progress through 'pills' to gain access to biologics
- For others, an acute admission was coupled with emergency surgery

## Treatment: Taking pills can be hard!

- Some people reported stopping their pills because they were “feeling better”
- Some people found the taste of pills off-putting, and worried what effects their medication might have long-term
- Side-effects of steroids were off-putting, particularly **insomnia** and **weight gain**
- People sometimes forgot to take their medication





## Treatment: Moving on to biologic therapy

- People feel that biologics are not mentioned until HCPs feel they are needed... and until all other avenues have been exhausted
- People with IBD had some knowledge of other therapies, but were mostly unaware of the treatment journey
- HCP's felt that people do not report being particularly active in seeking out information about treatment options
- People either want to engage with innovation - excited about new therapies: or, suspicious of new therapies and don't want them

## Treatment: Access to biologics

- Physicians tend to follow a step-wise approach, but are considered with every person
- Some physicians will start prepping people for biologics early in the process
- Variable depending on treatment centre
- Some people – only a few – given a choice

## Use of Complimentary & Alternative Medicine (CAM)

- CAM taken up or ignored depending on whether conventional medicine worked

- Most will 'try anything' out of desperation

"Until you have tried it, it is the **dance of the desperate** I think. I'd do anything to try and get better, so I'll give anything a go." [UMYA1]

- CAM can come at considerable cost

"Over the last four or five years, **I've probably spent over \$10 000 on supplements and minerals**....I've tried all sorts of diets from gluten free, to vegan, to juicing, shakes, and then GAPS and Paleo stuff." [UMYA1]

- Some people used illicit drugs to manage symptoms, particularly fatigue and pain

## Surgery: HCPs Perspective

- Surgeons aren't often mentioned by other Specialists until they are needed
  - Occasionally introduced as part of Multi-Disciplinary Team
  - Perception that surgery is the 'end of the road', and should be avoided at all costs
  - People can meet the surgeon for first time just before surgery

"All the way through when we're making decisions about treatment, ***I'll often bring up surgery as a treatment even when its clearly not the right treatment...*** The benefit is that they know that over time there are all these different options available, ***so if things change they'll know that they're not at the end of the line.***" [SCH1]

# Surgery: The Surgeon's Perspective

- Surgeons feel they are part of a multidisciplinary team

“If you're seeing patients in the acute phase in hospital it tends to be done on **a very collaborative approach** with the gastroenterologists, they will be under gastroenterology care.” [S1]

- Treatment decision-making – a collaborative approach
  - Surgeons take time to explore the costs and benefits of surgery with people

“It's a very individual thing from person to person but they **need to be empowered** to be able to make that choice clearly.” [S1]



## Surgery: The Surgeon's Perspective

- Meet people at any point along the patient journey, but typically further down the track when people start their own 'surgical journey'

“You're going through a **surgical journey** with them and following them up, mostly following them up afterwards, particularly with ulcerative colitis, then you actually have a **significant emotional engagement**” [S1]

- Ultimately, all treatments are aiming for remission

“I think for people with Crohn's, how I would like and, in fact, **I use the [biologic]** or the monoclonal antibody model if you like, that **surgery is just another tool to get into remission**, nothing other than that.” [S1]

# Surgery: Ostomy

- Gaining an Ostomy
  - Viewed as disruptive
  - Unwanted

"That's quite a journey [getting a bag]. It's okay. It can be quite **frustrating** because you get a new bag and you think that's it, lets go. And then all of a sudden you think, oh no I've got to change it... once, twice, maybe three times in half a day. Or you can go two days without changing a bag. So its really quite uneven." [CMOW1]

- But those who have them enjoy the convenience – as long as you plan

"**Travel angst**, about getting on a plane, I've had a colostomy, since then it has been **so much easier**....and travelling with drugs...I'm so going to get stopped and get searched." [CFYC9]

# Support Team



## Support

- The isolation caused by IBD has a significant emotional impact

"Yeah, especially last year .... **it made me really depressed**. .. *the only time I went out was to see doctors, get blood tests.*" [CMYW1]

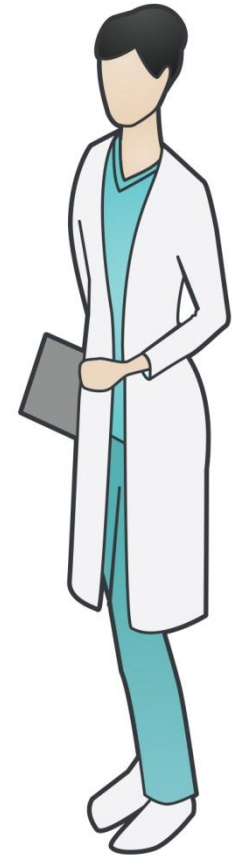
- Most felt their mood fluctuated in line with their physical symptoms
- Great value seen in obtaining support from others. However support is variable, and people often feel misunderstood.
- People can find it difficult to communicate what sort of support they need.

"I think **my family faced a real dilemma** because they didn't know whether I needed a boot up the arse or whether I needed sympathy..." [UMYC1]

## Support: IBD Nurse Invaluable

- IBD Nurses are seen as the key contact and support person within the medical system
- People find them:
  - Accessible
  - Knowledgeable
  - Responsive
  - Able to write scripts
  - Able to expedite treatment and referrals
  - Supportive of psychosocial needs

***"I cherish the ground she walks on.... she is just like really supportive and she is always there. " [CFYW1]***



## Support: Dietitians

- Some people questioned whether they needed a dietitian as there is no clear pattern between diet and symptoms

"**Not one thing works.** One day I might be able to eat a burger, but the next day if I eat the same burger it will be so painful." [CFYC4]

- Diet seen as one of the few things people can control

"More information regarding **diet**. Cause it is **something I can control.**" [CFYA3]

- Specialists felt dietitians useful, but only in certain cases

"If someone has distal proctitis, then they may receive minimal benefit, but if someone has Crohn's disease and has **malabsorption** of nutrients and inflammation, then **these people will benefit** a lot more." [SCH1]

# Dietitians

- Dietitians thought of their role quite differently

- Support not Cure

"It's a support role not a curative role and I think that is what some of the doctors are thinking, is that we [dietitians] think we are going to cure it. But of course we're not, it is a life long condition you have to manage." [DT1]

- Improving peoples confidence with eating

- Optimising nutrition when well

**"Once you are well you can eat what ever you like**, as long as it's a tolerance. And I tell people to really **maximise their nutrition** so that their **stores are built up**. So make sure all of your vitamins and minerals are well stocked up, so that **if you have a flare again you're not going to be in that bad place...**" [DT1]

## Support: Allied Health

- People felt Specialists were not particularly skilled at dealing with psychosocial issues and IBD nurses tend to fill this role
- Some people felt shy raising emotional issues with HCPs
- Access to psychologists desired but difficult to obtain
- Planning for psychology interventions to be delivered via apps/internet
- Access to social workers sparse, but do act as advocates in the health system

## Support: Unique Needs of Carers

- **Consequences of the supporting role**
  - Disease is unpredictable, so flexibility with working arrangements is cherished
  - Most took caring in their stride – one day at a time
- **Carers perspective on peoples' support needs**
  - People need flexibility from supporters and their employers
  - Greater education for carers/employers about IBD and what kind of support can be offered

# Non-Government Organisations

## NGOs

- Healthcare professionals very supportive of NGO's, although realise they may not have relevance for everyone

*"We refer them to Crohn's and Colitis... the support groups"* [SCH1]

"Most of the referrals to **Ostomates** are done through the surgeons as they are the ones who give them the stoma... they are **very good at linking them through to others with stoma**" [SCH1]

*"Mine think they are going to sit around having cups of tea with a bunch of old people"* [NA1]



## NGO: Crohn's and Colitis New Zealand (CCNZ)

- CCNZ feel they have a broad role in advocacy, supporting people living with IBD – young and old

"Advocacy, working with stakeholders, the broader issues. We provide support... we have an understanding with the support groups as to what we will do for them and what they can do for us, so it's a partnership." [CCNZ]

"The three fronts we work on - ***paediatrics, support groups, and at a national level. And at an international level***... attend the European Federation of Crohn's Colitis Associations - there are about 30 countries that meet. So NZ participates in that. We're an associate member" [CCNZ]

## NGO: Crohn's and Colitis New Zealand (CCNZ)

- CCNZ particularly passionate about supporting younger people with IBD

"There are about 500 paediatric families in NZ, and we're ... working to give them the **opportunity to linking up with local families**, so there is bonding or a buddy relationship being set up at a local level." [CCNZ]

"We are holding a national teen camp later this year. That will all be funded for the teenagers." [CCNZ]

- And raising public awareness of IBD

"We have **World IBD Day** each year - May 19th, and we tend to have a **week long set of activities around the country, get the press involved..** We have one sentinel event at Parliament. The Governor General's wife has just become our patron, so that really gave us some status. We speak to the Ministry of Health. We speak to the National Health Board. **We want Crohn's be become a national disease... it will come.**" [CCNZ]

## NGOs: Ostomates

- The Ostomates Society felt their strengths were supporting people – either through hospital visits or peer support in groups

"We ***visit people in hospital***. If the stoma nurse puts us in touch with the person we go into hospital. There's extreme cases where family members or people who don't quite understand, we go round to their homes to ***help and advise***. We ***help support the stoma nurses if they need some information or training for their nurses....***" [OSTO]

"It's being a group of people with the same interests or hobbies, but ***have gone through the same trauma***, if you will. There are things that you do that you think you're doing wrong, whereas you can ***talk to other people*** and you find that maybe you can do it a different way etc. So, it's really just a ***sounding board*** and somewhere that ***you can talk to others***." [OSTO]

## Ostomates

- They feel they could have more support from the hospitals

“The societies really have to try and promote themselves.....***This is where we struggle*** all we can do is give the information to the doctors, to the nurses, ***it’s up to the nurses and doctors to then forward that information to the people*** and then the people come back to us.”  
[OSTO]

“...As soon as they’re [the people] told that they’ve got a disease ***then there should be the link in the support group to help***, so that they [NGO] can also monitor.” [OSTO]

- Support from the Ostomates viewed favourably by other NGOs:

"The Ostomate people are excellent. They meet a special need. The people who go to them are ***very well supported by them.***" [CCNZ]

# Support Solutions

## Solutions: The People's Perspective

- People felt they would benefit from:
  - Greater social awareness of IBD
  - Improved education for:
    - Dietitians
    - GP's
    - Employers
  - Better access to specific disease information
  - Ability to track their disease with:
    - Apps
    - Diaries

# Opportunities to increase support

## Increasing access to IBD nurses

"There's *no-one outside the hospital* really is there?" [CMOW1]

## Internet and social media

"I've had *access to nothing* [CNS etc] except really the internet....it's *daunting* cause it affects your daily life, and it is quite *nice to know what I should be expecting* or what I shouldn't be expecting." [CFOC1]

## Ability to talk to people like them

"Being able to actually *talk to someone who is living with it* rather than everyone in white coats at the end of your bed....but having someone to actually speak to you who is *relevant to you* is so helpful." [CMOA1]

## Personalised apps: to monitor symptoms and food intake

# The Patient Journey



# Differences between UC and Crohns

- Very little difference in terms of
  - Treatment course
  - Emotional impact
  - Social impact
  
- Differences in
  - Symptom predominance
  - Cure vs Control
    - UC can be 'cured' through surgery
  - Path to diagnosis
    - Tends to be faster in UC

# Patient Journey: Snakes and Ladders

## Key insights

- Initial symptoms are often misinterpreted
- Lack of social and GP awareness can lead to big delays and distressing misdiagnoses
- Getting the right tests expedites diagnosis
- Almost all people start on oral treatment and are 'stepped through' therapy to biologics
- Surgery and biologics can be viewed as 'end of the road' treatments, even though this is not the case
- People are relatively passive in seeking out new treatments
- IBD nurses are central to all forms of care
- People feel relatively isolated and unsupported outside of the hospital system