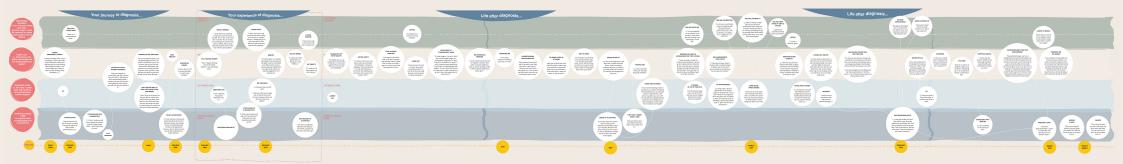


experience map irritable bowel syndrome

Overview of all maps





Your journey

See each panel in detail on pages 4-7



to you?

During Day TP'

"[W-BOOKS **GO FISHING** WITH DAD

How I spend

my time...

"WEATHER-DEPENDENT"

"I'm a weather-dependent person, so during the summer I'll go fishing outside all the time and during the winter it's more indoor activities because I have arthritis as well so my joints don't like the cold and the damp and neither does my chest".

ASTHMA

RESPIRATORY INFECTIONS

"I used to do childcare but I kept getting really ill and ending up in hospital with my chest, because I picked up every single bug going. So from October to February I was in and out of hospital constantly with respiratory infections so I gave up childcare".

HORSESHOE

OFF WORK & FURLOUGH

"[As has had Covid 3 times] I had quite a lot of time off work. I was furloughed as well for four and a half months, twice. It was weird not working but I missed

WATCHING

WITH CATS

"And then during the summer when it's nicer, I take the cats out on walks, they have harnesses and leads so they go out on walks as well".

ARTHRITIS

CHEST INFECTIONS

POLYCYSTIC OVARIES

ASTHMA MEDICATIONS

"I've got my asthma inhalers, I've got a steroid one that I take twice a day, I can increase the dose and obviously I've got my Salbutamol. Then, if it gets really bad, then I get steroids and antibiotics".

GENERAL HEALTH

"Sometimes my health can be really good and then the next time I'm just literally falling to bits, between my chest, my arthritis, obviously my stomach as well [..]".

IMMUNE SYSTEM

"I seem to have no immune system so I pick up every little cold and cough that's going so it goes into my chest straight away".

MINDFUL WORKPLACE

"If they need me to do additional they always ask first so I can work my childcare round about my shifts".

"If my childcare cancels or school is off and that, then they let me bring him [child] to work with

QUITE CLOSE TO DAD

"I'm quite close to my dad as well, even though he lives (up the road a bit). I used to see my dad quite often but with Covid, that sort of...stopped. We used to go out there almost every weekend but now it's maybe once or maybe every two or three months".

TWO CATS

PART-TIME JOB

OVER 3 YEARS

"I work part-time in a

hotel [on reception],

three days a week".

10 YEAR OLD CHILD

People in my

About you.

Where I

"I've had Covid three times now".

COVID-19

WEIGHT ISSUE

"I am overweight and it's got worse since I stopped smoking. [..] it's like five years since I've stopped smoking, so I've probably put on about five stone".

CHILDCARE IN PLACE

"If I need to do a late shift, my son goes to stay with my dad for the weekend".

"If I've got to work, he'll go to my dad or if it's just going to be a couple of hours, my son just goes down to my downstairs neighbours because he has his kids every weekend anyway so..".

DOWNSTAIRS NEIGHBOUR

"My downstairs neighbour, he's quite good, he looks after me when I'm ill or goes and gets my prescriptions (...)".

FRIEND WITH IBS

41 YEARS OLD

"It's nice to have someone to talk to that you can be quite open with and obviously a lot of people don't like talking about toilet issues and stuff like that, whereas obviously we have each other to talk to, we use certain words for stuff and she knows exactly what I'm talking about because she has the same issues".

LIVING IN ABERDEEN

"I've been in this flat [near the city centre] four years but I've lived in Torry for twelve years and then I grew up in Westhill which is just about twelve miles outside of Aberdeen".

Your journey to diagnosis...

EMOTIONAL
JOURNEY
i.e key moments where
care had a
positive impact, could
be improved or where
more support may be
needed.

MULTIPLE CONDITIONS

"Yeah, I'm a walking disaster area!".

HOME LIFE
i.e. interactions with
family and friends and
non medical/statutory
support

GP BASED CARE

i.e. GP visits or other

SEVERE ABDOMINAL CRAMPS

"It started probably when I was in my twenties, I used to get really severe abdominal cramps and stuff like that, but I was drinking quite heavily back then so the doctor always put it down to either my diet, drinking, being overweight.. [..]".

visits with health or care professionals outwith hospital

GP

AFTER POLYCYSTIC OVARIES DIAGNOSIS

"They just changed my contraceptive pill, they removed the cyst I had [..]. They told me that I was basically infertile, I wouldn't have kids, but that was wrong because I have my tenyear-old! Then they just left me to it".

MANAGE ON MY OWN NOW

"I've not actually been back to see the gynaecologist since but I do know I can feel when I get a cyst because I get the pain but they seem to burst themselves now because I can actually feel when they burst now, I get like a really bad pain just above my hip and I actually can feel when they pop ...".

VISIT DOCTOR ONLY IF PAIN LASTS MORE THAN TWO WEEKS

".. then I do go to the doctor but they just tell me it will be fine and if it doesn't go away, come back, but nine times out of ten, the pain goes away now, they just seem to get to a certain size and then go away themselves".

PAIN PERSISTS

HORSESHOE KIDNEY

"[..] then I found I had a horseshoe kidney so I had to stop drinking".

HOSPITAL BASED CARE
i.e. hospital visits including tests and consultations

GYNECOLOGIST

"They weren't sure if it was to do with my kidney or polycystic ovaries so they tried the gynaecology first [..]".

ULTRASOUNDS AND LAPAROSCOPY

"[..] I think I ended up with four ultrasounds and then they did a laparoscopy, which is where they found the cysts".

> CYST REMOVED

FOUR ULTRASOUNDS

"[..] I had...well four ultrasounds, before they discovered I had a horseshoe kidney, even though I'd been in hospital five times thinking I had appendicitis because I was in that much pain and all they could find was a kidney infection".

TIMELINE

EARLY 2000s AROUND 2005

NOW

AROUND 2006

Your experience of diagnosis...

EMOTIONAL JOURNEY

WHAT'S WRONG?

"I knew there was something wrong with me and the doctor was like, 'No, it's this, try this', and then I was like, 'No, it's not that, it's something else', and then they give you tablets, tell you to go away and you'd be back a month later with the same problem".

LOSING FAITH

"I think I had such a long period of time without going to the doctor to complain about it, I literally just got on with it and then I'm like, 'What's the point? Because they don't do anything'".

A LONG PROCESS

"It just took so long [..] It just seems like such a long process".

HO

STILL HAVING CRAMPS

"Once I stopped drinking and started eating healthier, I was still having issues".

WEBSITE

"I think they gave me a website [something to do with diet and like what to eat for controlling your IBS] as well to look up about eating and stuff like that but it was quite useless, the stuff they suggested I can't actually eat".

IBS GOT WORSE

"[..] obviously it kept getting worse so they gave me the tablets [..]".

IBS TABLETS

"[..] I was on the same tablets up until last year".

GP BASED CARE

INBETWEEN GPs

"I was in-between moving from Westhill to town [..]".

IBS DIAGNOSIS

" [..] they went down the IBS route".

"I did have a few tests to begin with so they all came back normal so they just said it was IBS, 'Here, have some tablets'".

STOOL SAMPLES & BLOOD TESTS

"I did the stool samples and they sent them away and I had blood tests, and everything came back normal".

GASTROENTEROLOGYST

NOT REFERED TO A DIETITIAN

"I've never actually been referred to the dietician, I don't think, possibly may have years and years ago".

AROUND 2008 AROUND 2010 Life after diagnosis...

EMOTIONAL JOURNEY

COPING

"It all depends on how well it's being managed".

MANAGING LIFE WITH TABLETS

"The tablets were sort of working and I learned when I needed to go to the toilet, what not to eat so it was just manageable".

EATING HABITS

"[..] I tend not to eat out, I just home cook most of my food. The takeaways, if I do get a takeaway, I know exactly what I can eat and where from, I don't order new stuff because I don't know how my stomach is going to react".

TRIAL & ERROR STRATEGY

"I just buy the same food that, if I do buy something new and then it doesn't agree with me, then I don't buy it again so I tend to stick to the same food all the time".

SAME DIET

"I know, because I've had it so long, I know what sets off my stomach so I tend to eat the same stuff because I know it doesn't set off my stomach[..]".

HOME MADE VS STORE BOUGHT FOOD

" If I make lasagne, I can eat it, but if I buy a store-bought lasagne, I'm horrendous the next day. So I don't know if it's the additives or what it is but if I make the sauce myself from scratch then I'm absolutely fine with lasagne. The same with chilli as well, I can have that if I make it myself but if I go out to buy a microwave meal, it doesn't work".

"[..] I don't drink any alcohol and I've stopped smoking as well, which is why the weight has gone up, but I'm working on that as well, to get the weight back down again".

NO DRINKING &

CHANGING JOB

SMOKING

From doing childcare to working part-time in a hotel. is why the weight has

UNDERSTANDING

"My work does know that [if I say] 'I'll be back in five', they know that I need to go [..]. There was one time I had a major flare-up [..] and my boss was like 'Just go home, you are not doing any work, just go".

NEW WORKPLACE

TO AVOID FLARE UP

"Well I get up about two and a half hours before I have to get to work because I know that I need to go to the toilet two or three times before I leave the house, so I get up earlier".

DIET AT WORK

"I try and watch my diet when I am working that three days, I try and have quite bland meals, stick to the same stuff, have the same stuff every day so that I know I'm not going to have a flare up at work".

MAJOR FLARE UP

"[..] I was in the bathroom for two days solid, I couldn't leave the house, couldn't actually go anywhere because my stomach, no matter what I ate or drunk it just literally came straight back out of me"

PAINKILLERS

"[..] I was in absolute severe pain they kept giving me painkillers".

NURSE PRACTITIONER

"Since I had the bleeding incident, I can phone up and then she'll phone me back because you can never get a doctor's appointment or the doctor to speak to you now. She's the one that's been dealing with my medication and changing it and then basically got it back settled that I could go to work again"

HOSPITAL BASE

GP BASED CARE

LATEST

ENDED UP IN HOSPITAL

"[..] last year it got to the point that I was living in the bathroom for two days, ended up in hospital. Because it was blood coming out at one point so I was in hospital for two days but all my tests came back normal again".

THEY DIDN'T KNOW WHAT IT WAS

"They just think it was a burst haemorrhoid but they are not actually sure [..]".

2019

Life after diagnosis... FEELING LISTENED TO FEELING UNDERSTOOD BEYOND **BEING LISTENED TO FEELING YOUR** EXPECTATIONS "[..] when I'm having a major POINT OF VIEW IS "[..] she [nurse practitioner] flare up but she [nurse "[..]she seems lovely! VALUED seems to be getting stuff "She [gastroenterologist] practitioner1 seems really nice And she actually BAD OR GOOD DAY done and then she was on the phone for and she's actually listening to listened to me, which "ſ..lshe ſnurse over half an hour, I was understands, when I say me. And not just fobbing me off, LINKED TO WEIGHT was really nice". "[..] it all just depends practitioner] knows expecting a quick five-'I'm in pain', I'm in pain, I she actually seems to be willing on my stomach in the that I know myself". minute phone call". don't complain until it's to help rather than, Here, have "Mostly they just tell me morning, I know when I really bad". some more tablets". to lose weight and then AGONY get up if it's going to be all my problems will go a good day or a bad away, that's one of the main things". absolute agony". ANTIDEPRESSANTS FOR PAIN **BALANCING PERIOD PAIN** MANAGEMENT WORKING ON KNOWING MY BODY & WITH IBS PAIN **IBS WORSE** STOPPING TABLETS MY WEIGHT CHANGE OF TABLETS RECOGNISING THE TYPE OF PAIN "The gastroenterologist put me on ANOTHER MAJOR SELF-MANAGEMENT SEVERE REFLUX "I had to stop my " [..] this one could be "I am working on losing weight, but "For ten years the (Alverine citrate) was antidepressants for gastroenterological use, FLARE UP UNTIL CRISIS "[..] I was living on Gaviscon for a "I know my body so if I get the working for the period pain and IBS and what's making my IBS stomach tablets for my so that they block the pain signals from my I'll lose two stone and then it all while, because my entire stomach STILL BAD then, up until two and a half years ago, it "I have severe reflux when worse as well because endoscopy and that's stomach to my brain so that I don't feel the seems to go back on again [..]. But I "[..] this time last year then I was burning basically, so she was "[..] obviously last year it got to go to the toilet and then I'll be fine just stopped working [for the IBS pain] I'm sleeping that I wake up of all this acid going caused my IBS to go pain as much. But they are not really am also quite lazy! Especially during had the major flare up again, "Now I'm on quite a lot the point that I couldn't manage just like, 'Right, I'll write your for the rest of the day or I know by and my stomach has just got a lot worse". being sick, I have to sleep into my bowels [..]". completely horrendous working, she gave me like a six week trial so the winter because it's just so cold but they are not sure whether of tablets a day but my it myself, I was in that much prescription for this, take an extra I'm just over three weeks in but they are not practically upright. I've just now". and damp and obviously my chest the type of cramp it's going to be a it's my stomach causing my stomach is still playing pain and living in the bathroom tablet here, take an extra tablet working. So I don't know if that's what's destroyed so many pillows doesn't like the cold, my joints spend-a-day in the house day. You "[..] so they changed me onto Mebeverine bowel problems or whether in for two days isn't the best". there, they are not working, we'll try up. I'm in the bathroon caused my IBS to get worse lately but it was doesn't like the cold and the damp. just get to know the different types but now my period pain is 100 times because stomach acid just I've got something wrong with you with these ones', she's been like four or five times a of cramps and pains". worse. [..] So it's trying to find a balance of comes up while I'm sick". obviously bad before they put me on that tend to hibernate during the winter". my bowels as well". quite good". what works for both?". tablets but it's just been worse lately". GP APPOINTMENTS CHANGES SAME NURSE NURSE PRACTITIONER IN THE GP PRACTICE PRACTITIONER "[..] trying to get a doctor's "[..] she told me to stop all appointment in my doctor's "[The GP practice] it got REFERRAL "She seems to be the same the painkillers and she surgery is like gold dust, I've not taken over by the NHS one I've had for a few times changed my stomach and seen a doctor in my surgery for and now it's just changed that I can phone her up and "It was the nurse "[..] they don't know if my IBS tablets and then all about two years now. I've spoken hands into this weird practitioner who I've got bile reflux or she knows my medical history, the pain went away and to them on the phone but if I've almost semi-private". stomach acid reflux or referred me to she knows that if I need to then my stomach calmed managed to get an appointment gastroenterology [..]' change my tablet or if I need". down [..]". to go in, I get to see the nurse practitioner". GASTROENTEROLOGYST "[..] I was referred last year but it **ENDOSCOPY WITH** BARIUM SENSOR took almost a year to get the BIOPSIES X-RAYS BARIATRIC TEAM [telephone] consultation and I had "Then I've got another the consultation and then a week "[..] I'm iust waiting "I think the "[Got to go and get] A one that I need to go and later I had the procedure. That was on the results for barium x-ray, you know, get a sensor put down gastroenterologist I spoke quite quick, it was just waiting for you swallow the stuff and into my stomach and to in February, she's the initial consultation". they x-ray you to see where then I'm not sure after referring me to the it goes". that [..]". bariatric team?". FEBRUARY MARCH MARCH WHAT'S 2022 AHEAD

PAIN MANAGEMENT

"Having someone that specialises in either pain management or which pain tablets or medication you could get to manage your pain that doesn't give you more issues".

LESS WAITING TIME

"Last year she referred me and I

only got an appointment this

year! The waiting times as well, obviously Covid has put a lot of waiting times to pot just now, but

it used to be when you got

referred to a specialist you'd get

a letter saying you'd been seen within eighteen weeks".

QUICKER REFERRALS

"[..] if you go [to the GP] twice within a certain period of time, then they send you for a referral rather than waiting for five times over two years".

ENGAGING WITH SPECIALISTS

What could be better for you?

"It would have been better if they'd explained or if they had a booklet to say this is what it is, this is what you can do".

A DEDICATED NURSE IN THE PRACTICE

"[..] a nurse at the practice that would take you on like your asthma review, just to go 'This is working, this is not, what's changed?' just have a wee management plan of how you are getting there and if it's getting worse or if it's...working? I had so long that my tablets were working, I thought that's me for life then all of a sudden I had a massive flare-up and then nothing was working and now I'm half and half".

FOLLOW-UP **SUPPORT**

ANNUAL REVIEW

"It would be nice if you had a bit more support in that you actually had follow-up or reviews, even like an annual one, you get your annual asthma review, they take you in and ask you if your medication is working and how you are getting on but they don't do that with any of your other tablets".

hat did you value?

SELF-MANAGEMENT **TOOLS**

HELP **GROUP**

"A help group that you could speak to other people that have the same condition, to

INFORMATION &

SUPPORT

discuss [..]".

A TRACKING APP

"Even like I have a period tracker app that I put in when my period is, symptoms and stuff like that, but you could have one for when you are having flare-ups then you could write what you had to eat the day before or if you'd done something different or been somewhere different, then help track it a bit more".

"So you could track your medication, your flare-ups, what you are eating...If I knew how to design an app, I would!".

ONLINE DIARY

"[..] even like an online diary or something so you can keep track of when you have flareups [..]".

SHARING IT WITH HEALTH **PROFESSIONAL**

"[..] it would be handy if you could share it, obviously my memory is rubbish when I do this, but at least that way you could have your information to hand".

SHARING **EXPERIENCES**

"[..] just to share your experience of how you manage it and obviously not every medication works for every person but just having someone else to speak to".

AFTERCARE

"More aftercare, so once you get your diagnosis, [..] having a follow-up with the doctor for any questions or stuff like that, even annual reviews, just something. Just so that you don't think you've been forgotten about".