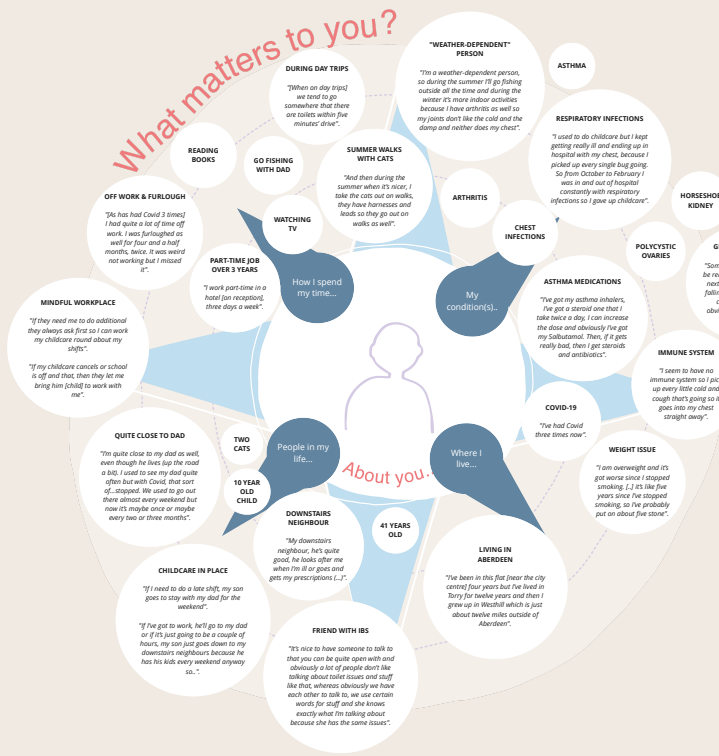


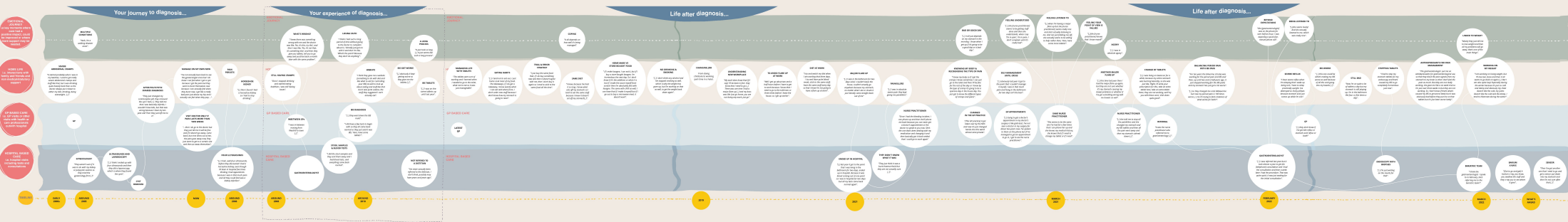
experience map
irritable bowel syndrome

Overview of all maps

What matters to you?



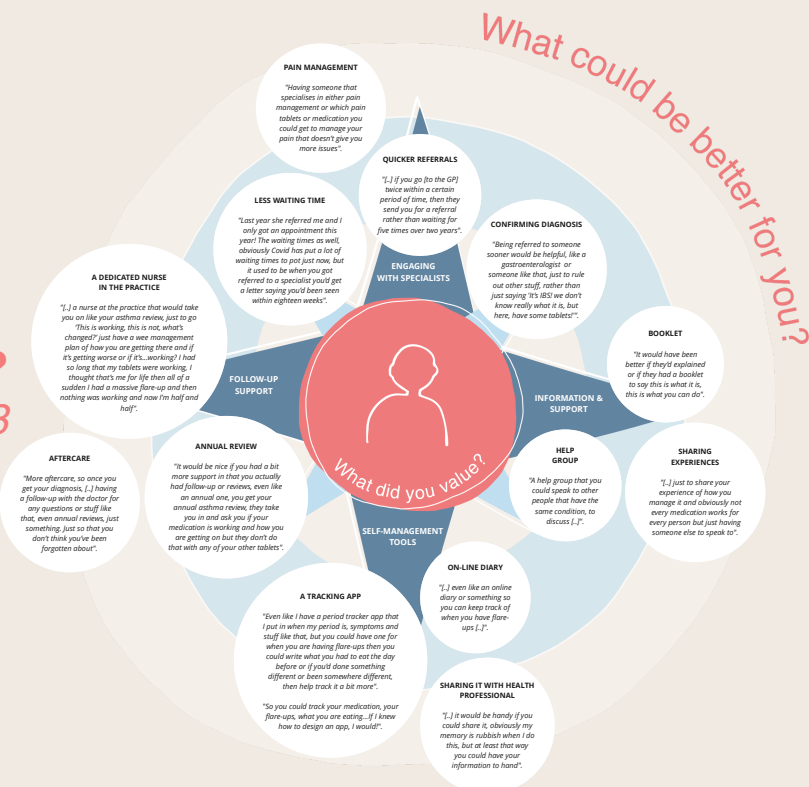
What matters to you? See in detail on page 3



Your journey

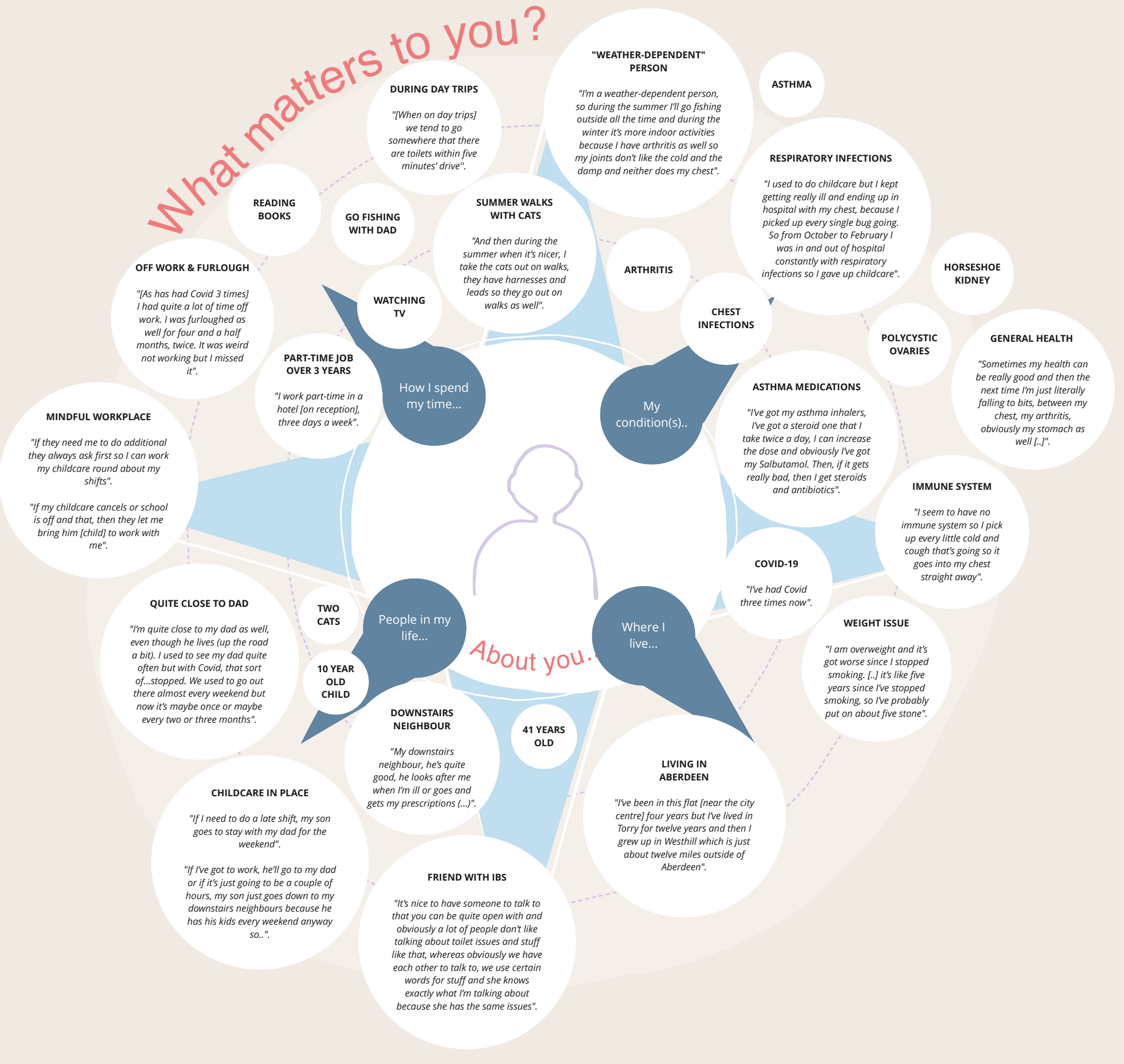
See each panel in detail on pages 4-7

What could be better for you? See in detail on page 8



What matters to you?

About you.



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.

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

GP BASED CARE
i.e. GP visits or other visits with health or care professionals outwith hospital

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

MULTIPLE CONDITIONS

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

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.. [..]".

GP

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

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 ten-year-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".

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".

HOSPITAL BASED CARE

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".

GASTROENTEROLOGIST

NOT REFERRED 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".

NO DRINKING & SMOKING

"[...] 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".

CHANGING JOB

From doing childcare to working part-time in a hotel.

UNDERSTANDING NEW WORKPLACE

"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'".

TO AVOID FLARE UP AT WORK

"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"

GP BASED CARE

LATEST GP

HOSPITAL BASED CARE

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".

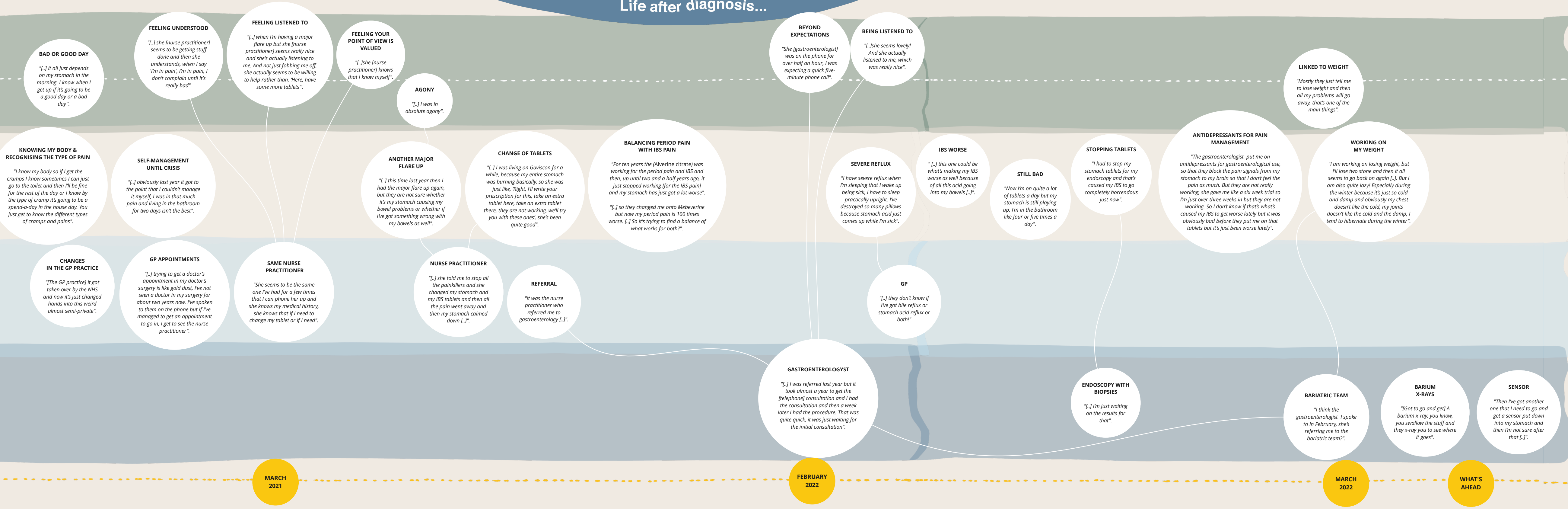
THEY DIDN'T KNOW WHAT IT WAS

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

2019

2021

Life after diagnosis...



What could be better for you?

