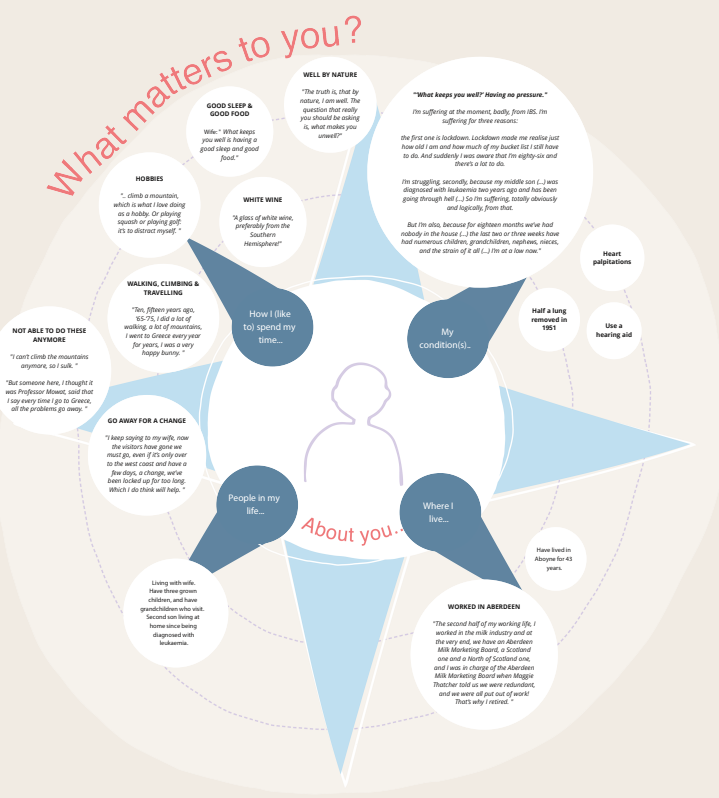


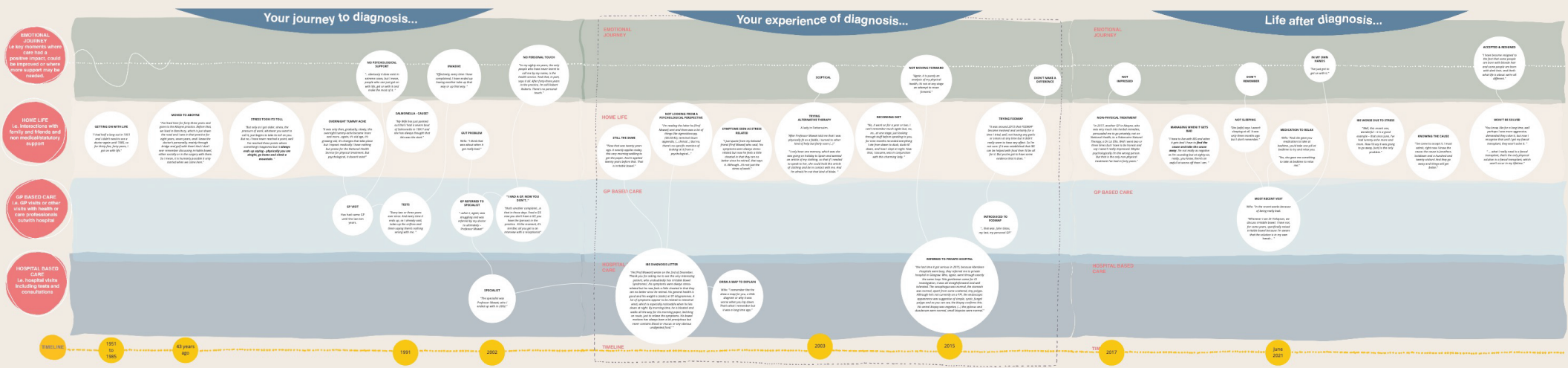
experience map
irritable bowel syndrome

Overview of all maps

What matters to you?

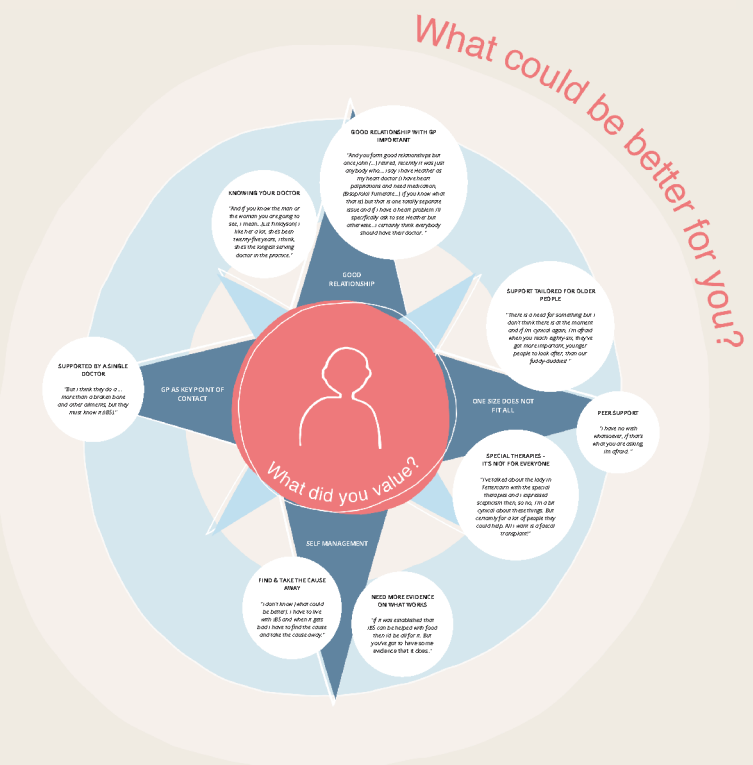


What matters to you? See in detail on page 3

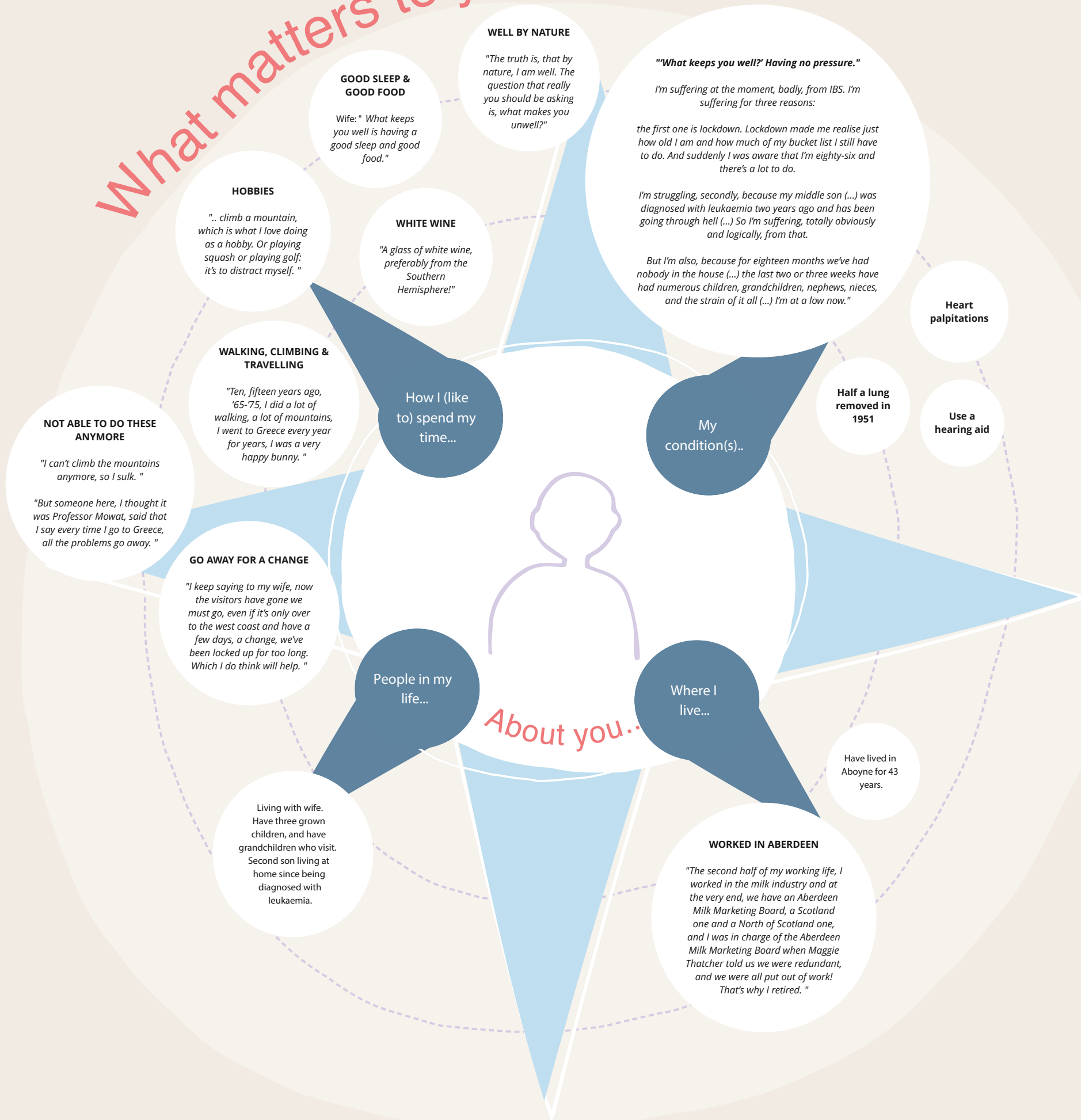


Your journey See each panel in detail on pages 4-6

What could be better for you? See in detail on page 7



What matters to 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

GETTING ON WITH LIFE

"I had half a lung out in 1951 and I didn't need to see a doctor again until 1985, so for thirty-five, forty years, I got on with life."

MOVED TO ABOYNE

"I've lived here for forty-three years and gone to the Aboyne practice. Before that, we lived in Banchory, which is just down the road and I was in that practice for eight years, seven years, and I knew the doctor's personally, mainly through bridge and golf with them! And I don't ever remember discussing irritable bowel, either socially or in the surgery with them. So I mean, it is humanly possible it only started when we came here."

STRESS TOOK ITS TOLL

"But only as I got older, stress, the pressure of work, whatever you want to call it, just begins to take its toll on you. But no, I have never reached a point, well I've reached these points where something's happened but it **always ends up saying - physically you are alright, go home and climb a mountain.**"

OVERNIGHT TUMMY ACHE

"It was only then, gradually, slowly, this overnight tummy-ache became more and more...again, it's old age, it's growing old, it's changes that take place but I repeat: medically I have nothing but praise for the National Health Service for physical treatment. But psychological, it doesn't exist!"

NO PSYCHOLOGICAL SUPPORT

".. obviously it does exist in extreme cases, but I mean, people who can just get on with life, get on with it and make the most of it."

INVASIVE

"Effectively, every time I have complained, I have ended up having another tube up that way or up that way."

NO PERSONAL TOUCH

"in my eighty-six years, the only people who have never learnt to call me by my name, is the health service.' And that, in part, says it all. After forty-three years in the practice, I'm still [full name]. There's no personal touch."

SALMONELLA - CAUSE?

"My Wife has just pointed out that I had a severe bout of Salmonella in 1991? and she has always thought that this was the start."

GUT PROBLEM

Wife: "I think that was about when it got really bad."

GP VISIT

Has had same GP until the last ten years.

TESTS

"Every two or three years ever since. And every time it ends up, as I already said, tubes up the orifices and them saying there's nothing wrong with me."

GP REFERRED TO SPECIALIST

"...when I, again, was struggling and was referred by my doctor to ultimately - Professor Mowat"

"I HAD A GP, NOW YOU DON'T.."

"that's another complaint...is that in those days I had a GP, now you don't have a GP, you have the (person) in the practice. At the moment, it's terrible; all you get is an interview with a receptionist"

SPECIALIST

"The specialist was Professor Mowat, who I ended up with in 2002."

TIMELINE

1951 to 1985

43 years ago

1991

2002

Your experience of diagnosis...

EMOTIONAL JOURNEY

SCEPTICAL

NOT MOVING FORWARD

"Again, it is purely an analysis of my physical health, it's not at any stage an attempt to move forward."

DIDN'T MAKE A DIFFERENCE

HOME LIFE

STILL THE SAME

"Now that was twenty years ago. It exactly applies today, this very morning walking to get the paper. And it applied twenty years before that. That is irritable bowel."

NOT LOOKING FROM A PSYCHOLOGICAL PERSPECTIVE

"I'm reading the letter he [Prof Mowat] sent and there was a lot of things like sigmoidoscopy, (00:30:43), terminal ileum appendix, (...clinical...) but no, there's no specific mention of looking at it from a psychological..."

SYMPTOMS SEEN AS STRESS RELATED

"I just quote from my beloved friend [Prof Mowat] who said, 'his symptoms were always stress-related but now he feels a little cheated in that they are no better since he retired', that says it. Although...it's not just the stress of work."

TRYING ALTERNATIVE THERAPY

A lady in Fettercairn.

"After Professor Mowat told me that I was physically fit as a fiddle, I turned to other kind of help but fairly soon (...)"

"I only have one memory, which was she was going on holiday to Spain and wanted an article of my clothing, so that if I needed to speak to her, she could hold this article of clothing and be in contact with me. And I'm afraid I'm not that kind of bloke."

RECORDING DIET

"No, it went on for a year or two. I can't remember much again but, no, no...at one stage, just looking through stuff before speaking to you, for nine months recorded everything I ate from dawn to dusk, dusk till dawn, and how I slept at night. Now that, I assume, was in conjunction with this charming lady."

TRYING FODMAP

"It was around 2015 that FODMAP became involved and certainly for a time I tried, well, not having any garlic or onions at any time but it didn't really seem to have any effect. So I'm not sure. If it was established that IBS can be helped with food then I'd be all for it. But you've got to have some evidence that it does."

GP BASED CARE

INTRODUCED TO FODMAP

".. that was John Glass, my last, my personal GP."

HOSPITAL CARE

IBS DIAGNOSIS LETTER

"He [Prof Mowat] wrote on the 2nd of December, 'Thank you for asking me to see this very interesting patient, who undoubtedly has Irritable Bowel Syndromes', his symptoms were always stress-related but he now feels a little cheated in that they are no better since he retired. His general health is good and his weight is (static) at 91 kilogrammes. A lot of symptoms appear to be related to intestinal wind, which is especially noticeable when he lies down at night. By morning-time, he is bloated and walks all the way for his morning paper, belching on route, just to relieve the symptoms. His bowel motions has always been a bit precipitous but never contains blood or mucus or any obvious undigested food.'"

DREW A MAP TO EXPLAIN

Wife: "I remember that he drew a map for you, a little diagram or why it was worse when you lay down. That's what I remember but it was a long time ago."

REFERRED TO PRIVATE HOSPITAL

"the last time it got serious in 2015, because Aberdeen Hospitals were busy, they referred me to private hospital in Glasgow. Who, again, went through exactly the same loop: 'this gentleman came for GI investigation, it was all straightforward and well tolerated. The oesophagus was normal, the stomach was normal, apart from some scattered, tiny polyps. Although he's not currently on a PPI, the endoscopic appearance was suggestive of simple, cystic, fungal polyps and as you can see, the biopsy confirms this. His antral biopsy was negative, (...) the pylorus and duodenum were normal, small biopsies were normal."

TIMELINE

2003

2015

Life after diagnosis...

EMOTIONAL JOURNEY

NOT IMPRESSED

NON-PHYSICAL TREATMENT

"In 2017, another GP in Aboyne, who was very much into herbal remedies, persuaded me to go privately, not on National Health, to a Fettercairn Natural Therapy, a Dr Liz Ellis. Well I went two or three times but I have to be honest and say I wasn't really impressed. Maybe psychologically I'm the wrong person. But that is the only non-physical treatment I've had in forty years."

MANAGING WHEN IT GETS BAD

"I have to live with IBS and when it gets bad I have to **find the cause and take the cause away**. I'm not really as negative as I'm sounding but at eighty-six, really...you know, there's an awful lot worse off than I am."

DON'T REMEMBER

NOT SLEEPING

"She [wife] says I wasn't sleeping at all. It was only three months ago but I don't remember."

IN MY OWN HANDS

"I've just got to get on with it."

MEDICATION TO RELAX

Wife: "And she gave you medication to take at bedtime, you'd take one pill at bedtime to try and relax you."

"Yes, she gave me something to take at bedtime to relax me."

IBS WORSE DUE TO STRESS

"Well, this recent one, wonderful - it is a good example - that since June, I've had tummy-ache more and more. Now I'd say it was going to go away, [son] is the only problem."

KNOWING THE CAUSE

"I've come to accept it. I must admit, right now I know the cause; the cause is Jonathon, lockdown and a hundred and twenty visitors! And they go away and things will get better."

ACCEPTED & RESIGNED

"I have become resigned to the fact that some people are born with blonde hair and some people are born with dark hair, and that's what life is about: we're all different."

WON'T BE SOLVED

"You know, like for a long time, well perhaps I was more aggressive, demanded they solve it, but now I recognise that until I get my faecal transplant, they won't solve it."

"... what I really need is a faecal transplant, that's the only physical solution is a faecal transplant, which won't occur in my lifetime."

GP BASED CARE

MOST RECENT VISIT

Wife: "In the recent weeks because of being really bad."

"Whenever I see Dr Finlayson, we discuss irritable bowel. I have not, for some years, specifically raised irritable bowel because I'm aware that the solution is in my own hands.."

HOSPITAL BASED CARE

TIM
2017

June
2021

What could be better for you?

