HOW MY CROHN'S DISEASE DIAGNOSIS WAS A DRIVER FOR BEHAVIOUR CHANGE

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After graduating from Cardiff University in 2017, I went travelling around Southeast Asia with three friends, drawing a line under the hours spent on essays as we bussed, biked and flew across Vietnam, Cambodia and Indonesia. The trip was timely because it bookended our three years as undergraduates, but shortly after returning home I began to lose a substantial amount of weight.

At first, I was worried that I may have contracted a tropical disease while travelling because my symptoms initially mirrored those of a number of conditions. However, after multiple visits to my GP surgery and a local specialist gastroenterologist department, I was diagnosed with Crohn's disease.

Understanding my diagnosis

Up until that point, I had little knowledge, let alone an understanding, of Crohn's disease, learning only at diagnosis that it is a form of chronic inflammatory bowel disease (IBD).[1] Crohn's disease is believed to be multifactorial; genetic factors, dietary and environmental exposures, immune events and dysfunction of the gut microorganism material (microbiome) are all thought to play a role[1] – though what factors had an impact for me, I'm still not sure.

After diagnosis, I was prescribed first-line steroid therapy as a method of effective symptom control to help reduce the inflammation;[2] however, the extent of the inflammation I was experiencing resulted in me developing a fistula complication, which worsened and ultimately led to emergency surgery for bowel perforation. It was during my recovery that I was presented with a framework of information through patient booklets and discussions with consultants, changing my understanding of Crohn's disease and enabling me to initiate my own behaviour change as a way of managing any future inflammation.

Initiating behaviour change through information and self-experience

Although the role of diet in IBD is not fully understood,[3] some studies suggest it could be a key factor in the development (pathogenesis) of Crohn's disease.[4] Animal-sourced foods, increased dairy fats and the adoption of refined wheat, emulsifiers and thickeners can also be associated with intestinal inflammation.[4] Despite being unable to control many of the factors that may have played a role in me developing Crohn's disease, I recognised that I would be able to take charge and modify my diet as I learned to live with and manage the disease long term.

As I continued to explore the disease area, dedicated information and advice played a key role in supporting my behaviour change, and I was introduced to studies that placed emphasis on dietary modification for symptom management in Crohn's disease. For example, in a survey of 223 healthcare professionals (HCPs), 48% believed that diet was involved in IBD development, 53% believed that diet could trigger disease relapse and 61% recommended limiting specific foods to reduce risk.[3]

In addition, gastroenterologists were substantially more likely to believe that red meat and additives/preservatives initiated IBD development.[3]

With this information and self-experience, I began to omit specific foods from my diet and adopt alternatives, with the intention of preventing relapse. I swapped processed ham and pork products for plant-based alternatives, opted for vegetarian options when available and avoided certain food groups identified as risk factors for inflammation, such as corn kernels and beans – all while listening to my body and letting it play a role in guiding my choices.

I'm now aware there are some foods I can simply no longer tolerate and have learned to avoid. As with many chronic IBD cases, part of my diet modification – alongside advice from HCPs and other individuals with Crohn's disease – derived from self-experience.[5] I read patient support websites, scientific journal articles, Crohn's disease forums and more, all of which fed into my behaviour change.

Managing Crohn's disease with dietary modification

Evidence tells us that relapse prevention – including problem solving and identification and implementation of coping strategies – is one of the factors that best supports dietary behaviour change.[6] While it may be challenging to maintain behaviour change in the long term, it is relapse prevention, driven by improved disease understanding, that has been a determining factor for me.

Taking ownership of my wellbeing was, I found, a worthwhile strategy for mitigating the social alienation that individuals with Crohn's disease sometimes feel when they are forced to modify their diets through necessity.[7] To my mind, it was more of a positive choice and a change in perception when I was required to rethink my beliefs around what had been the norm, what I had been required to adjust to and what changes were rational for me to move towards.

I now focus on maintaining a semi-vegetarian diet with plant-based sources of protein because studies have shown it to be beneficial in the maintenance of Crohn's disease remission.[8] Yet it remains important to recognise that, while dietary modification can be an effective adjunct to the management of symptoms and inflammation, more research is needed to define the most effective dietary strategies.[9] Those with IBD are already likely to have nutrient deficiencies at baseline that require repletion; therefore, it's important to evaluate how the nutritional adequacy of different diets compare to avoid exacerbating nutrient deficiency.[9]

Together, these factors mean that my Crohn's disease management and dietary behaviour changes are aspects of my health that I must continue to monitor, alongside regular follow-ups with HCPs. Just as patient booklets and consultant discussions were responsible for modifying my diet previously, new information may necessitate further behaviour change in the future to continue to manage this progressive disease effectively.

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