Supplementary Table 3. Open end answers with comments about employment, questions about law and suggestions for improving health services and work supports

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| Person | **Do you have any comments about your employment that may have been missed?** | **If there was a question you could ask an employment law expert in New Zealand, what would it be?** | **Do you have any other suggestions for improving health services and work supports available for persons with IBD when they are having problems with symptoms?** |
| 1 | x | x | At the time of my diagnosis, I was given no information about the support available or my legal rights. It could have saved a great deal of stress, at the time |
| 2 | Current role is inherently high stress due to project commitments, involving a fair bit of travel - IBD at this time has not impacted too much on this. | x | x |
| 3 | x | How many sick days can you take before you have to explain why to your employer? | Maybe info pamphlets for employers as many don't understand the implications and problems encountered. |
| 4 | There is little to no understanding in the workplace and you are treated like [expletive]\* for something that’s out of your control | x | x |
| 5 | One different aspect is how much detail you disclose to the wide group of colleagues, clients etc you work with. They know something is going on with your health, but it is not always easy/comfortable to share these very personal health issues. Some people will find this harder to deal with than others, but it can be embarrassing to discuss especially when it is to do with bowel control/illness. | x | There needs to be easier and more streamlined pathways for accessing sickness benefits, when these are sometimes needed. My experience is that there are a lot of hoops to jump through at a time when life is already very different health-wise. A more shared-agency approach between health services, and sickness benefit services would make this much less stressful and hopefully reduce the volume of paperwork and provision of 'proof' of medical condition/income/ability to work etc. |
| 6 | I am judged on macro results, not micro processes | How long can I take off work with illness without getting fired?  Are employers allowed to refuse these workplace accommodations?  Where can people with IBD get accurate legal advice for employment? | A specialist law expert for people with IBD (in employment) |
| 7 | x | x | I have been single for many years bringing up 3 children and could not afford income protection. Due to the nature of the work I did I felt pressured to resign knowing I could be off work for months getting symptoms under control. |
| 8 | My workplace was very understanding with my frequent trips to the doctor. | x | People should be able to work from home, if possible. |
| 9 | I have changed jobs 4 times since being diagnosed with Crohn’s in 2015 due to needing to reduce hours of work to a point where I can balance work and health. I have gone from a 40 hour week to 15 hours. Each employer has been very good but the work load has increased and my ability to meet it has decreased so I have left at my own choice. | x | x |
| 10 | I pay a higher premium on my insurance even though my IBD it not covered it is 1/3 more (would not be able to pay this if I was not working) | x | x |
| 11 | I would just comment that ironically , in the past when my IBD has been at its worst, I wondered how I would ever cope with being at work again - I felt too much pain, too low in energy, and too unwell to work. However since I have been working - and you can see that I work extremely long hours and it’s a reasonably active job, I've had very little trouble with my IBD. This is partly to do with what I eat - mostly low FODMAP, but I think mainly that my mind is occupied, I feel useful and positive and extremely capable, and my positive mental state has almost settled my IBD right down. Note that I have not taken my pentasa IBD medication for around 6 months as I don't need it, and have not had any severe IBD for a long time. | Can I just add that getting out of the depression & hopelessness I felt for the first year or so of being very unwell with IBD has been very much down to the positive effects of contributing to society through work - albeit unpaid at the moment. So I actually recommend that even though an IBD sufferer might feel that they cannot work and cannot see any future for their good health - I have found work to almost be a cure for my IBD. I never expected to feel again like a fully functioning & well member of society, but I actually do. Getting my IBD under control to start with by following a low fodmap diet, getting myself well, and returning to work, and getting off all my medication is fantastic. I recommend work !! | When I experience bad symptoms, I have sometimes needed to lie down to try to relax my abdomen. This is not practical at work! However, the pain is also helped by going to the toilet, and sometimes by using relaxation techniques for my mind & body. Just having access to a toilet close by is also a relief for the mind, and I have found that my IBD can be quite connected to my state of anxiety. |
| 12 | x | x | Doctors to make diagnosis of seriousness of IBD early- treated by traditional methods had no good effect on my IBD until I had regular infusions of Infliximab which made a dramatic improvement- stopped diarrhea overnight when hospitalized. |
| 13 | I am essentially a self-employed contractor working for an agency. | x | x |
| 14 | I was lucky to work for the same employer for 31 years and able to move up the management line they were incredibly supportive. However the extreme tiredness/exhaustion every day was challenging to deal with. I wonder what I could have achieved without IBD. | What can be done to reduce the financial impact of IBD, the family of those with the disease | x |
| 15 | I am/was self-employed. Farming and working at home so it has been easy for me to take time off with understanding family. | x | x |
| 16 | x | Why is it so difficult to get any income insurance, if you have IBD? | x |
| 17 | x | x | Do more tests when admitted into hospital rather than giving pain relief and sending home. |
| 18 | Most difficult thing is the urgency of needing the toilet but during random times of day so if you were busy with clients etc was stressful | x | Specified toilet to use during flare |
| 19 | My employers are very sympathetic to my disease and grant me time of when needed | I am Maori and Maori life expectancy is less than European as I am over 60 years will my disease further lessen my life expectancy. Therefore why can’t I apply for the old age pension at age 60 years. | More media advertising around the topic - Education   Some people have an understanding of the disease |
| 20 | Sometimes it is the mere energy used opening a truck to be loaded which can throw me, luckily it is only for a couple of hours a day. But this is barely covering my expenses therefore I am currently looking for new employment. | x | x |
| 21 | A general comment: I feel these questions target something that is highly contextual. Given the limited time frame (last 12 months) I don't think I can accurately convey my circumstances. Presently I work in a job that has very limited requirements. I opted for this as I was struggling to perform as a software engineer and chose to leave due to my inability to focus, brought about by malabsorption/anemia. I've experienced much else but again, a lot of it is overlooked because of the time frame. | Can I be dismissed due to unplanned leave due to illness, e.g. 6 weeks in hospital? | x |
| 22 | I am the sole employee for my organization with an unpaid board being my decision makers/managers. Therefore flexibility has been quite high but knowledge of how to support me very low. | x | Making short term winz payments easier and less going in to the offices. Altitude that I have dealt with these also negative and make you feel low. More transparency with your own notes (Blood test results etc) so that the patient can feel more in control of their own disease |
| 23 | x | x | I have had Crohn's for 12 years and I think it would be nearly impossible for me to keep a full time job, with getting sick, doctors and specialist visits and the fatigue. The stress would make me so much more sicker |
| 24 | x | If you are on extended medical leave but still employed by company are you entitled to paid stat holiday and does your annual leave still accrue even though you are not working? | x |
| 25 | Placement of the toilet is right near reception and that bothers me. | Are you entitled to more sick days because of your illness? Can my sick days be paid for by the public health system rather than employer? | Assign a support person that's available 24 hours to help. Better communications on your care plan. Someone from the gastro department comes to see you if your admitted to hospital. GP's and general Nurses do not understand this disease fully. |
| 26 | x | x | Private insurance is a must. NZ Health system slow, unreliable, money driven (Not enough) |
| 27 | x | Can you be fired for missing too much work time? | x |
| 28 | Questions have sometimes been hard to answer because I was diagnosed 12 months ago and have been on sick leave for the last four months. | Can an employer make you redundant because of sick leave due to IBD? It's about job security and illness | IBD patients should have access to mental support (e.g. clinical psychiatrist) |
| 29 | x | x | Online forum would be great to share each other’s symptoms/concerns etc |
| 30 | x | Can I take paid time off for hospital apt without using sick leave or annual leave? | x |
| 31 | My employers were fantastic when I was in hospital & arranged a laptop for me so I watch movies etc until I was up to working. And then they arranged high speed Internet for me at home so I could work. | x | x |
| 32 | x | x | Just that people are kind and don't judge - often the illness is invisible so sometimes people don't believe there’s anything wrong |
| 33 | x | Trust to clarify what entitlements you have when a disease such as colitis affects your work situation | I consider myself very lucky with such a good doctor and able to contact my specialist at the hospital at any time. This type of support means such a lot |
| 34 | Not really - I have always found the odor the main concern with IBD. Really embarrassing and hard to disguise | x | I don't think the workplace can do anything other than provide toilet facilities and be flexible and understanding about time off. |
| 35 | x | x | Being able to see a doctor sooner  Easier access to certain drugs- you have to try first |
| 36 | x | x | An understanding boss was helpful - she suffers from IBS on occasion herself |
| 37 | (regarding question about life insurance: had insurance until could no long afford it but then costs doubled because of my colitis)  I have finished my job as I could no longer keep doing 40 hours a week. Currently looking for part time work | x | x |
| 38 | Being self-employed, I have forced myself to keep working. At times it has been difficult and uncomfortable but I cannot afford to cut down hours. I have no choice but to work | x | x |
| 39 | My current manager is fantastic as had suffered a similar situation however if she had not may not have been as genuinely understanding | x | x |
| 40 | x | x | Allow for breaks when you need it |
| 41 | As I work in a factorya with overalls and plastic overalls go over normal clothes, we pride ourselves on cleanliness so washing hands 3 or 4 times upon return to the factory and leaving factory.   This is where the stress is often just poo into pad and then go to toilet then change and come back. | Crohn's disease disability car parking saves everyone an embarrassing situation! VITAL! | I am not a talker but having the ability to talk to staff or HR department is important.  That the country is made more aware of this problem as I understand it, it is a growing one. |
| 42 | I charge per hour. If I don't work, I don't get charge. I need to deliver results, so sometimes have to work more; UC does not materially impact my ability to do so. | x | x |
| 43 | I was a sales rep ??? ..... | x | More IBD nurses to ... help network available ??? |
| 44 | Healthy people don't understand what we go through on a daily business. | x | x |
| 45 | I work from home, even though there is an office in my city. This substantially reduces stress and anxiety I feel about my IBD.  If I had to work in an office I believe my symptoms would be very worse. At home I can wear comfortable clothing and visit the toilet as often as required, for the required time. I would be embarrassed in the office using shared facilities. | x | A card that allows access to toilets in shops, businesses etc. should be more widely available. But this would require more public awareness of such a card and acceptance.  I would like to say that I believe I am well looked after in the hospital great service :) |
| 46 | No, but I think I could not manage full time work that was not office based.   i.e. Nothing physical! | Can I be told to take less/shorter toilet breaks as I might need multiple breaks! | x |
| 47 | x | x | When someone first gets told they have IBD, make sure someone can explain to them what they have and it will be ok. |
| 48 | When work is very stressful my symptoms seem worse | x | Understanding the relationship between stress & IBD |
| 49 | Self-employed | x | Mental and physiological aspect & impact of IBD is large & understated. Fatigue is also a HUGE factor ! I perhaps more so then anything |
| 50 | I am very lucky to work in the disability sector. My employer is very reasonable and supportive.  They give me any time off needed. | x | Insurance is very difficult-I have life cover and it is very expensive. I had medical cover but it would become too expensive to keep-this is unfair.  Holidays can be difficult and I am concerned medical insurance will be a waste of time as so much can be put down to Crohn's disease!  Therefore, the cover is pointless. |
| 51 | x | x | Having GPs more aware that medication is available. It might be me but it took a long time for me to get admission and to get proper diagnostics on what was actually wrong. |
| 52 | x | Be considerate to people’s needs | Be considerate to people’s needs |
| 53 | x | x | Nicer toilets |
| 54 | When unable to work just have to rearrange my work which is home visiting pediatrics | Not relevant to me now- would be if I was younger in full time work | Health services have been supportive for me |
| 55 | x | If I have an IBD diagnosis, can employers reduce my work hours because of the illness? | WINZ sickness payments are barely survivable. not only that, the process of receiving them is long and difficult when suffering from fatigue and you're expected to attend numerous appointments. |
| 56 | x | x | Not necessarily relating to myself but variable starting times/hours. Options for non-clinical duties if appropriate during difficult times. Option for increased sick leave/I would have no idea whether there is any financial support available if sick leave runs out. |
| 57 | My boss helps me out of work | x | mental state |
| 58 | x | x | Having somewhere to lie down and rest |
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\*Swear words were replaced by ‘[expletive]’

aAnswer was deidentified to guarantee privacy