GP LINK Lunches | Dr Fiona Mackintosh

Dr Kenneth McCroary, Chair of Sydney South West GP Link, hosts a series of meetings with clinical/ political/regional individuals or organisations to discuss issues and solutions for GPs working in South Western Sydney.

Dr Fiona Mackintosh

Dr Ken McCroary

Ken McCroary - The COVID-19 pandemic has been an interesting ride for all of us with varying experiences as physicians, but also our own personal experiences with the infection itself and vaccination.

As the pandemic has played out, we are now seeing the emergence of post COVID sequelae and long COVID syndrome. I recently presented at a webinar on long COVID and subsequently met Dr Fiona Mackintosh, a fellow GP working in our region. I learnt about Fiona's personal experiences with COVID infection and long COVID symptoms. I thought her own lived experiences would be a great resource and repository of experience and she accepted an invitation to join the South West Sydney COVID Working Group which continues to make invaluable contributions. I also asked her to share some of her experiences with GPs from South Western Sydney.

Dr Mackintosh works in Moss Vale, in the Southern Highlands. After starting general practice in the city, she moved to the highlands 10 years ago and has enjoyed practicing medicine in a regional area. Fiona has an interest in medical education and has taught AMC candidates, medical students and GP registrars. She has been a conjoint lecturer at Western Sydney University and is currently a GP supervisor. She is the Wingecarribee representative for antenatal shared care for South Western Sydney Primary Health Network.

Fiona caught COVID at the end of February 2022. She has post COVID symptoms of fatigue and pain and has been unable to return to clinical work. She is interested in long COVID research and responses around the world, and recently joined the Long COVID Working Party for South Western Sydney Primary Health Network.

Fiona, tell us about contracting COVID, your experience of the infection and the subsequent events of ongoing symptoms and eventual long COVID.

Dr Fiona Mackintosh - I contracted COVID at the end of February 2022 and had a mild to moderate case. I had a week of feeling pretty awful with temperatures and aches and I remember being very fatigued at the time. I had a little bit of coughing, just that horrible chesty feeling. What I noticed after that was the ongoing and persistent fatigue. I had to sleep every day for a few hours … I would get up, have a little bit of activity in the morning and then I would have to go back to bed and sleep for two or three hours. I can't go back to work because I am too fatigued. I realised the feeling was staying - after a couple of months it was still there. It really was that realisation the fatigue was quite persistent and what I know now was post-exertion - the more I did the more I would get fatigued, to the point where I felt like I was walking through quicksand. I would seize up if I walked too quickly or if I walked from the car to get the milk at the back of the supermarket, that sort of level of exertion. What I also started to notice was I would become quite tachycardic when I was tired, even going to the shower. I wouldn't say I was the fittest person beforehand. I was working full-time as a GP, but I was exercising at least three or four times a week, take a good 5km walk with a friend and do other things. This was a considerable slowdown for me and, at that time, we were getting a lot of information from WHO about chronic fatigue and long COVID being post 12 weeks. In those early days I just monitored my symptoms to see how long this was going to last for, and doing sensible things like cutting back my activity to a level I could cope with and seeing if it would just naturally settle. Then, of course, it hit the 12-week mark and then the six-month mark and now it's 12 months later. The other interesting thing that happened was the change over the 12 months. Initially, it was very much the post exertion of malaise and exertional fatigue up until about six months when I was eligible for a second booster or a fourth COVID vaccine. I had a vaccination at the end of July and my symptoms changed, where the fatigue improved a little and I noticed particularly the foggy brain feeling of fatigue change. I felt a little more alert during the day, but I then got some chronic pain. After that booster, I started to get a very generalised body ache. It's not really describable - it is a strange feeling, probably like you are just extremely exhausted and your whole body starts to ache. It is a heavy pain and quite unusual, and the insides of my elbows and strange areas ache. I notice that too much exertion - if I carry too much, if I do a thing that is too heavy or over-exert myself - causes the pain as well as the fatigue now.

Ken McCroary - You mentioned that feeling - we all know of the cough and the chest - but that is the thing with COVID, we don't all know this because everyone gets affected differently. A lot of people have no idea what you are talking about with this cough and chest stuff. What is it like with the cough, the chest, fatigue, the malaise and the post exertional stuff? You can have a rest and it doesn't get any better, does it?

Dr Fiona Mackintosh - No, I am tired, but I just get these small improvements if I am rested. I had this very tired sort of variation feeling of fatigue. I would sleep for 10 hours and I would wake up tired. I would sort of get myself moving and I would start to feel that tiny bit better after breakfast. I would have a couple of hours where I would feel a bit alert and I could maybe do something like hang up half the washing or check an email. By 9.30am I would be tired again and almost ready to go back to bed. I would try to push on until about 11am, have something to eat, then by about 11.30 I would be back in bed. I would have two or three hours' sleep and then I would sort of lay around for a while before I got going again. I'd be okay for dinner break with the family, I could potter around and be up and going for a few hours in the evening before I went back to bed. That was the pattern of the fatigue in the first six months. The coughing was initially with the first infection. My son had it at roughly the same time and he had something similar where he described a tight irritated chest, not chest pain per se, but what I imagine is more a sort of pneumonitis or an irritation. It's that irritating cough I noticed, and then it triggered for me exercise-induced asthma. I had some breathlessness that continued until we recognised and treated it. That was the cough pattern for me.

Ken McCroary - You also had some experience with the long COVID clinics as well. Could you expand on that?

Dr Fiona Mackintosh - Luckily or unluckily, who knows, it was about the time in March when my GP and I realised that maybe I did have long COVID as the symptoms were persisting for a bit longer. The COVID clinic at St Vincent's was opening and my GP suggested we put in a referral and get things looked at. We did that and I had the barrage of bloods tests and made the referral. It was noted the only unusual thing in my blood was my EBV I'd had previously was quite reactive - both my IBM and IGT were reactive. We now know that happens in long COVID. Unfortunately, the clinic had so many referrals it was six months, in August, until I was reviewed. I had a review by the rehabilitation specialist, which was very comprehensive in the sense they looked at all of the symptoms of long COVID (I really only had breathlessness and the fatigue at that point) including functional capacity and things like that. It was a very targeted review and, at that time, I got the impression what they were looking for was: did we need to do an MRI for brain fog and confusion, did we need to do further testing on scans for lungs, and did I need to have anything else done? It was decided "no, I did not", it was predominately fatigue, so it was very much "okay, go off and manage your fatigue and here are some resources you can use, but we don't have any capacity to follow that up". That didn't seem particularly useful for me at that time, and maybe the two reasons for that were they had not really defined what they were doing with the clinic, or what the clinic was. Were they just screening for those more significant people or cases or looking for other possible complications? We hadn't been dealing in fatigue management and rehabilitation for the post exertional sort of symptoms.

Ken McCroary - It is one of my frustrations as well. As GPs, we have been dealing with post viral syndromes, chronic fatigue syndromes and myalgic encephalitis for decades. Then you get these tertiary centres or quaternary centres setting up clinics to deal with breathlessness in the vast majority of people who are not actually hypoxic, are they?

Dr Fiona Mackintosh - There are a few with those symptoms and that is something that should be managed through primary care, but that is not how things are prioritised these days.

Ken McCroary - You have an interesting dynamic about the physician becoming the patient. I find that concept quite interesting and terrifying. How was it?

Dr Fiona Mackintosh - It was interesting and terrifying. It was interesting because you are suddenly a study, and you start researching and trying to look at chronic fatigue literature and doing your own searches and finding all sorts of off-label things that people have used or trying out like Coke U10. There is lots of "will that work?", "won't it work?" or "is it worth giving it a trial?". So we tried, but it didn't make any difference. You start doing those sort of processes as well as just trying to reassure yourself you must be patient sometimes and go with the flow. You observe the symptoms more and see what you can do to control that anxiety about "how long is this going to be?" and "when can I go back to work?". It is an interesting process. Over the whole year our information boomed as well. The information about COVID was very little and suddenly over 12 months we had so much more.

Ken McCroary – With the whole patient experience, obviously there is a lot of vulnerability we are not used to. Did that have any benefits as well, in terms of empathy and compassion as a physician?

Dr Fiona Mackintosh - I think so, absolutely. We have heard many stories about doctors who become unwell and then write books or articles about their experiences. It reminds you the systems and processes are sometimes long-winded, complicated and confusing. Sometimes, when seeing specialists, the communication isn't clear. You pick up different things to what they think they are saying or what us GPs are saying. We think we are explaining things well, but sometimes we are just not on the same page or giving that same impression. I would pick up something widely different to what my husband thought the specialist was saying. Communication is really important, especially when there is this complex uncertainty around the disease process. It can be very difficult to settle with it, calm yourself and go with the flow. Because we don't really know, it is hard to sit with that uncertainty sometimes.

Ken McCroary - I think being so forthcoming with sharing your experiences, that is helpful for us as well, to appreciate living with these chronic symptoms because it has obviously had a major impact on your life, home life, professional life … everything, hasn't it?

Dr Fiona Mackintosh – Yes, it has. I have taken the 12 months off work. I haven't returned to clinic work in that 12 months so that has impacted on my patients. They have just disappeared, unfortunately. I had been working seven sessions plus administration and GP supervisor, I had two registrars - and suddenly I was not available at all. My clinic has taken over that load and I have managed to do some teaching and some gentle once-a-week teaching for the registrars. In regard to more formal things, I haven't been able to return to that patient load. Family-wise, I was lucky I had put in some income protection in our self-employed status. I think we should all have some income protection in place in our insurances. I was fortunate I had done that many years ago. But, you know, it is hard on my husband. I get tired, I can't do housework, take kids to places or do things to support the family. I have a 16-year-old daughter in Year 11, and she has stepped up to do some things maybe she wasn't ready for.

Ken McCroary - A lot of adjustment for everyone?

Dr Fiona Mackintosh – Yes, it is hard. Socially you can't go places very much. I feel I've gone through my COVID lockdown again because I don't really leave a small area around my house. I am stuck to a small location.

Ken McCroary - How do you cope with that change in your life? Suddenly, one day, you have a chronic illness.

Dr Fiona Mackintosh - When I first started looking at information, I thought to myself, "Okay, if this lasts over 12 weeks then on average this may take up to 12 months to settle down". I had that in my head from very early on that I would have to just relax into it. This is going to take time and go away eventually, but you are just going to have to do what you have to do to get over it. I was very certain about that and then I think I was so tired and sleepy that I couldn't really become too worried about it. I found a rhythm of just being, doing my mindfulness, doing the relaxation, doing the calm things, doing what I could during the day and taking each day as it came. I tried to cut it down to that daily pacing, the only way I could manage, and that kept me comfortable mood-wise and functionally it helped me get through what I needed to do. That was the only way I could think about it.

Ken McCroary - We have other patients with chronic fatigue syndromes, post viral stuff, autoimmune conditions that live with chronic fatigue and that malaise, and the pain syndromes, all day every day. Now you have been on the other side of that experience, how would you comment on the understanding doctors and medical professionals have about trying to live like that, or how government decision-makers have an understanding, even in the community and those close to you. What sort of misunderstandings are out there?

Dr Fiona Mackintosh - It is difficult from a community perspective. I think initially what is difficult is that people see you at your best. When I am out socially or when I manage to get to the supermarket that is actually my best for the day. Right now, I sound quite good, but in an hour or two I may be resting in bed. That is one perception, that people don't see you at your worst all of the time, so it is that type of disease where it looks a bit more mysterious. The other thing is that it is really time-consuming to manage. The guidance around pacing your activities and watching your fatigue levels is really intensive, so making sure you don't become tired means you have to monitor and catch yourself before you are tired and stop that activity. So, 20 minutes of reading, stop; 10 minutes of exercise, stop, and have a rest to do some mindfulness; five minutes of washing up and then pause and sit down for 10 minutes; get up and finish five more minutes, then pause, then stop. It's a labour-intensive process to do that every day, monitoring your fatigue, so even that level is quite intense. We all don't do it very well because sometimes our nature is to go at things and you push harder just to get a task finished and then, of course, you regret it the next day. Those things are difficult. In a logistics sense, I think the difficulty with managing chronic fatigue is that we've never had fantastic guidelines around pacing. It looks different for every person, so it has to be very individualised. The evidence is difficult to obtain as to what makes meaningful differences for everybody. That is probably the most difficult unless, and I see that with long COVID, people get the definitions and good information about what is going to treat their fatigue well and put those guidelines in place early. We have spent 12 months sort of waiting for something to happen, with the post viral syndromes ongoing. I think they just never have been able to get that momentum of information, but hopefully this means there is going to be big boost in some good research.

Ken McCroary - Living with chronic fatigue is absolutely exhausting, isn't it?

Dr Fiona Mackintosh - Just even having to manage it is exhausting, let alone the actual fatigue.

Ken McCroary - Throughout your journey, what have you found most helpful and what have you found most challenging?

Dr Fiona Mackintosh - What have I found most helpful? Probably starting to do that deep rest or mindfulness. That sort of meditation rest does work … deep breathing and taking that rest can give me a little spark in energy. Five minutes before I need to do a computer task, I do deep breathing, take that rest and I have a much better focus and energy level. That's been helpful. I think learning a bit more about pacing has been helpful …

breaking it down into the small daily tasks and planning where I can put my essential tasks in, if that makes sense. I know I have a telephone interview this afternoon, so I will need to have a rest beforehand and then I will need to plan what I do afterwards. I'm very careful with my diary calendar for the week so I don't overdo things. Being able to plot my daily steps with a Fitbit really gives me an overall number so I know I'm not overdoing things. All I was given initially was a heartrate monitor so I could check that I wasn't overdoing things. Those things were really helpful just to guide me with my version. What has been really hard is when you feel good not doing too much. I'm having a good day today so I might do two or three things rather than just one. And then you spent the next 48 hours regretting it. Of course, your mood drops once you feel worse again, so you suffer for the next couple of days. It's about learning how to avoid the boom and the real busts and that's not a natural thing for anyone, especially if you are used to being a fully employed mum and a busy person. It's really hard not to do it.

Ken McCroary - You mentioned the learning and the research you have done - what have you learnt from researching your own illness for a change?

Dr Fiona Mackintosh - From long COIVD, as a different possible pathogenesis, we know a little bit more about the immune system. Seeing that change in my EBV serology, it's actually quite common in a lot of people with long COVID. That vaccination seemed to reduce the after-effects of long COIVD … maybe it would have been worse if I hadn't had my three vaccines by the time I got sick, you know, the pathogenesis of micro emboli and things like that. I've noticed my Dad's dementia got worse after his episode of long COVID, so we know a lot more about those other effects now. It's good to have that understanding. We certainly know more about tailoring or tailoring programs to patients' symptoms - looking very much at the core symptoms and taking that really patient-centred approach. "Okay, what is important to you to make a difference to your function and your life at the moment until some of these symptoms improve?" How can we really target those symptoms effectively and look at those self-help strategies to do that? And whether that is a mix of cognitive retraining or what I described with pacing, fatigue management, physiotherapy or speech therapy - or are all of those components being able to really target and individualise it for patients?

Ken McCroary - I am grateful you have joined us on our COVID working group. How's that experience been for you after having not worked for so long?

Dr Fiona Mackintosh – I've found it's been really good again. I'm up to the level where 45 to 50 minutes is my attention span. I'm good up until that level then I feel myself fatiguing by the end of the hour … I'm getting better at keeping that focus going. I enjoy it, I think I have that unique perspective of being a patient and a clinician. I'm fascinated where this will go in the next few years, how we are going to manage, quite possibly, a surge of patients with long COVID, how we can make general practice better and to have the resources to manage this effectively. We really can. I think GPs are so burnt out from the last few years and it's another big thing to tackle the information behind long COVID and what we can do to help our patients. That's where I see it as being a really positive thing that I can do.

Ken McCroary - What advice would you give to people living with long COVID?

Dr Fiona Mackintosh - Go to your GP early and check in with them. Find a GP you trust and can talk to. Find that person, stick with them and then get them to help you work along that journey because I think that's important to start with. There are some good self-help resources out there, too. Your GP should have them as they are definitely in our health pathways in South Western Sydney; I have checked. Get onto those as early as possible, and then really believe it will improve. But you have to slow down and not fight the process. It is frustrating, it is immensely frustrating, but I found it easier when I slowed down and stopped myself rather than constantly being frustrated with it.

Ken McCroary - What about advice for people like me and the rest of our GP colleagues locally who are managing patients with long COVID?

Dr Fiona Mackintosh - GPs just need to be really confident in this diagnosis, that we need to know it is real: it is easy to diagnose, there are positive symptoms and there are definite criteria we can use. You want to assess those complicated complex patients, that it's not something else you are missing - if it looks and smells like long COVID it probably is. And start, as I say, addressing the symptoms you see very specifically. Also ask patients what they need and what is it they are struggling with, because everyone's symptoms are so varied. There are some specific tools you can use to help a person function normally and get on with their week and get on with their days.

Ken McCroary - You plugged the health pathways, well done.

Dr Fiona Mackintosh - The guidance is all there; the self-help guides are there and the pathways to investigate or to have a look at respiratory symptoms or fatigue or cognitive symptoms. It's all in our pathways. I have been a health pathways user from years ago and used it lots and loved it.

Ken McCroary – There are lots of resources there and otherwise …. and divisions in Southern Highlands and with links in Campbelltown, Camden, Macarthur, Bankstown, Fairfield and Liverpool as well. Having lived through this and call on your experiences, do you reckon there has been much change in your internal philosophy, your goal-setting and that sort of thing?

Dr Fiona Mackintosh - Definitely more self-care. You look at that differently when you've had something like this. Just being much more acutely aware of limitations and not overdoing things, that's interesting, because I don't think I've ever done that very well. In terms of philosophy, I think patient-care and talking about patient-centeredness - we don't understand it completely or have the time to get there. But we need to take the time to see what someone needs at that moment. Everyone's needs are different - sometimes I've needed insurance paperwork or sometimes it's more about talking about how I'm going – and that has become a lot more obvious to me over the time. Personally, it's the long-term planning about what work looks for me in the future, is this a fork in the road or will I go back to full time general practice, or just keep plodding? Or is this an opportunity to look at doing something else slightly differently?

Ken McCroary - You mentioned previously the extra burden on family members and other changes in your life. I see people with this kind of fatigue who have illness guilt. It's unfair people would feel like this. You didn't ask for chronic disease and you didn't ask for long COVID. How do you think we can do better to help people going through these syndromes to not feel guilty?

Dr Fiona Mackintosh - I've always thought this was a society problem, when we look at such a wellness culture. If we exercise properly, if we eat properly, if we don't drink too much alcohol, if we do all the right things then we will never become unwell, we will never be sick. Then, suddenly, something happens and we are unwell and we feel a level of guilt that we deserved this for some reason. I see that as being a problem with all diseases, people who can't win. I'm sure you've had people saying, "no I'm 70 and I've never been sick" and "now I'm sick". Unfortunately, illness and diseases do happen in our world. That's a part of life and that's what happens. There needs to be discussion about chronic illness and how it is another part of life, an unlucky event that has happened. But how do we manage and make the best of that? I think all we can do is to keep talking about it. I don't know if there are any other specific wisdoms I've got there.

Ken McCroary - Just pressing you for wisdom once more to finish … we have a particular interest in well-being and burnout prevention and the stresses we are all under, what about some final words of advice to your colleagues about self-care.

Dr Fiona Mackintosh - I was aware I was burning out at the time when I got COVID and, unfortunately, that was the whammy of being a female, over 50, burnt out and then COVID. A healthcare worker should see all the risk factors - they start to add up - so I was certainly looking at that. I think we have to be careful in general practice. We have to support each other, look at not being so isolated in our own practices and being able to share a bit more of the load between us, even if it's just getting advice from colleagues or debriefing. We have to put those self-care things into place: getting some exercise, eating, taking breaks, enjoying some sunshine - whatever it is that gives you those five minutes of relief from your day. I'm a big user of mindfulness techniques and meditation. I know that's not for everyone, but I find them extremely useful. They've been shown to be very helpful so I would say start there, if anything.

Ken McCroary - You mentioned finding a good and consistent and continuous GP relationship as well.

Dr Fiona Mackintosh - Absolutely, especially when you hear there have been a few media personalities who've talked about their long COVID symptoms, they've gone to five different doctors and shopped around and they're still not getting answers. You've got to have those relationships with one GP, and that really helps to give you that continuity and a good relationship. We know the outcomes are better, we know the relationships are good. You need to choose one GP.

Ken McCroary - Hopefully you've done that waiver before you do end up with (laughing) a chronic illness or a significant need.

Dr Fiona Mackintosh – Exactly. You've got your trusted person that you can see and who knows you.

Ken McCroary - Thanks for sharing, it's been so enlightening and, yes, a lot of food for thought for us as well in how we manage people with chronic disease, chronic illness, chronic fatigue and particularly the long COVID and post COVID. I really appreciate your time and your efforts, so thanks so much.

Dr Fiona Mackintosh - That's a pleasure, I hope it was helpful.

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