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Tori's account of Long C★

I don't wade into public debate that much these days. But there's something happening at the end of this week which makes it difficult to stay quiet.

I got C★ on Jan 3 2022. I was triple-vaxxed. Ten months on, I am still unwell. (I am not alone. It's just it takes energy to advocate about these things and that is something in short supply for those affected.)

Long C is awful.

There are better weeks where I dig deep for book events and public functions and bad weeks where I hide. I am grateful for flexible work - and yet, I should be neck deep in a draft for a new book by now. But I am not.

I am beyond grateful for Andy's (husband) salary- without it I would be stuffed. Since March there have been thousands spent on neurologists and alternative (acupuncturist) medicine practitioners and GP appointments to get me to a baseline where I could launch a book and tour. And now after pushing through I'm paying for it. There are days when I wonder if this is life now, with its dimmed horizon and thorny consequences for reaching back to a place you once easily skimmed through.

I have just spent another chunk of time these holidays unable to properly form words and thoughts thanks to my LC MVP; neurological inflammation and chronic migraines which come with aphasia. The aphasia is like trying to communicate with a brain that's a fiery bog splintered from your tongue. Names, faces, memories and thoughts are untethered from context and explication and there is no timeline for when the shit-tide of inflammation in your head will recede. Sometimes with the specialty drugs I now inject monthly it's in a 24 hour cycle. I've learned I can often text much better than talk when they arrive, but at its peak I've been in a blinking dumb state for more than a week.

Conversation with friends is no longer a source of comfort - it's hard. Writing is a strain, when once it was seamless. Words give us meaning and without them, the world is bleached and barbed. (And then there's the pain and nausea and vision impairment with migraines as well as the ulcers, joint pain, dizziness and ongoing fatigue. But I would take those symptoms any day over losing my ability to think and speak freely. Because that's what LC is. It robs you of who you want to be).

At my best I'm an extroverted author and friend and partner and frequent sole carer of small children - and since we got C★ there are days where I'm the equivalent of a Tellytubby. I am fortunate to have family support and grateful to the small town where we have made a pandemic tree change, though if there are days when anyone finds me quiet, I misplace a name or grasp for a word, am still masked in shops or turn down an invitation to a large event, this is why. I don't want this to be my story, but it is. I'm hoping that with another spell of rest and convalescence, I'll be back to a better baseline - but each day is a calculation of what energy can be spent where. And some days, you run out of spoons to share.

It's also why we are about to make the tree change more permanent. Cities to me no longer feel safe. I am deeply concerned about what another dose of c★ will do to me and what that will mean for my children if and when it happens. And considering Will's (her son) own battle with LC I'm worried for him too. This latest government choice to abandon mandatory isolation is a kick in the teeth to so many. (And that's not even taking into account the rest of the immuno suppressed and disability community. Their anger and grief must be white-hot).

Do I trust that people when they get C★ will still think of what passing it on might mean to others? That if their symptoms are relatively mild, they will mask and stay isolated out of collective concern? That employers will allow staff to take the leave they should? Not really. Because our government no longer sees this as important. It's a devastating myopia. Because for so many of us, this will not be just a cold. Let me tell you a canary tale from down here in the coal mine.

Long c★ can happen to ANYONE, but it seems to be more likely in people who push through infection.

And the more often you get infected, the greater your chances of succumbing are. The current stats out of the US and UK suggest that with an infection you have a 4% chance of getting LC. Those odds are not ones I would casually play with (and there's a reason that D & D players and poker folks still require masks at tournaments in the US. Those who deal in stats and risk assessments know what those odds shake out as). That's a 4% chance of not being able to work. Of long-term health consequences. And no government support.

And before you say you don't know anyone with LC - you do. (Hi). It's also that people don't talk about it that much - partly because it's exhausting and also because not everyone wants to admit publicly that their body or brain doesn't work the way it once did. But I'm an

over sharer from way back. And I'll trumpet about it because LC is also an intensely feminist issue. More women than men are going to get this - partly because of the way our immune systems work (and also because we are often frontline carers).

But if you want some more public demonstration of what it can look like - check out Tracey Spicer's Instagram.

All I want to put into the world beyond my deep dismay in a government that I thought was better than this is... please take this seriously still. The UK are a year ahead of us. We should learn from what they are going through. As much as we want this all to be over and we could go back to how it was (how I want that too), wishing won't make it so. On an individual level, we still have to care about others. Because that's how contagion works.

Please think of others when you get unwell. Isolate when you are infected and encourage others to do the same, even though you don't legally have to. Morally it's a different thing. Keep testing. Please don't send your kids to school with it or be cavalier about reinfection. This is not just the flu. It never was, even if you were fortunate enough to just have had a sniffle or a cough when you first got struck (that's called health privilege and is also pure luck).

We are all still in this together. And you and your loved ones don't want this.

Long and repeated Covid, an integrative medicine approach

Whether it's called 'long-covid', 'post Covid-19 syndrome' or 'long-haul Covid19' it is shaping up as one of the looming public health crises of the pandemic, and focus is now turning to its longer lasting effects on people, and the anticipated healthcare needs of populations. Between 41 to 53% are reported to experience ongoing symptoms after acute Covid infection.^{1,2} Long Covid has been hard to define due to its large number of symptoms, but researchers at King's College London have identified three distinct profiles, with long-term symptoms associated with specific variants of the virus.³ In short, SARS-CoV-2 has been found to be multisystemic. In addition to respiratory illness, it can heighten disease risk in people with pre-existing conditions, including neurological,⁴ renal^{5,6} digestive⁷ and cardiac diseases,^{8,9} as well as trigger autoimmune diseases.¹⁰ Furthermore, in otherwise healthy individuals, acute symptoms such as fatigue, pain and brain fog, that are difficult to quantify, can become chronic and cause long term psychological and emotional impacts.^{11;12} To minimise personal risk, people appear to be using health boosting and preventative measures to an unprecedented extent.¹³⁻¹⁵

The increased uptake of complementary medicines in Australia in 2021 represented a doubling in size over the past couple of years, with more than 73% of Australians purchasing at least one complementary medicine during the past year.¹⁶ Although data are scant, it stands to reason that there has also been an increase in consults with integrative medicine practitioners, as people seek preventative and (self-perceived) low-risk treatments. So how do integrative medicine practitioners approach their care of people with lingering symptoms from Covid 19?

Although disease mechanisms are poorly understood, long Covid is thought to be at least partly mediated by chronic inflammation.¹⁷ This is the rationale for treatment with nutritional supplements and herbal medicines with anti-inflammatory properties, such as *Curcuma longa* (turmeric), and N- Acetyl-L-cysteine (NAC), both with demonstrated anti-inflammatory effects through inhibition of pro-inflammatory mediators.^{18 19} From an evidence-based integrative medicine perspective, these remedies make sense, especially when supported by published evidence. There are however other mechanisms at play in long Covid, such as persistent (intracellular) viral infection, genetic alterations, maladaptive healing and tissue damage that cause organ dysfunction in various body systems and auto immune responses similar to rheumatoid arthritis, Lupus erythematosus and anticardiolipin and Sjogren syndrome.^{17,20} Missing these other pathological mechanisms, whilst focussing on reducing

inflammation could be a crucial mistake in determining effective and safe treatment. Plus, clinical decisions based on disease mechanisms is only one small part of evidence-based practice, and a primary focus on inflammatory markers, especially in complex ‘unknown mechanism’ types of illness,³ is the epitome of reductionist management. There is plenty of perfectly placed reductionist healthcare already, with targeted anti-inflammatory treatments. But it isn’t the healthcare that many people want.^{21,22}

The essential value of integrative medicine in long Covid lies in integrative practitioners’ knowledge, skill and expertise to map complex presentations of long Covid against interventions that touch all aspects of the disease. Complex interventions consist of multiple bioactive parts with multiple simultaneous effects. It is an approach that starts with knowledge about the person and their individual experience of long Covid, an understanding of pathological mechanisms based on pathology investigations and clinical presentation, respect for individuals present resources, capacity and susceptibilities, as well as knowledge about selecting interventions in terms of the way they work, and the anticipated clinical efficacy as reported in the literature and building multidisciplinary teams based on clinical experience and what is accessible, available and at a reasonable cost. This approach is supported by modern evidence-based medicine where patients values are included in the evidence triad (along-side research evidence and clinical experience). And evidence of its potential emerging.

Evidence summaries of integrative medicine

Intravenous Vitamin C

1. Systemic oxidative stress plays a pivotal role in the pathophysiology of Covid 19 and long Covid.²³ Because of its anti-oxidative, anti-inflammatory, endothelial-restoring, and immunomodulatory effects the supportive intravenous (iv) use of mega-dose vitamin C has been investigated in 12 controlled or observational studies including 1578 hospital in-patients with SARS-CoV-2. In these studies, an improved oxygenation, a decrease in inflammatory markers and a faster recovery were observed. In addition, early treatment with iv high dose vitamin C seems to reduce the risks of severe courses of the disease such as pneumonia and death.²⁴
2. A systematic literature review evaluated vitamin C for post-viral fatigue including long Covid fatigue.²⁵ Nine clinical trials including 720 participants were identified. Three

randomized control trials showed a significant decrease in fatigue scores in the vitamin C group compared to the control group. Four of the five observational or phase 1 before-and-after studies observed a significant reduction in pre-post levels of fatigue. Attendant symptoms of fatigue such as sleep disturbances, lack of concentration, depression, and pain were also frequently alleviated.

Low dose naltrexone – LDN.

1. Naltrexone is an opiate receptor antagonist at doses of 50 mg, but at lower doses of 1 mg–4.5 mg, it appears to have a unique immune modulation activity and is termed by the acronym LDN. This low-dose effect may be due to antagonism of opioid growth factor receptor (OGFr), inhibition of toll-like receptor-4 inflammatory signalling, immunomodulation of macrophages and microglia, inhibition of T- and B-lymphocytes or other unknown mechanisms.²⁶ LDN has been shown to be beneficial for a number of conditions including Crohn's disease; induction of remission and reduction in need for anti-inflammatory medications, chronic fatigue syndrome, reduction in use of disease modifying drugs in rheumatoid arthritis, fibromyalgia, multiple sclerosis and complex regional pain syndrome. Evidence is in an emergent phase as many trials are small and low quality.^{26,27}
2. A clinical trial evaluating safety included 52 long Covid patients found no adverse events for LDN in this patient group. Patients who took LDN 1mg per day for one month followed by 2mg per day for a consecutive month, showed significant improvements in limitations in activities of daily living, energy levels, pain levels, levels of concentration and sleep disturbance ($p \leq 0.001$), and mood ($p = 0.054$) compared to those who didn't take LDN for various reasons.²⁸

Hyperbaric oxygen therapy (HBOT)

1. Growing evidence shows that new hyperbaric oxygen therapy (HBOT) may induce neuroplasticity of the brain and improve brain function for months to years after acute brain injury. Pathways that are involved modulate the immune system, promote

angiogenesis (blood vessel growth), restore mitochondrial function (cellular energy production) and induce neurogenesis (nerve cell growth) in injured brain tissue.²⁹

2. In a RCT of 73 patients who received 40 daily sessions of HBOT (n=37) or sham (n=36), significant improvements in global cognitive function, attention and executive function, energy, sleep, psychiatric symptoms, and pain were demonstrated for patients taking HBOT compared to controls.³⁰ These clinical outcomes were also associated with significant improvements in brain MRI perfusion and microstructural changes.



<https://www.seslhd.health.nsw.gov.au/prince-of-wales-hospital/services-clinics/directory/hyperbaric-medicine>

Hyperbaric oxygen therapy is available at many hospital locations throughout Australia and New Zealand.

Multidisciplinary practitioner teams

Evidence-based clinical practice guidelines emphasise the importance of multidisciplinary rehabilitation teams, determined by the needs of individuals.³¹ Along with medical practitioners including general practitioners (GPs), integrative health teams may include input from degree qualified complementary medicine practitioners and accredited health coaches to address other aspects of patients wellbeing.

Complementary medicine and therapies (CM&T) is a broad set of healthcare practices that sit outside conventional medicine in many countries.³² They are described by users as preventative and holistic, aimed to treat illness, promote health and well-being and used due to personal beliefs, preferences and resonance with traditions and cultural practices. Common

therapies include acupuncture, naturopathy and physical and manual therapies such as yoga, and massage. Complementary medicines sold in pharmacies and health-food shops including herbs, vitamins, minerals and nutritional supplements are regulated under the Therapeutic Goods Act 1989. Few high-quality studies of the effect of CM&T on long and repeated Covid have been undertaken. Of the published studies, most have focused on acute Covid infections. Systematic reviews of randomized controlled trials investigating nutritional and herbal supplements have been reported elsewhere,^{33,34} and evidence summaries can be found on the NIH website <https://ods.od.nih.gov/factsheets/COVID19-HealthProfessional/>. Amongst the many showing promising effects has been zinc³⁵ and propolis³⁶ researched and published by AIMA associated academics.

Evidence summary of naturopathic medicine in long Covid

Naturopathy is a form of natural medicine recognized by the World Health Organization that is codified by holistic philosophy and principles of practice.³⁷

1. In a retrospective analyses of 30 people with mild to moderate Covid 19 who received treatment by naturopaths of dietary interventions (bone broth, greens and beetroot), nutritional supplements (vitamins A, B6, B12, C, D3 and zinc), herbal medicines (*Inula helenium*, *Ligusticum porteri*, *Echinacea purpurea* and *angustifolia*, *Mahonia aquifolium*) and probiotics, none went on to develop long Covid, despite many being at high risk from pre-existing conditions.³⁸ Some of the simultaneous effects included supporting the viability of immune cells, preventing damage to DNA, attenuating injury to lung and endothelial tissue, protecting the heart, kidneys and liver against hypoxia and symptom relief in addition to specific anti-inflammatory effects.
2. 100 people with long Covid, were randomized to take either a naturopathic blend of *Rhodiola*, *Eleutherococcus* and *Schisandra*, or placebo. After only 2-weeks those taking the herbal medicine reported significantly less fatigue and pain, without any adverse effects.³⁹ In this case interestingly, there were virtually no changes to inflammatory cytokines, which means that laboratory evidence of anti-inflammatory effects for each herbal medicine⁴⁰⁻⁴² were not demonstrated in people with long Covid. This RCT showed that although herbal adaptogens were effective at reducing fatigue and pain in long Covid, the therapeutic mechanisms were more likely due to

synergistic effects in the immune, sympathetic and central nervous systems rather than single anti-inflammatory effects.³¹

3. Over 50,000 acute Covid patients, including 15,000 in hospital, received formal adjunct naturopathy as a component of multidisciplinary healthcare in the Indian state of Tamil Nadu.⁴³ Although it may be a coincidence, Tamil Nadu was shown to have one of the fastest SARS-CoV-2 recovery rates in India (7 days, 95% CI 5.7 to 7.9).⁴⁴ Furthermore, the prevalence of long Covid in high risk hospitalised individuals in Chennai (Tamil Nadu), where uptake of adjunct naturopathy was highest, was only 2-6%, one of the lowest prevalence rates of long Covid in the world.⁴⁵
4. Common naturopathic treatments with evidence of efficacy in preventing Covid 19 include zinc 100mg per day,³⁵ and propolis³⁶

Role of health coaches in long Covid

The mission of accredited health coaches is to help their clients feel supported and accompanied in recovery. People suffering long Covid may be dealing with paralysing emotions including fear, uncertainty, loss, and unprecedented challenges. They may not be sure how to talk about these struggles. Health-coaches provide an opportunity to express these feelings and feel validated in a safe, compassionate and non-judgmental coaching relationship. Personalization, or respecting the clients emotions, is key to assisting recovery. Resetting reasonably achievable goals can help build resilience. Every individual has a unique story, and their circumstances and can resources vary greatly. Health coaches are trained to make no assumptions and stay focused on what matters most to the client. Some people may be dealing with survival issues, while others are fortunate enough to face challenges that are easier to cope with. Many long Covid symptoms are general malaise, sporadic and undefined. Whatever the circumstances, coaches stay empathic and sensitive to their clients' needs, and day-to-day environment supports.

Health Coaches work with clients as part of a collaborative care teams. They do not diagnose or prescribe. Health coaches do, however, use the powerful tools to support behaviour change to improve whole health and wellbeing. Health coaches focus on:

- Collaborating with clients and health care teams to develop maximum understanding and client engagement and adherence

- Supporting clients to mobilise their internal strengths and external resources and develop self-care and management strategies that are sustainable
- Encourage motivation, by setting achievable goals on the road to recovery
- Empathise with client's day to day reality (including acceptance of the bad days)
- Active listening to increase self-awareness and personal insight and reset old behaviours supporting new health goals
- Provide accountability
- Focus on what is working and recalibrating expectations without judgement

Some of the most powerful levers for recovery are developing a mind-set to support healthy lifestyle behaviours including healthy dietary choices and regular physical activity. Health coaches empower individuals through sustainable self-care strategies that facilitate health and well-being and support recovery, reset and resilience often when faced with adverse health, at a pace that is tailored and matched to individual needs.

In Australia, the role of integrative medicine practice in response to the pandemic is often overlooked. In many other countries integrative medicine practice is being embraced. It offers a lot to the Australian public in terms of whole health and wellbeing. This submission urges the committee to consider a role for integrative medicine practice in developing policies to respond to the emerging health crisis of long and repeated Covid.

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