

Ivermectin, blood washing, ozone: How long COVID survivors are being sold the next round of miracle cures

August 8 2022, by Deborah Lupton



Credit: Niklas Hamann/Unsplash

People with long COVID are going online to look for support. But these valuable discussion forums, chat groups and other online peer-support networks can also spread harmful misinformation.

Online groups allow unproven therapies to be promoted, sometimes by members who believe they are sharing helpful information. Sometimes

entrepreneurs are promoting their unproven therapies directly.

Health researchers admit there are few evidence-based treatments for long COVID. In the face of such uncertainty, people with debilitating symptoms can be tempted by unproven options such as "[blood washing](#)," [stem cell infusions and ozone treatments](#).

Some despairing people with long COVID [say](#) they are willing to try any therapy if there's hope it improves their health.

Long COVID: with no treatment options, it's little wonder people are seeking unproven therapies like 'blood washing.' It's time to increase our focus on testing potential long COVID treatments in clinical trials. <https://t.co/HkXrly0xnE>

— SHA Scotland (@shascotland) [July 22, 2022](#)

The fight for recognition and medical attention

People with long COVID can suffer debilitating [health problems](#) that make it difficult to return to work or activities they once enjoyed. [Symptoms include](#) fatigue, brain fog, [chronic pain](#), depression and anxiety.

They have had to fight to receive [medical attention](#) or recognition of their symptoms. Indeed, it was patient-led activism that first made the public and [health professionals](#) aware how symptoms can extend for months, even after an initially mild COVID infection.

Online communities made a huge difference

Online discussion forums [such as Reddit](#), as well as networks on

[Facebook and Twitter](#), have made a major difference to the long COVID community.

In the face of a lack of medical knowledge about long COVID and sometimes denial it exists, these peer networks offer emotional support and share important information about symptoms and treatments.

Reddit has a [forum](#) with tens of thousands of members discussing supplements and treatments for long COVID. This approach has been called "[crowdsourced medicine](#)."

But there are pitfalls

However, there are pitfalls and potential dangers of this kind of online networking and crowdsourced medicine—the potential for spreading misinformation.

This issue has been a problem for a long time, particularly with other "[contested illnesses](#)" the [medical profession](#) has often dismissed. These include the chronic pain condition fibromyalgia and myalgic encephalomyelitis (chronic fatigue syndrome).

We've also seen the spread of health misinformation in online patient forums and social media content about earlier [infectious diseases](#), such as [Zika virus](#), as well as [throughout the current pandemic](#) on topics including masks and vaccines.

The misinformation

Medical science is attempting to research long COVID and find treatments, but this kind of research takes time.

Meanwhile, people wanting answers and help for their symptoms are forced to turn to online sources, where the testing and review of treatments are under far less expert scrutiny.

On Reddit and other sites, the [volume of content](#) members must somehow make sense of is overwhelming.

"What do I have to lose?": desperate long COVID patients turn to 'miracle cures' <https://t.co/ngLEowsLW1>

— The Guardian (@guardian) [June 2, 2022](#)

Individuals, doctors and pharmaceutical company representatives are among those who have [promoted](#) experimental therapies that have not been thoroughly tested with clinical trials.

Some individuals or groups are exploiting people's desperation, using long COVID support networks to attempt to profit from offering [treatment plans](#) or alternative therapies such as [vitamin supplements and ozone treatment](#).

Some long COVID groups are [are still recommended](#) drugs such as the now scientifically discredited COVID treatment ivermectin.

Some patients have spent [large sums of money](#) on dubious therapies. Serious ethical concerns are raised by these actions, including the potential for these therapies to cause harm and worsen people's health.

How could we improve things?

People with long COVID

People with long COVID should carefully weigh any anecdotal

recommendations about treatment they come across online and think twice before sharing it.

Some have suggested a [code of conduct](#) for long COVID support groups that prohibits members from recommending treatments while allowing them to discuss their own experiences. This could help limit the spread of false information. A code of conduct could also ban the promotion of for-profit treatment programs to remove the risk of members being scammed.

However, this would require close moderation and not all sites or social media groups have such resources.

Hunting down the source of information about long COVID treatments and seeing if there's any links to published scientific evidence is another way to exercise caution.

Health workers

There are important lessons for health-care providers in understanding the needs of people with long COVID.

This includes the importance of providing a timely diagnosis and access to up-to-date valid medical information as well as acknowledging the uncertainties and distress many people feel.

Partnering with patients by acknowledging their lived expertise and together working for a solution would go a long way to help people who feel unheard and want to play an active role in improving their health.

The medical profession is beginning to recognize these issues and has also begun to identify how a better understanding of long COVID could cast light on better recognition and treatment for [other contested](#)

[illnesses](#).

Information about long COVID is available on websites from the [federal](#) and [state](#) health departments; you can find a support group via the [Lung Foundation of Australia](#); or try the [COVIDCAREgroup](#), which brings together patient-led expertise with evidence-based medical knowledge from around the world.

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