COVID-19 LONG HAULERS: WHO THEY ARE AND NEW DEVELOPMENTS

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SCRIPPS MERCY HOSPITAL CHULA VISTA WELL BEING CENTER

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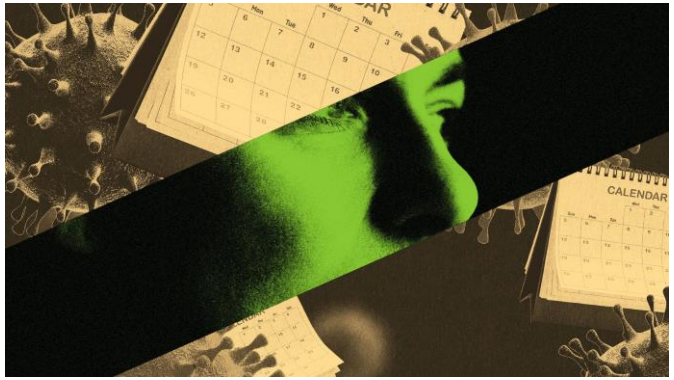
TODAY'S TOPICS

- Who is a long hauler
- Who is at risk of becoming a long hauler
- Long haulers' most common symptoms
- Which organs are impacted
- How to function with chronic disease and long COVID
- New developments
- What we know now
- Testimony from a long hauler



WHO IS A LONG HAULER

- People who are said to be suffering from 'long COVID'
- Someone who still has not fully recovered from COVID-19, weeks or even months after first having symptoms
- Long haulers include two groups of people affected by the virus:
  - Those who experience some permanent damage to their lungs, heart, kidneys, or brain that may affect their ability to function
  - Those who continue to experience debilitating symptoms despite no detectable damage to these organs

WHO IS AT RISK OF BECOMING A LONG HAULER

- Researchers from King's College London have identified five main factors that are associated with people being more likely to experience long-term COVID-19 symptoms:
  - Being older
  - Being overweight or having a slightly higher than average body mass index (BMI)
  - Being female
  - Having asthma
  - Having experienced a greater number of different COVID-19 symptoms during their first week of illness

WHO IS AT RISK OF BECOMING A LONG HAULER

- Their study (one of the largest surveys so far) examined data from 4,182 users of the COVID Symptom Study app who had tested positive and were consistently logging their symptoms
  - Found that 1 in 20 people (4.5%) with the coronavirus are likely to suffer symptoms for at least eight weeks
  - About 1 in 50 people (2.3%) suffered symptoms for longer than 12 weeks

- However, long-term COVID-19 appears to affect every kind of patient – it hits both the old and the young, someone with pre-existing conditions and with none

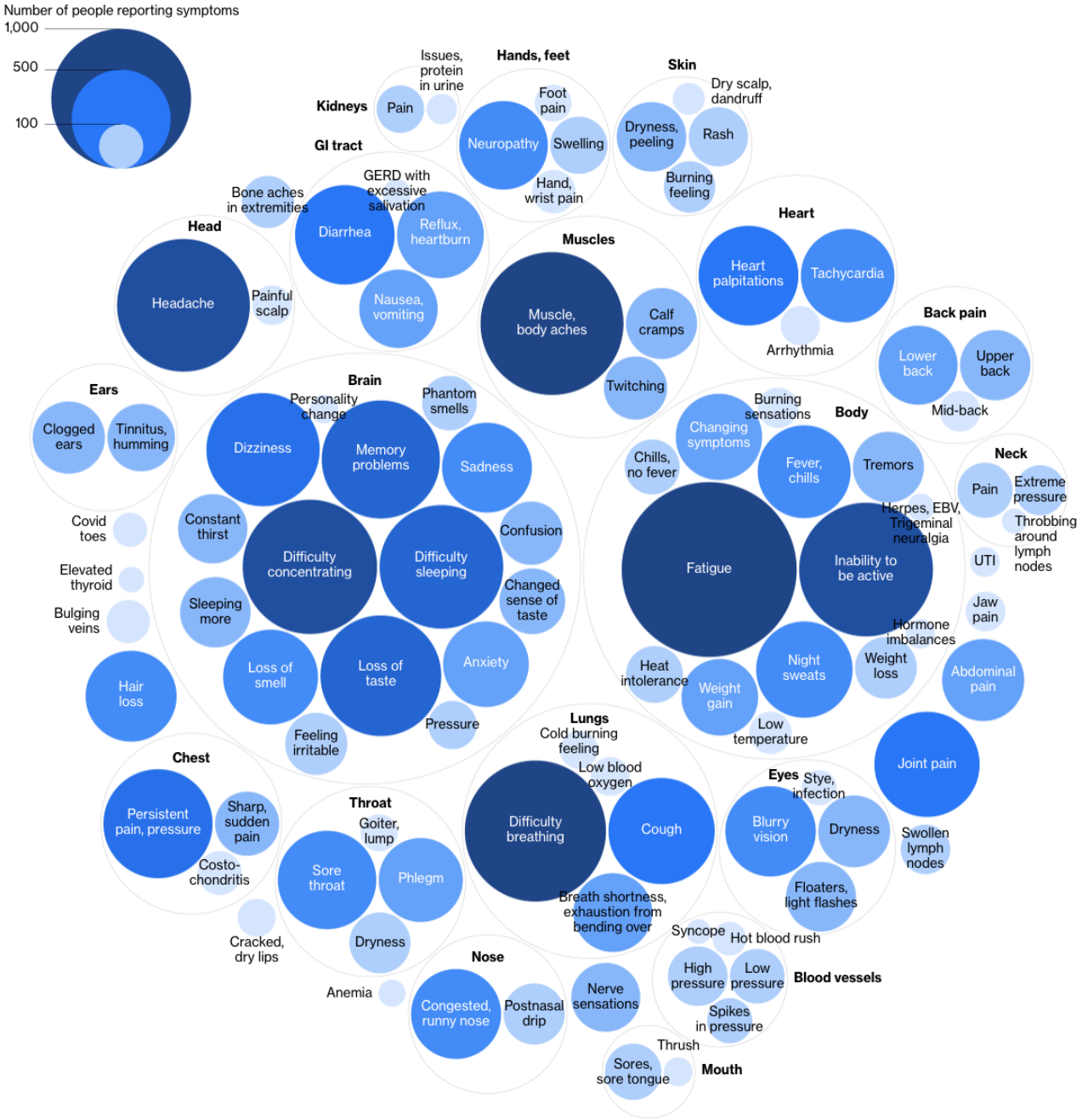
LONG HAULERS' MOST COMMON SYMPTOMS

- Coughing
- Ongoing fatigue
- Body aches
- Joint pain
- Shortness of breath

- Loss of taste and smell
- Difficulty sleeping
- Headaches
- Brain fog
- Racing heart rate

The Long Haul

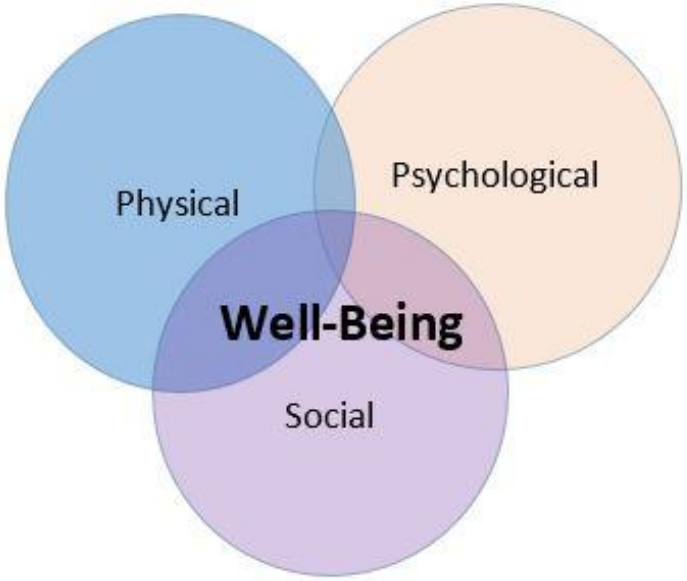
Covid survivors report a wide range of long-term symptoms



Source: Bloomberg Opinion

WHICH ORGANS ARE IMPACTED

- **Lungs**
  - COVID usually begins as a respiratory infection
  - COVID is associated with a type of pneumonia that can cause long-term damage to the alveoli in the lungs
- **Heart**
  - COVID has shown lasting damage to the heart muscle
  - Damage to the muscle increases the risk of heart failure or other heart complications in the future
- **Brain**
  - COVID can cause strokes, seizures and Guillain-Barre syndrome (causes temporary paralysis)
- **Kidneys and Liver**
  - COVID causes blood cells to form clots, weakening blood vessels and potentially long-term problems with the liver and kidneys



HOW TO FUNCTION WITH CHRONIC ILLNESS

- Learn about and understand your condition
  - Acknowledge new limitations
- Speak to your provider about your emotional health
  - Not just physical
- Find your support system
  - Family, friends, neighbors, support groups
- Make goals
  - Both big and small
- Practice mindfulness

A MINDFUL APPROACH TO CHRONIC DISEASE AND 'LONG COVID'

- "Mindfulness encourages us to find peace and a sense of control over our situation, reflect on what is most meaningful and important, and treat ourselves and others with openness and compassion" -Dr. Shauna Shapiro
- For people living with chronic illness or 'long COVID,' it is important to take care both body and mind daily
  - These diseases can cause significant stress, as well as feelings of powerlessness and frustration
- Mindfulness helps people stay more rooted in the present moment instead of worrying about a future that does not yet exist

NEW DEVELOPMENTS

- The most common theories about long-term COVID include the hypotheses that the virus remains in the patients' bodies in some small form, or that their immune systems continue to overreact even though the infection has already passed
- Some infectious disease experts, including Dr. Anthony Fauci, director of the National Institutes of Health, theorized that long-term COVID might be a form of what is called **chronic fatigue syndrome**, or ***myalgic encephalomyelitis* (ME/CFS)**
  - Unfortunately for long haulers, ME/CFS is not well understood either

NEW DEVELOPMENTS

- Another chronic condition that long haulers have developed secondary to COVID-19 is a dysautonomia condition called **postural orthostatic tachycardia syndrome (PoTS)**
  - The body's inability to regulate own heart rate
  - Symptoms of PoTS includes dizziness or lightheadedness, fainting, and problems with thinking, memory and concentration - this combination of symptoms is also known as brain fog
- Dysautonomia is a failure of the nervous system to regulate certain body functions, including heart rate, blood pressure, temperature or respiration

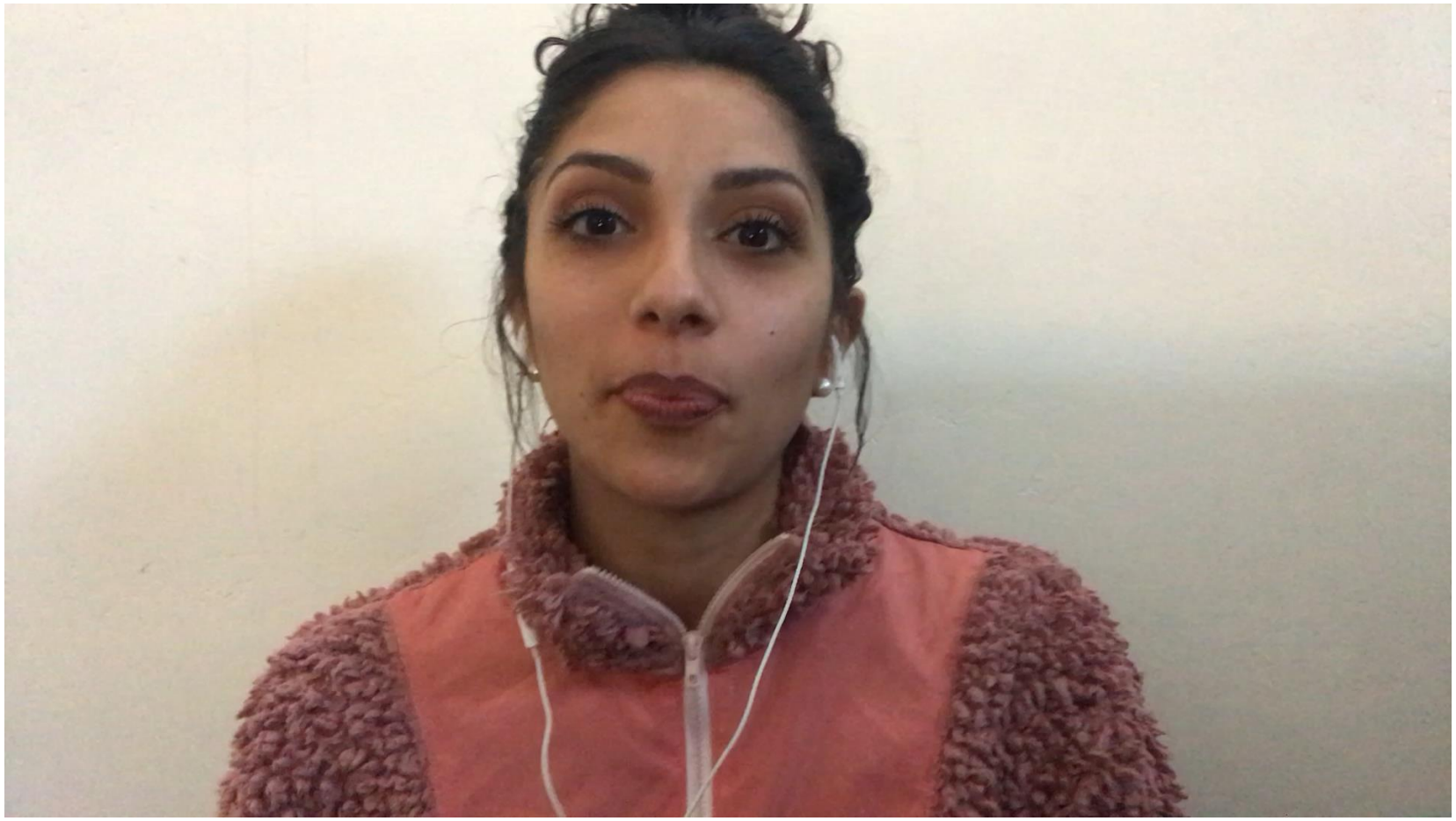
WHAT WE KNOW NOW

- Because the disease is so new, much of the information about long-haul COVID cases and care is anecdotal
  - However, that is changing as researchers are starting to bring their expertise together to help patients
- As this pandemic continues, the more we will learn about COVID long haulers and how to support and care for them

TESTIMONY FROM A LONG HAULER-

MARIANNA CISNEROS, RN

RECORDED ON 11/11/2020



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