

## VENTILATOR-ASSISTED LIVING

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### Ventilator Users Speak: Navigating the Pandemic

It's been nearly a full year since daily life began to dramatically change as a result of the pandemic. March of 2020 saw a number of restrictions put in place including stay-at-home orders, business and school closures, and limits on hospital visitors, among other measures.

Over the course of the year, some of these restrictions were relaxed (and then reinstated), but daily life remained vastly changed from what it was pre-pandemic. Our social circles shrank. The celebrations for birthdays, weddings or anniversaries we were accustomed to were transformed into small private affairs. Some of us were forced to bury loved ones without being able to properly mourn them. Yet, many of us found ways to adapt and persevere.

IVUN asked our members to talk about their experiences over the past year - about the challenges, new ways of doing things, and the ways they've been able to adapt and cope with life during a pandemic.....**MORE**

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**Ventilator-Assisted Living**

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## Ventilator Users Speak: **Navigating the Pandemic**

It's been nearly a full year since daily life began to dramatically change as a result of the pandemic. March of 2020 saw a number of restrictions put in place, including stay-at-home orders, business and school closures, and limits on hospital visitors, among other measures.

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### **Deshae Lott, Bossier City, Louisiana**

In some ways the emergence of COVID-19 brought others nearer to the lifestyle I had been living. For example, my days already included fairly stringent sanitary procedures and a good deal of social distancing that turned to virtual communication for online work, health care management and interaction with family and friends. In my home, the COVID-19 pandemic inspired us to augment and intensify previously formed habits and efforts. And many former activities that were infrequent were no longer deemed wise at all. And so it remains. That is, nearly a year into this, we apply the steadfastness we cultivated prior for living an atypical life. Unlike some we know, our unwavering diligence has not been decreased as many we know thankfully have survived COVID-19 infections. The risks to me remain too high for us to lessen our carefulness. And in January, I learned that I am not a candidate for the current COVID-19 vaccines.



One of my most noteworthy COVID-19 experiences happened just as the pandemic began. My ventilator provider of nearly two decades (and my only vent provider until then) announced (verbally and in writing) that they would be taking my vent and not replacing it; attorney involvement limited the provider from removing the vent until a new vent provider could be located. COVID-19 complicated the process but also heightened others' awareness of my need. During that time, my backup vent failed, and the original provider (the only one in network fully covered by my health insurance) refused to replace it. Vents were in short supply globally; manufacturing of my vent type was on hold; businesses had new restrictions due to limited access to resources and employee safety concerns. Heroic widespread efforts for two straight months moved me into a better situation, with which I am pleased and for which I am grateful.

I have read and watched broadcasts about persons with disabilities whose lives ended due to pandemic-related situations. I understand how fortunate I am that many expressed concern for and contributed to my safety after learning of my perilous situation. Some efforts

were beyond extremely generous; they were heroic. Although problems like my vent crisis are quite unpleasant, it was beautiful to witness, participate in and benefit from problem solving that affirmed the value and dignity of human life. As a result of many caring behaviors, I continue to breathe with a ventilator, which means I continue to live.

During the precarious period with no backup ventilator or ventilator provider, my minister offered me communion using virtual technology.

Although important things were navigated, others were not. Since March 2020, I have left my home only once, for a doctor's appointment. A different doctor deemed it too risky for me to receive at a facility a needed medical treatment - a series of iron IV infusions for an untraceable iron level (severe anemia). An overloaded home health system could not provide the treatments. My process to explore and select alternative and augmentative communication devices appropriate for my new physical needs also came to a halt.

So medically things haven't been readily available, including equipment, backordered supplies and treatment plans.

We also have not had our usual visitors or discretionary outings.

That said. I am grateful for a safe place to live, and I am even more grateful than I already was for the broad possibilities a smart phone provides (mine has been part of what sustains my life and my quality of life). And I am grateful for the individuals who have helped me navigate my situation.



### **Jeff DeTray, Napoleon, Ohio**

As a result of the COVID-19 pandemic, my wife and I have been in self-imposed isolation for nearly a year. Both of us have medical conditions that put us at risk for a bad outcome if we contract the virus. Since we are both retired, it has been fairly easy to adopt a stay-at-home lifestyle. We are pretty much homebodies in any case.

I am a polio survivor. Since 1988, I have been on nighttime ventilation using a nasal mask. My first machine was a LP6 volume ventilator, but since 1990, I have been using various Bi-PAP ST machines. That's 33 years on non-invasive ventilation! A few years ago, I also acquired an oxygen concentrator for use during the day. Recently, my concentrator required its annual service, so we permitted a masked and gloved technician to enter our home – the first and only person we've allowed inside our house since the pandemic began. I order all necessary supplies for both machines by mail.

During the pandemic, all of my medical appointments with both my PCP and my pulmonologist have been conducted online via video conferencing. This avoids sitting in the doctor's waiting room with other patients. I still must travel to our medical clinic for lab work. Because of my COVID concerns, I'm not thrilled about being in the presence of clinic staff and other patients at the lab, but there is no other option. The clinic does a good job with COVID precautions.

We are fortunate to have two nearby grocery stores that offer contactless pickup, so we are able to avoid going inside the stores to buy our food. We have both lost some weight during the pandemic, which is a good thing. We attribute much of our weight loss to no longer patronizing fast food restaurants and instead making healthier meals ourselves. We still occasionally order from Pizza Hut, which offers contactless delivery. Our prescriptions are all delivered by mail.

I wear a KN95 or N95 mask as well as vinyl gloves whenever I leave the house. The slight inconvenience is a small price to pay for the peace of mind.

By avoiding contact with other people – even close relatives – we have done our best to minimize our chance of exposure to the COVID virus. Being over the age of 65, I am due to receive my first dose of the vaccine this week, a welcome milestone.

**Audrey King, Toronto, Canada**

Unlike some others in Toronto, I have been extremely lucky during this pandemic. My workers have continued to support me without hesitation, in spite of their own fears, especially as some of them come by bus and are in crowds at times.



During June of last year I was in hospital for a week. It was difficult as no visitors or outside support workers were allowed. Thanks to some strong advocates who went to bat for me, after a few days I was allowed to have one of my attendants for 12 continuous hours. He had to bring his own lunch and could not leave my room.

On a social level, there is really no place to go to as nothing is open and we are still under “stay at home” orders. In the warm summer months, I did lots of “distancing” walking (wheelchairing?) on nearby trails and parks . . . but it’s too cold to get out now.

Medical trips are allowed and thankfully, the Wheeltrans transportation service is committed to carrying only one passenger at a time, masks and distancing (as much as possible) required. I cannot wear a mask but use a visor instead.

In October and November, I had two cataract surgeries done. These were postponed several times due to COVID-19. I had to wear a mask, sealed below the eyes, for the procedure, which only took five minutes while oxygen was fed in from below the mask. All went well.

In Ontario, people who live alone have been allowed to visit with one other family. At Christmas and on my recent birthday, my niece and her family came in from out of town. I have not seen other family members since the pandemic began, over a year now.

I’ve been doing lots of ZOOMING with my book club, friends, neighbors in my condo, doing virtual lectures, church attendance and so on. I’ve also discovered some wonderful audiobooks.

Many, many “able-bodied” people complain about boredom, frustration and being confined, but I have found that years of wheelchair and ventilator dependence has rendered persons like myself a huge advantage. A long time ago we found alternative ways to be creative, contributing, tolerant and supportive of others who “just can’t stand it!” I have become an even greater “listener” these days, as has my socially deprived Siamese cat who spends his days (and nights) curled up on my feet.



**Nico Meyering, MPA, Philadelphia, Pennsylvania**

Two months before COVID-19 lockdown began here in Philadelphia, I switched to a new vent. All of the troubleshooting and follow-up had to be done by telemedicine or over the phone. I’ve taken to that very easily and I actually hope telemedicine has an expanded role in healthcare once the nation is vaccinated. I wouldn’t even complain if my own job moved to a work-from-home status!

By now I’ve lost several friends to the pandemic and other ailments. It has been a difficult year. When I began being active in the disability community, I knew I’d experience some losses; I just didn’t know the sheer number. It’s especially difficult knowing people who have died from COVID and then seeing other disabled people downplay the seriousness of the pandemic or deny its existence entirely.

While I am an introvert and a homebody by nature, I’ve also come to appreciate the strong bonds I share with friends and family. Needing to rely more heavily on those relationships has also made me a better communicator. Not a day goes by that someone doesn’t check in with me. I’m thankful for that.

**Ronnie Jo Grieva, Wisconsin**

## **Donna-Jo Greve, Wisconsin**

This March will mark the ten-year anniversary of my being on NIV. In 2010, I developed atrial fibrillation. The months of subsequent evaluation led to a 2011 cardiac ablation. The arrhythmia cause was hypoxia from ventilation (respiratory) failure. This in turn was caused by severe polio scoliosis and chest/diaphragm polio weakness from acute polio with total paralysis and iron lung care in New York City at age 4.

As the local physicians were not aware of polio hypoventilation at that time, it took almost a year to go from incapacitating arrhythmia to ablation. Joan Headley, IVUN's executive director at the time, was invaluable in steering me to the appropriate evaluation that uncovered the polio hypoventilation as the underlying cause of the arrhythmia. This led to my being started on high pressure BiPAP via NIV.

The first few years on NIV were via a tabletop BiPAP unit with a built-in humidifier. Then it was realized that I was hypoxic in the daytime as well, and I was switched to a Trilogy ventilator which handles both daytime "sip and puff" (MPV Mouthpiece Ventilation) as well as the overnight high pressure BiPAP. This Trilogy system has a separate humidifier with a heated wire hose set and more complex tubing that requires cleaning and maintenance. The provider decided I could do the hose replacements myself and started mailing me monthly replacements for the disposable parts. They had respiratory therapists to come to my home each month to check the machines and document usage.

Back then, the ventilators had SD cards which the pulmonologist would download at each visit. My usage went from 8 to 9 hours overnight in 2011 to about 12 to 14 hours per 24 hours with oxygen currently. When I have a respiratory illness, my usage goes up to 22+ hours per 24 hours. Fortunately, I have not had COVID.

Several years ago, Trilogy compliance checks were switched to Bluetooth. They gave me a modem to send in data each day. The modem transmits all of the usage information, the settings and any changes. The provider reduced the respiratory therapist visits to once every three months, and they would come in my house and check the machines.

When COVID restrictions were put in place in Wisconsin in mid-March of 2020, the respiratory therapists agreed that I needed to be isolated, and they in fact wanted to be isolated, as well. So, the RT home visits stopped. The provider continues to mail me replacements for the disposable items associated with the Trilogy system, and I do the changeouts myself. Groceries are either pick-up with mask and gloves, or delivery. I wipe down all incoming items while masked and gloved. No shopping in stores, no fast food, no visitors. I have grandchildren in a nearby town and have made window visits.

Doctor visits have been only once a year and remote, via phone. Fortunately, I require no prescription medications, which greatly simplifies COVID isolation. I have never had diabetes or hypertension, and I don't take any medications for my post-polio syndrome, nor for the atypical Parkinson's that I have developed during COVID isolation. Apparently, this can be a late complication associated with having had polio and, as such, is typically resistant to the usual Parkinson's meds.

The current RT has totally agreed with our both remaining isolated, so he has not requested the once-every-three-months home visits. He is aware that, as a physician, I understand the ventilators and take care of them properly. I follow my ventilation needs with daily pulse ox checks. The RT, the provider and the pulmonologist have access to the machine information daily via Bluetooth, so he has me provide him with the ventilator readings that he needs via text message.

Since the pandemic began, the Trilogy machines themselves have needed to be switched out a few times. The RT and I communicate via text. He arrives in my driveway in his car. I wear mask and gloves and put the outgoing machine on the bench outside my front door and retreat back into my house. He gets out of his car masked and gloved, brings the new Trilogy encased in plastic, leaves it on my bench, and takes the outgoing Trilogy back to his car. I come back out of my house and take the new Trilogy from my bench. In the house, I remove the plastic wrap, wipe down the new Trilogy, put it on a chair away from where I sit, and plug it in. Then I remove my mask and discard my vinyl gloves. I let that new Trilogy sit for a few days before putting it to use.

Thus far, I have not caught COVID. As I am now 72 and have post-polio syndrome, respiratory failure and atypical Parkinson's. I am currently qualified for the COVID vaccine several times over. Fortunately, I was able to obtain the first vaccination last week. The current

RT tells me that he has not had COVID either. and as a health care provider. he also obtained

... told me that he had not had COVID either, and as a health care provider, he also obtained his first vaccine. Once we have both received our second shots, there is a possibility that the RT may do some home visits - though there is now some concern over new coronavirus variants that the vaccines may not protect as well against.

Even so, once fully vaccinated, we now have a hint of partially returning to normal. Even after the second vaccine, I will continue to use mask and gloves because of the new COVID variants. I am going to continue pick up groceries and get delivery of everything else as my ability to walk has deteriorated during this COVID year, undoubtedly partly from disuse from the prolonged home confinement. So, life will never be the same for me as it was prior to COVID, but at least there will be more visits with grandchildren – some of them even in person.

### **Warren Peascoe, Vienna, West Virginia**

We became aware of COVID-19 on a cruise celebrating our 50th anniversary. Another cruise ship had positive tests and ours went onto a higher level of sanitation. In the week it took for us to drive home, it felt like we were being chased by the virus. In the weeks that followed, it appeared that there might be a national shortage of ventilators.

I use a ventilator because of weak diaphragm muscles to prevent sleep apnea during the night. I had trouble exhaling with a BiPAP. It's a chronic condition, not an acute life or death situation. As the concerns of ventilator supply became critical, I wondered if my ventilator might be needed to save someone's life. How would my life be affected if I did not have the ventilator? Fortunately, the conditions never became that severe, and I was not faced with that decision.

I made sure that I had an adequate supply of facemasks and circuits, which are replaced periodically. The vendor supplied these materials and a respiratory therapist maintained in-home quarterly check-ups. I postponed all of my medical check-ups except for the annual pulmonologist visit required for Medicare authorization.

My wife shops once a week using her car, and the van I drive has used less than a tank of gas in the last year! I stay at home.

We have both received two vaccinations, and I celebrated by attending an in-person Pacemaker check-up. I was fortunate to schedule our first shots for the day after our age group became eligible.

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# ADVOCACY

## **Senators Urge Biden Administration to Invest in HCBS**

Thirty-one Democratic senators sent a [letter](#) to President Biden and VP Harris this month requesting that the administration proceed with a plan to expand offerings for people with disabilities.

In the letter, the senators remind Biden of his pledge during his campaign to invest \$450 billion in Medicaid home and community-based services (HCBS), commending him for recognizing the needs of children with complex medical needs, youth and adults with disabilities as well as aging adults.

They note how the pandemic has highlighted the need to invest in HCBS more than ever, stating, "An essential HCBS workforce supports millions of older adults and people with disabilities to live in their own homes and communities, but many of these workers struggle to support themselves and their families financially. Even worse, too many of these workers have been without basic personal protective equipment, timely COVID-19

these workers have been without basic personal protective equipment, timely COVID-19 testing and enforceable safety standards as the pandemic ravages our Nation."

The senators, led by Bob Casey, D-PA, and Cory Booker, D-NJ, argue that investing in HCBS would help drive economic growth, create good jobs in the caregiving field and meet the needs of aging Americans and people with disabilities.

## The Lifespan Respite Care Reauthorization Act

In January, the Lifespan Respite Care Reauthorization Act was signed into law. The law increases funding for the program to \$10 million annually through the 2024 fiscal year. The program supports a system of community-based respite care services across the country.

Authored by Rep. Jim Langevin (D-RI) and Sen. Susan Collins (R-ME), along with Sens. Tammy Baldwin (D-WI) and Cathy McMorris Rodgers (R-WA), the legislation was also endorsed by [100 caregiver and respite-related organizations](#), including the National Association for Home Care and Hospice.

Authorities estimate that there are 53 million family caregivers across the country providing some \$470 billion worth of unpaid care each year, most of who have not received any respite services.

## HHS Issues Request for Information on Disability Discrimination in Health Care

The Department of Health and Human Services(HHS) is considering rewriting regulations designed to ensure that people with disabilities do not face discrimination from medical providers in response to concerns about unequal access. HHS says it wants input from people with disabilities, their families, providers, disability advocates, hospitals, child welfare agencies and other stakeholders.

From the HHS Office for Civil Rights (OCR): OCR has issued a Request for Information (RFI) on disability discrimination in health care and child welfare contexts. In carrying out its enforcement activities under Section 504, OCR has become aware that significant discrimination on the basis of disability still exists in the nation's health care and child welfare systems. OCR has received reports of discriminatory practices from researchers, advocates, organizations of persons with disabilities and the agency's own enforcement, monitoring, and technical assistance activities.

OCR has undertaken a review of its existing regulation and is considering revising it to address some of the most consequential and pressing disability discrimination issues that have been raised in health care and child welfare in recent years. To that end, OCR is soliciting feedback on such issues in these areas. Because of the extensive reach of the issues in these areas, it seems appropriate to solicit public comment on them.

[Request for Information - PDF](#)

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NETWORKING

## COVID Vaccine Answers from CHEST

CHEST has published an [infographic](#) (below) and Frequently Asked Questions (FAQ) page regarding the new Moderna and Pfizer vaccines. The FAQ page can be found online [here](#) and addresses such questions as: Are there side effects from the vaccines? Would it

be safer to wait to get the vaccine until more people have received it? Can I get the

be safer to wait to get the vaccine until more people have received it? Can I get the vaccine if I have an allergy or have had anaphylaxis in the past? Are there any medications that complicate/prohibit someone from getting the vaccine? Are there any medical conditions that would be complicated or made worse if I got the vaccine?

### New Resources from Cure SMA

Cure SMA has a new resource for adults with spinal muscular atrophy (SMA). The [Adults with SMA Virtual Therapy Program](#), sponsored by Genentech and the Dhont Family Foundation, provides adults with SMA three complementary, 30-minute live video sessions with a licensed therapist through the online therapy company, Talkspace. The program is only for adults with SMA, ages 18 or older in the U.S.

Cure SMA is also offering a new [Physical Therapy Webinar Series](#), sponsored by Biogen and The Luke 18:1 Foundation. These educational webinars will be led by licensed physical therapists who are experienced in providing care for both adults and children with SMA. These experts will discuss a wide variety of home exercises during two, 1-hour webinars dedicated to adults with SMA and children with SMA, respectively. Details about each are below.

- [Adult Discussion on Home Exercises with a Physical Therapist:](#)
  - Tuesday, March 2nd at 5:00 pm ET
- [Pediatric Discussion on Home Exercises with a Physical Therapist:](#)
  - Tuesday, April 6th at 5:00 pm ET

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## RECENT RELEVANT PUBLICATIONS

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**"Tricks and tips for home mechanical ventilation" Home mechanical ventilation: set-up and monitoring protocols**



Duiverman ML.

“Outsourcing more and more of this chronic care to the home situation is a big challenge for the future: especially for the home situation, monitoring has to be non-invasive, reliable and easy to use, data security needs to be ensured, signals need to be integrated and preferably automatically processed and algorithms need to be developed based on clinically relevant outcomes.”

*Pulmonology*. 2021 Mar-Apr;27(2):144-150. doi: [10.1016/j.pulmoe.2020.08.002](https://doi.org/10.1016/j.pulmoe.2020.08.002).

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### **Mechanical Insufflation-Exsufflation With Oscillations in Amyotrophic Lateral Sclerosis With Home Ventilation via Tracheostomy**

Sancho J, Burés E, Ferrer S, Lahosa C, Signes-Costa J, Servera E.

“Mechanical insufflation-exsufflation (MI-E) applied via tracheostomy tubes in patients with amyotrophic lateral sclerosis (ALS) who are on home mechanical ventilation via tracheostomy is an effective procedure for respiratory secretion management. Nonetheless, tenacious secretions may remain and increase the risk of respiratory infections. The aim of this study was to determine whether adding oscillations to MI-E could reduce the rate of respiratory infections and the need for bronchoscopy to remove secretions in patients with ALS on home mechanical ventilation via tracheostomy.”

*Respir Care*. 2021 Mar;66(3):378-383. doi: [10.4187/respcare.08145](https://doi.org/10.4187/respcare.08145).

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### **Tracheostomy to Noninvasive Ventilation: From Acute Care to Home**

Brown J.

“The number of patients experiencing prolonged mechanical ventilation is increasing over time. Patients who have a tracheostomy placed in a critical care setting have been described as having an average of 4 separate transitions between the acute care setting, long-term acute care (LTAC), and home. Transition points can be problematic if not addressed adequately; however, proactive planning can optimize patient care. Individual patient factors will determine if the patient will require long-term tracheostomy, transitioned to noninvasive positive pressure ventilation, or able to be decannulated. Patients and caregivers should be included in transition planning to optimize outcomes.”

*Sleep Med Clin*. 2020 Dec;15(4):593-598. doi: [10.1016/j.jsmc.2020.08.003](https://doi.org/10.1016/j.jsmc.2020.08.003).

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### **Transition From an ICU Ventilator to a Portable Home Ventilator in Children**

Willis LD, Lowe G, Pearce P, Spray BJ, Willis R, Scott A, Carroll JL, Agarwal A.

“The process of changing from an ICU ventilator to a PHV in children requiring long-term mechanical ventilation was improved through the use of a standardized protocol. Both the number of failed attempts and the length of time to achieve successful transition were reduced when the protocol was applied. Further study is needed to evaluate other medical and nonmedical factors that may affect successful transition to a PHV.”

*Respir Care*. 2020 Dec;65(12):1791-1799. doi: [10.4187/respcare.07641](https://doi.org/10.4187/respcare.07641).

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EDUCATIONAL  
OPPORTUNITIES

## Canadian Respiratory Conference

The Canadian Respiratory Conference 2021 will take place virtually **April 8-10, 2021**. CRC 2021 [Program at a Glance](#) and detailed web-based [Preliminary Program](#) are now available online. Learn more [here](#).

## CCHS Network Family Conference 2021

The CCHS Network Family Conference will take place **July 6-9, 2021**, in Newport Beach, California. Family conferences foster a supportive and collaborative CCHS union between professionals and families, all with the intent of improving outcomes for CCHS patients. Rooms may be [reserved](#) at the Hyatt Regency Newport Beach.

## CHEST 2021

CHEST 2021 will be both an in-person and a livestreamed. It will take place **October 17-20, 2021**, online and in Orlando, Florida. For more information, go to <https://chestmeeting.chestnet.org/>.

## JIVD/ERCA Conference in 2022

The 4th International Joint Meeting of the JIVD (Journes Internationales de Ventilation Domicile) and ERCA (European Respiratory Care Association) will be held **March 3-5, 2022**, at Cité Centre de Congrès, Lyon, France. For more information, go to [www.jivd-erca2022.com](http://www.jivd-erca2022.com).

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