

# Long COVID-19 Resources And Provider Shortages Solutions

Barbara E. Ward, MPH



Barbara Ward
Master of Public Health
Temple University

- Resided in Latin American and Caribbean Countries, and 6 states
- Multi-cultural Family located throughout the US

### Skills:

- Epidemiology
- Cross-cultural Competency
- Establishing Working Partnerships
- Interest in Public Health History and Activism

### **Employment Experience:**

25 Years Public Health
 Disease Control and Prevention
 HIV / AIDS Epidemiology

### Interests:

- Long COVID Advocate
- Smartphone Photography
- Board Member: Technology Club of the Newark Senior Center
- Civic Engagement Committee of The Newark Partnership



# **Contributors**

Janet Arenson, MS, Retired Nursing Instructor

Charonda Johnson, COVID Survivors for Change

Julia Centrella, Psy.D., Christiana Care, Behavioral Health Dept.

**Long COVID Support Groups Members** 



"Photography is how I am recovering from Long COVID." Barbara Ward Illustrations by
Natasha C.
COVID: Silver
Linings / Dark Clouds
– UUFN service



### IN AMERICA



In America Remember Flag

# Dedicated to: Pamela Jean Ward

Lost to COVID-19
October 26, 2022
Madill, Oklahoma

I sing to you the songs you love.

Larry Ward



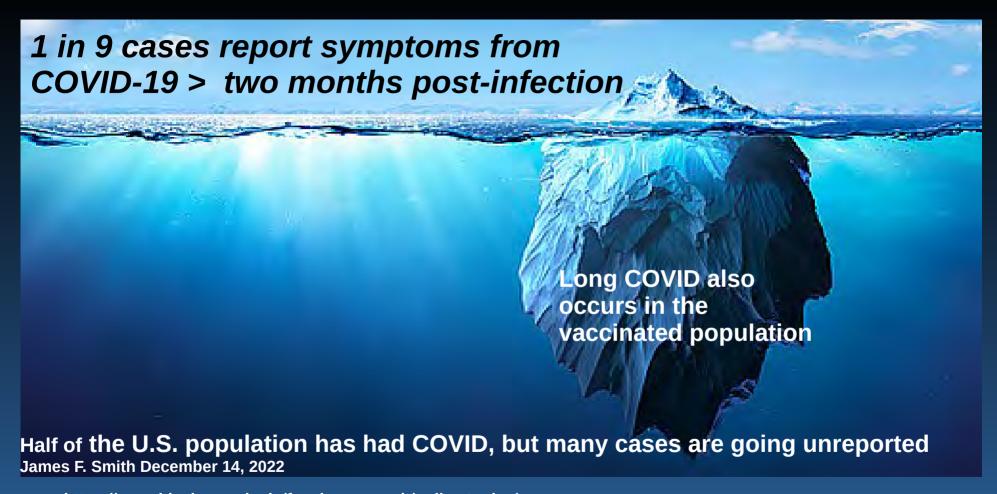
# **Brief Epidemiology Points**



### **Disease Iceberg Theory**

The total burden of a disease in a population is unknown





https://www.hks.harvard.edu/faculty-research/policy-topics/health/half-us-population-has-had-covid-many-cases-are-going

# **Long COVID**



- \*\* Fully vaccinated individuals have developed Long COVID
- \*\* Not well understood and there are > 100 Long COVID conditions
- \*\* Symptoms are not easily differentiated from other conditions

- \* Only one condition reportable to CDC
- Providers struggle to provide care

\* Can be difficult to access care and treatment



# We're still in the "high plains plateau" of of the COVID Epidemic."

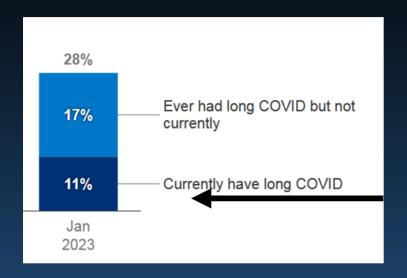
Michael T. Osterholm, PhD, MPH

**Weekly Podcast - Episode 127** 

His first COVID-19 infection is Discussed in the March 23, 2023 podcast. https://www.cidrap.umn.edu/covid-19/osterholm-update-covid-19



# **Estimated Delawareans with Long COVID**



333,306
Confirmed Delaware
COVID-19 Cases
myhealthycommunity.dhss.
delaware.gov/locations/stat = 4/7/23

36,666 > may have Long COVID in Delaware now with the number to increase

https://www.kff.org/policy-watch/long-covid-what-do-latest-data-show/

Long COVID: What Do the Latest Data Show?





# **COVID Orphan Groups**

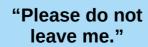
Who have lost family or friend(s)

## \* Children < 18 years old

The Division of Family Services does not know how many children under their care are orphans due to COVID.

\* Adults > 18 years old

\* Seniors > 50 years old





# Solving the Resource Shortage



### Al Tools to supplement intervention





"The key to success is how you respond to failure."

eric\_akin\_md Instagram

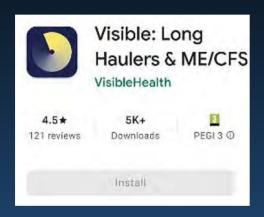
Neurosurgeon & fitness coach

Exercise as medicine.

Great coach to listen to start your day.

# APPS

### Al tools to supplement intervention



- \* Morning heart rate variable to predict daily stamina
- \* Track symptoms
- \* Track activity levels



- \* Education and tools for self-care to improve emotional well-being
- \* Trackers to check your mood and goals
- \* Graphs to visualize progress over time

# **COVID Survivors for Change**

https://covidsurvivorsforchange.org/

# Advocacy Group Many resources





Cindy Johnson Offers iRestore / Grief Yoga Class Sign up for email notification

COVID Survivors for Change via Mobilize
Instructions for iRestore Fitness & Grief Yoga with Cindy

National Online Since 2020 Virtual Support Group Team Thursdays - 8:30 pm Eastern Time

**Program of Rotating Topics** followed by a Discussion.

Easily replicated.

### **Amy Stewart, LCSW-S**

Emma Mahn, LCSW Alejandra Stoltzfus, LMSW **Brandon Willis, LCSW Brenda Mitchell, Pastor** Esmirna Corona, LCSW Doreen Dodgen-Magee, PhD and

Also has Lay Peer Mentoring Program

### Engaging with Post-traumatic Growth

- Engage with the world around you, and appreciate all the good things that it has to offer
- Allow yourself time to talk honestly about how you feel, particularly with people who si
- Reflect upon what you can do to cope with your grief and practice those skills
- Accept offers of help
- Help others
- Be open to new experiences and opportunities, including new friendships
- Take on new challenges, learn new skills



# https://www.survivorcorps.com/





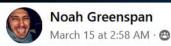
### **Posting:**

While I was home recovering from COVID my 80 year old mother caught it from me and died.

This Facebook narrative reflects the diversity of Long COVID experiences







### https://www.survivorcorps.com/

Today is National/International COVID Awareness Day! If you want to see and hear firsthand accounts of what it's like to have Long COVID, check out the Pulmonary Wellness Foundation's Documentary at



LONGHAUL MOVIE

Home | Long Haul Movie

Posted March 15, 2023

MOVIE: Long Haul A Pulmonary Wellness Foundation Film

March 15, 2023 National COVID Awareness Day

# https://longcovidalliance.org/



Join Us About

Resources

Press

For Members ~

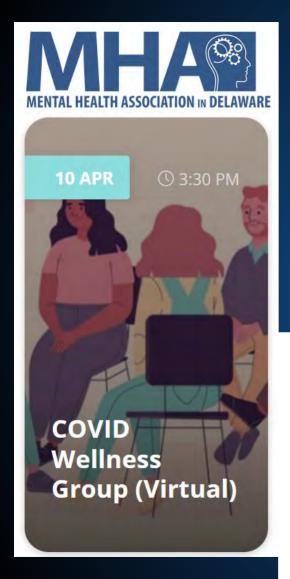
Contact



Offers Mental Health Resources

# **Delaware Resources**





# MHA has an established peer- led recovery training program

# A similar program could be developed to model Long COVID recovery.

#### **Contact**

Phone: 302-654-6833

Email: Peereducation@mhainde.org

### A Peer Recovery Specialist is:

An individual who has lived experience with mental illness, addiction, co-occurring conditions, AND recovery. Peer Recovery Specialists are specially trained professionals who support others going through similar life challenges they once experienced. They assist individuals in developing the skills and resources they need to live an independent and productive life in the community.

# Community-based Support Groups Can Help with the Journey of Long COVID Recovery

Support groups exist for cancer, diabetes, lung, and other reasons.

Schools
Libraries
Faith Based
Senior Centers
Community Centers



hard this is.

https://www.healthydelaware.org

#### Healthy Delaware: Support for Chronic Diseases

To stay well, you need to be well informed. **Healthy Delaware** — Delaware Cancer Consortium — is a resource you can trust. Here, you will learn how to live better ...

#### Self-Management Programs

Don't put off taking care of your health. Sign up for a virtual ...

#### Diabetes

Know more about diabetes to make the right decisions for ...

#### Cancer Prevention, Screening ...

Lifesaving information for individuals about Delaware's ...

#### Healthy Living Overview

The path to good health starts with little choices. Discover what you ...

#### Diabetes Self-Management

Learn how Delaware's Diabetes Self-Management Program ...

#### Delaware Cancer Consortium

The Delaware Cancer Consortium was originally formed as the ...

### **Delaware Division of Public Health**

# healthydelaware.org

# NIH developed programs provided by trained lay leaders.

### Self-management programs help you learn how to live better by managing your disease.

Free six-week step-by-step self-management workshops are offered to adults who have or care for someone, living with a chronic condition, a cancer diagnosis, or diabetes.

#### How can Self-Management Programs help you?

All programs are highly interactive and led by a team of professional lay leaders. Lay leaders are people from the community who have experience in dealing with the same difficulties as those participating in the programs. They have received comprehensive in-person training to deliver the program content from a highly detailed manual. During the sessions, you will:

- · Learn how to build skills to manage your disease
- . Share experiences with others like you
- Help each other solve problems encountered
- · Offer support to each other



# An Example of a Faith-based Initiative



# Coping with Chronic Conditions & Aging Across the Life Span

A Six Week Program

Unitarian Universalist Fellowship of Newark, DE Barbara Ward, MPH Janet Arenson, MS

It helps to share our experiences.



## An Example of a Faith-based Initiative

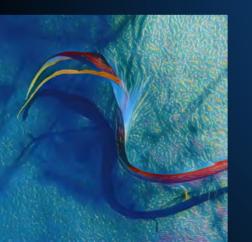
Coping with Chronic Conditions & Aging Across the Life Span

A Six Week Program



# **Purpose:**

Support for those living with aging or chronic illness.



# Goal:

Enhance self-compassion to increase resilience.



### An Example of a Faith-based Initiative

**Coping with Chronic Conditions & Aging Across the Life Span** 

A Six Week Program

- 1. Introduction and Overview
- 2. Productive Living thru Our Life Spans



- 3. Self-Compassion
- 4. Acknowledge Emotions
  - 5. Grief and Trauma
  - 6. Resilience and Joy





Julia Centrella, Psy.D.
Support Group Leader for Persons with Long COVID
Christian Care

**Results for Participants:** 

\* Facilitates Improved Medical Care

\* Education on Long COVID Management

\* Support \* Resilience

\* Self-Compassion \* Joy





Mental Health Professional

# **Other Delaware Resources**

Chantel Bratcher-Coleman, LPCMH / CAADC Shaping Minds, Newark DE

- \* Survived a COVID-19 psychosis.
- \* Her husband and son advocated for her care
  - \* They researched treatment solutions for medical providers who did not know how to treat her condition

Sharing her story and journey of recovery Can help develop resources.





Candidate for Unitarian Universalist Ministry

# **Heather Petit, MDIV**

In 2020 had a mild case of COVID lasting 3 days

- \* Long COVID symptoms started 10 days later and is **WO**'Se than the initial infection
- \* Affecting the following areas

She can facilitate connections to the faith communities while sharing her ongoing journey of recovery, to support the development of resources.





Berkeley Antonioli, PhD, LCSW, Med Trauma Specialist

**Coping with COVID-19 Isolation Support Group – 2020** 

### Coping with Covid-19 Support Group - Self-care Ideas Wellbeing daily to-do list / ideas: Essential tasks: Shower Medication · Clean one thing / space Tend to something growing: Plant Child

THE DUALITY OF LIFE DURING THE COVID-19 PANDEMIC

YOU CAN GRIEVE THE LITTLE THINGS THAT HAVE BEEN TAKEN FROM YOU



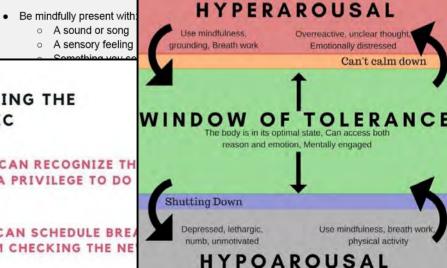
YOU CAN RECOGNIZE TH IT'S A PRIVILEGE TO DO

o Self

YOU CAN STAY INFORMED ON UPDATES AND THE NEWS



YOU CAN SCHEDULE BRE FROM CHECKING THE NE



Dennis J Carradin, Jr., LPCMH, NCC, BCETS

Trauma Specialist

Clients include:

- \* First Responders
- \* Long COVID Survivors
- \* Health Care Professionals

Began treating a person With Long COVID in 2020

Action steps:

- \* Goal Setting
- \* Nature Bathing
- \* Speech Therapy
- \* Trauma Recovery
- \* Trigger Management
- \* Gradual Return to Work
- \* Keep a Journal of Progress
- \* Cognitive Rehabilitation Recommendations





Dr. Judith Pierson, ED.D.

"Learning to Love Your Aging Self"
Positive aging and grief specialist, Sussex County, DE

Her work could be adapted to "Learning to Love Yourself while Recovering from Long COVID."



"Without prior experiences coping with of chronic disease or aging, the suddenness of recovering from Long COVID conditions can be challenging." - Melissa Higgins PT, DPT



"One day,

we will go our separate ways, but

we will remain in each other's thoughts,

remembering the support of this group."

Delaware Long COVID Survivor
Support Group Member





# National and local resources can help

Delaware find the way forward to develop

services through mental wellness

providers and community-based initiatives

transforming our lives to hope and resilience

\_\_\_\_\_



Photos by Barbara Ward

# Questions?

**Postscript Resources** 





# Support for rehabilitation: self-management after COVID-19-related illness

second edition

Name:

Onset of COVID-19 symptoms (date):

Date this leaflet was given:

Name and contact details of health care professional providing leaflet:

Name and contact details of local health care services:

Name and contact details of rehabilitation support services:

**WHO** 

Resource

Physical Therapy Guidelines



### **PROGRAMS** Virtual Programs Widows Voice Blog Widowed Village Online Forum **Newly Widowed Virtual Program** Pen Pal Program Regional Social Groups In-Person Programs Camp Widow® Events Regional Social Groups Resources for the Newly Widowed

https://soaringspirits.org/programs/

Soaring Spirits connects widowed people with each other.

Live and and virtual support

Help people transformation to hope after loss

Offer resources, community, and hope.

## **SENIOR PLANET**https://seniorplanet.org/

Donate Now

## All Online Events Newsletter April 16, 2023

#### **Virtual arm of AARP**

# Technology Education Wellness Activities Support Groups

View all classes

### **Upcoming Classes**



MON, APRIL 17 10:00AMET / 9:00AMCT / 8:00AMMT / 7:00AMPT

#### **Morning Stretch**

Online

Start your day with a short morning stretch!



MON, APRIL 17 11:00AM ET / 10:00AM CT / 9:00AM MT / 8:00AM PT

#### Intro to Translation Tools

Online

This lecture will introduce digital translation tools and apps, such as Google Translate.



MON, APRIL 17 12:00PM ET / 11:00AM CT / 10:00AM MT / 9:00AM PT

#### **Fit Fusion Workout**

Online

Get your heart pumping during this fun, high-energy workout!



MON, APRIL 17 12:30PM ET / 11:30AM CT / 10:30AM MT / 9:30AM PT

#### Google Maps

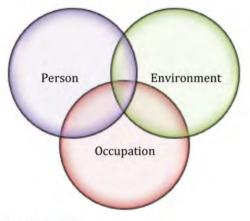
Online

During this lecture, you'll get an introduction to Google Maps and a demonstration of how to use it.

## Productive Aging Occupational Therapists help people overcome internal and external limitations to obtain better quality of life

#### What is distinct about the approach of occupational therapy professionals?

Occupational therapy practitioners work with aging adults and their caregivers to promote safe performance of occupations (daily activities) at home and in the community.



Occupational therapy practitioners seek to understand who the person is; what occupations (activities) the person wants, needs, and is expected to do; and where the person does these activities.

Based on diagram by Law et al., 1996

https://
www.aota.org/-/
media/corporate/
files/practice/
aging/distinctvalue-productiveaging.pdf

### If You Didn't Know How Much You Mean to Me...

By Wes Morrison

https://www.iona.org/if-you-didnt-know-how-much-you-mean-to-me/

- \* Note how long you been friends.
- Mention significant memories good and bad.



\* Thank the person for supporting you.



\* Ask for them not to respond to this at this time stating we will talk another time.



Developed during the COVID-19 Epidemic.



Barbara Ward & Janet Arenson - Feb.1, 2023 contact: Ward at: clematis2023bw@gmail.com

#### Living Productively with Chronic Conditions Across the Life Span

Whether or not we have acute or chronic conditions, degenerative changes due to aging or otherwise, with any limitations. We the Health Consumer can use the tools and resources of the community to better achieve a quality of life.

- . Keystone Provide by the community
  - Access to medical care and resources.
  - Education to enable people to manage the disease
  - Support of health care providers resources to provide care

#### Keystone beliefs

- Acceptance of the condition in order to allow one to take action
- Self-acceptance and self-compassion. (Acknowledge the hard work.)
- Address beliefs in a culturally appropriate manner.
- One can manage their disease
- One is responsible for ones own health
- Medical providers are one's consultants unless it is acute condition

#### Keystone Behavior

- Working with your medical care partners to mange your condition
- is a sustainable core strengthening, however mild, that despite other limitations helps maintain balance, daily activities, manage chronic disease and increases ability to function.

#### Your resources include those listed below.

Work Recreation/ Exercise Hobbies Medical Services - MD, OT, PT, Pharmacists Engage in Natural World Intellectual Activities Centering / Meditative / Religious Activities Mental Wellness Resources Community Activities Social Relationships Maintain Independence Activities of Daily Living Self-Compassion Exercise Work/ Hobbies Social Relationships self-Compassion Religious or Centering Activities Humor Joyful / Inter-satisfaction Engage in the Activities: Singing, helping Natural World others, animals, nature Community Resources and Activities: Parks, Commun Centers, Transportation, Services. Medical Services: MD, OT, PT, Pharmacist, Alternative Medicine Internet, Libraries, - etc Mental Wellness Resources etc.

Adapted and Expanded from Productive Aging – Occupational Therapy https://www.aota.org/-/media/corporate/files/practice/aging/distinct-value-productive-aging.pdf For a copy contact Barbara ward clematis2023bw@gmail.com

**Expanded from Productive Aging** 





### The Only Long COVID Reportable Condition To Date

COVID-19: Multisystem Inflammatory Syndrome Children (MIS-C) Adults (MIS-A)

**Ongoing fever PLUS more than one of the following:** 

Stomach pain Bloodshot eyes

Diarrhea Vomiting

Skin rash

Dizziness or light headedness (signs of low blood pressure)

Rare Serious Inflammation of Heart Brain Eyes Lungs Skin GI Systems

https://www.cdc.gov/mis/about.html



Sarah Schenck, MD

### "Dream Team"

Clients may now self-referal directly to Dr. Schenck via Christiana Care Portal



Julia Centrella, Psy.D.

Christian Care COVID Clinic

Sarah Schenck, MD
James Becker, MD
Terry Brooks, RN
Randi Durbano, CMA/PDA
Bradley Sandella, DO (Sports Medicine)
Dominic Valentino III, DO (Pulmonology)
James Lenhard, MD (Endocrinology)
Henry Weiner, MD (Cardiology)
Allison Potter, MD (Neurology)
Julia Centrella, Psy.D. (Psychology)
Sean Lasota, Clinical Pharmacist Specialist



### https://recovercovid.org/

### Study Enrollment



# RECOVER: Researching COVID to Enhance Recovery

The National Institutes of Health (NIH) created the RECOVER Initiative to learn about the long-term effects of COVID.

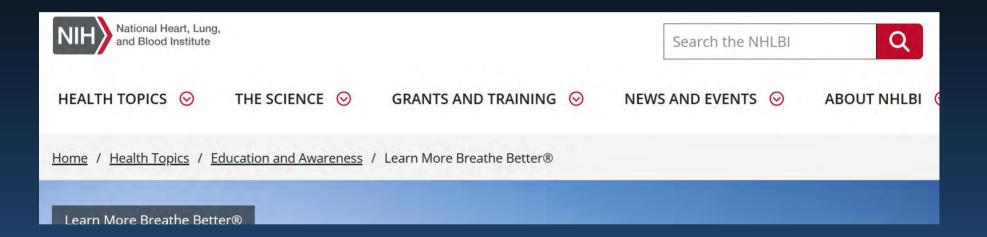
Whether or not you have had COVID, you may be able to participate in RECOVER research.



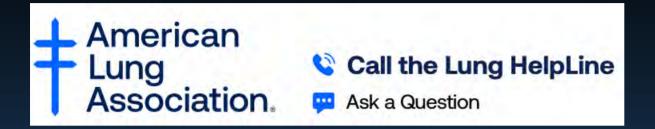




### https://www.nhlbi.nih.gov/BreatheBetter

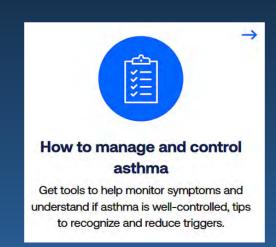


#### https://www.lung.org/lung-health-diseases/lung-disease-lookup/covid-19



Lung Disease Information Education Research Support

Many with Long COVID develop asthma or Or previously had asthma hhat is worse after infection



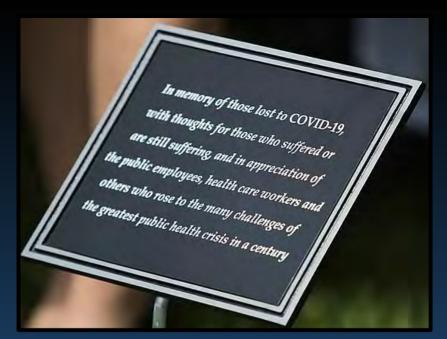
### Long COVID Support Community

Join our online support community to connect with others who have lingering or delayed symptoms from COVID-19.

JOIN COMMUNITY

## Grief Resources







### IN AMERICA

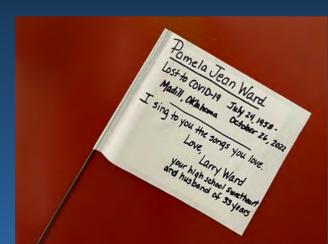


September 17 - October 3, 2021 Visitors were invited to personalize flags for someone they loved.

**Exhibit now closed but the project continues.** 



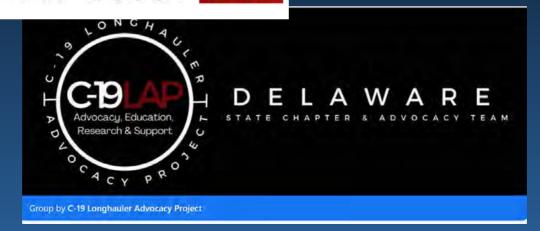




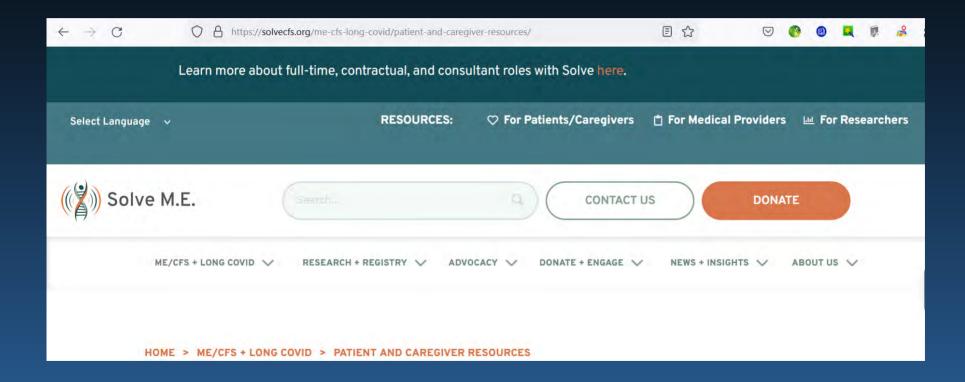
#### https://www.longhauler-advocacy.org/our-work



https://www.facebook.com/groups/delonghaulers/



### https://solvecfs.org/me-cfs-long-covid/patient-and-caregiver-resources/



#### Example of Personal Rehabilitation Program

Management of Asthma and of Degenerative Changes of Spine Rotating Cross training, core strengthen and restorative treatment: 30 - 60 minutes daily Asthma and Program - Avoids harming pinched nerve in lower back and slipped disks Adapted and integrated slowly over time

- \* Asthma Management- Medications as prescribed, follow asthma trigger recommendations. Manage asthma incidents. (including Inratropium w bromide via Nebilizer 2 x day or PRN) Manual Incentive Spirometer use 2-4 x day. Breathing exercises, control asthma induced GERD control. Make of incidents as progress report.
- \* Winter: Humidify Home and Sun Lamp Use 20 minutes daily
- \* Home 6 days a week -30 60 minutes daily Rotating PT exercises from Back Clinic and 4 OiGone movements - OT balances and Matter of Balance Program
- \* Acupuncture- 2 x month treats deep fascia degenerative changes of the back Justin Toltison Moa - Chrysalis Natural Medicine
- \* Wednesday Evening Via virtual Meditation Unitarian Universalist Society of Newark
- \* Monday & Friday Newark Senior Center Seated Oigong - Scott Martin

HTTP://earthbalance-taichi.com /qi-gong-for-health/eight-pieces-brocade/

At home my coach is - Seated Eight Pieces of Brocade Youtube program

8 Brocades Sitting Form: Medical Qigong

(Ba Duan Jin) Eight Pieces of Silk Brocades - Bing vide



- \* Saturday- Yoga with Cindy (mostly stretch movements) Survivors of Long COVID Survivorsoflongcovid.org ) - visit site to sign up
- \* BACK Clinic 2 x week TX to maintain core function due sciatica Water Pt Therapy - Ice / Heat and / EMS TX / Needling (stimulates the muscles) / Traction / ELS Supervised Exercise - balance, core strengthening, elliptic bike, assign of PT home PT
- \* Interests / other As able -

Walking mild and Photography - Sunlight Exposure use core strengthen and locking of muscles to take photos Small seated bike use -gradual so not to cause neuropathy

\* BACK Clinic - Home PT Program

Pelvic Clock - front to back Straight leg raises (alternate leg bent) Short are quad w coffee can wrapped in towel EMS - home up to 3 x a day for pain per body site Sit to stand - slow controlled to build core strength / at 20 -

Heel on Knee - pull and push on knee- stretches back muscles concurrently



- alternate reaching arms overhead arms out side palms up
- Reach up both arms

- Finger Wall Crawl 2 directions reach up alternate arms
- Reach down to feet both arms

#### \* Balance OT from PH student - Home PT Program - waiting in line etc 10-30 seconds \* one foot half step ahead (paired)

- \* feet together time 30 seconds
- \* feet heel to toe (one foot in front of other)
- \* side step and knee bent return
- \* forward step knee bent & back
- \* leg stretch heel on floor 20 sec

### "Show up until it works!"

**Example of Personal Rehabilitation Program** 

- \* Diet \* Exercise
- \* Interests \* Spiritual
- \* Physical Therapy
- Something everyday --Take breaks as needed -

For a copy contact Barbara Ward clematis2023bw@gmail.com

#### Supplements

- Magnesium 400 mg
- High quality Vit D 1000 IU Probiotic
- Potassium 99 mg - B Complex



Diet High in Mono-fats: I eat avocado, oatmeal and nuts almost daily



Performed seated while watching TV or waiting in anywhere Matter of Balance a Comprehensive Set of Core PT Exercises Modified PT Exercises (Developed by NIH as a fall prevention program and increased flexibility)

#### https://www.voutube.com/watch?v=2U b2B3ivO

- 1. Deep Breathing and Good morning stretch push out
- 2. Shoulder rolls 5 front, 5 back
- 3. Diagonal Arm Press Across the body 5 to 10 each direction
- Seated foot circles heal on floor 5 x in each direction
- Seated Knee Raises Marching 5 10 X
- Diagonal Arm Press Across the Body and Toward the Floor 5 10 X each direction
- Diagonal Arm Press Across the Body and Slightly overhead 5×10 each direction
- 8. Rowing Exercise 5 to 10 X
- 9. Seated Leg Extension 5 to 10 X
- 10. Not Alternating Seated Leg Raises 5 10 X
- 11. Toe Stands (Heel Raises) 5 10 X
- 12. Alternating Steps Holding on Chair 15 30 Seconds
- 13. Wrist Raise and Fall 5 X or more
- 14. Finger Spread 5 X or more and wrist spread 5X
- 15. Touch Elbows stretch front back (chicken wing) 3-5 times
- 16. Support elevated foot circles 5 each foot in each direction
- 17. Ear to shoulder hold 10 seconds repeat 3 x each side
- 18. Moving slowly look left, middle and right repeat 5 X.
- 19. Good morning stretch and giant bear hug

### "Show up until it works!"

**Example of Personal Rehabilitation Program** 

- \* Diet \* Exercise
- \* Interests \* Spiritual
- \* Physical Therapy
- Something everyday -
- -Take breaks as needed -

For a copy contact Barbara Ward clematis2023bw@gmail.com