



The University of Texas at Austin
UT Health Austin

Living with Invisible Chronic Illness: Best Practices for Patients with Long Covid/PASC

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Objectives

- Acquire an understanding of Long Covid/PASC including being able to describe the most common symptoms, prognosis of illness and current available treatments.
- Be able to evaluate patients for co-morbid mental health conditions and learn about suggested psychological based treatments.
- Formulate a biopsychosocial assessment to effectively determine needs of care and plan appropriate interventions.
- Illustrate the role that social workers can take on interdisciplinary care teams in the treatment of Long Covid/PASC including the cultivation of hope.



Long Hauler

Unending Covid

Long Covid Post Covid Syndrome

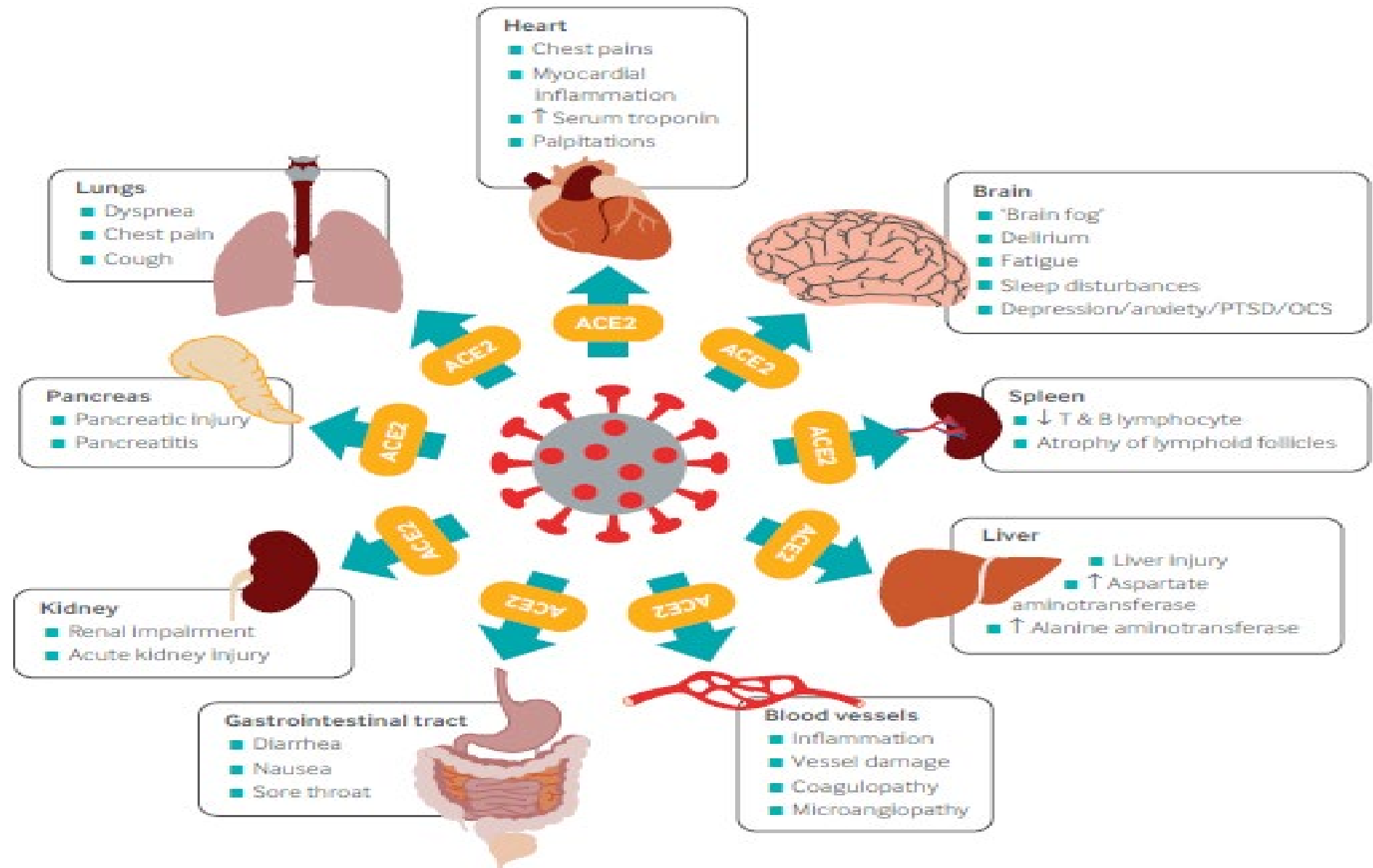
Official Name by the CDC:

Post-acute sequelae SARS-CoV-2 infection (PASC)

Key Characteristics

- Affects 30% of those with Covid-19
 - Develops after 4 weeks
- Occurs in hospitalized and non-hospitalized patients
 - Impacts asymptomatic individuals







Frequently Reported Physiological Symptoms

Fatigue

Post Exertional
Malaise

Brain Fog

Concentration

Shortness of
Breath

Cognitive
Difficulties

Chronic Pain

Neuropathy

Chest Pain

Gastrointestinal
Issues



Co-morbid Psychiatric Symptoms

Depression

Anxiety

PTSD

OCD

Nightmares

Irritability

Mood
Dysregulation

Psychosis



Self Reported Symptomology

confirmed or suspected covid infection n= 3762

≤ 35 weeks for recovery

55 symptoms

9 organ symptoms

6 mts fatigue and cognitive dysfunction

85% relapse from exercise, physical or mental stress

45% reduced work schedule

22% not working



A APMR Post Covid Care Review

46 clinics in 2020

96% clinic visits ≤ 30 min

71% clinic visits ≤ 45 min

60% interdisciplinary team





A APMR Post Covid Care Review

- 18% sw consult on initial visit
- 24% provide sw consults as needed
- 40% sw member of care team
- 51% manage behavioral health
- 75% referral process for behavioral health
- 33% offer support groups
- 64% assist with disability paperwork
- 64% public education materials
- 4% mindfulness





AAPMR Barriers to Care Review

45% more established protocols

24% more clinical resources including social work/case management

11% Behavioral Health Resources

Treatment for PASC

- Currently no consensus on treatment
- Treatment is symptom management
 - Full work up for organ damage
 - Referrals for specialty care



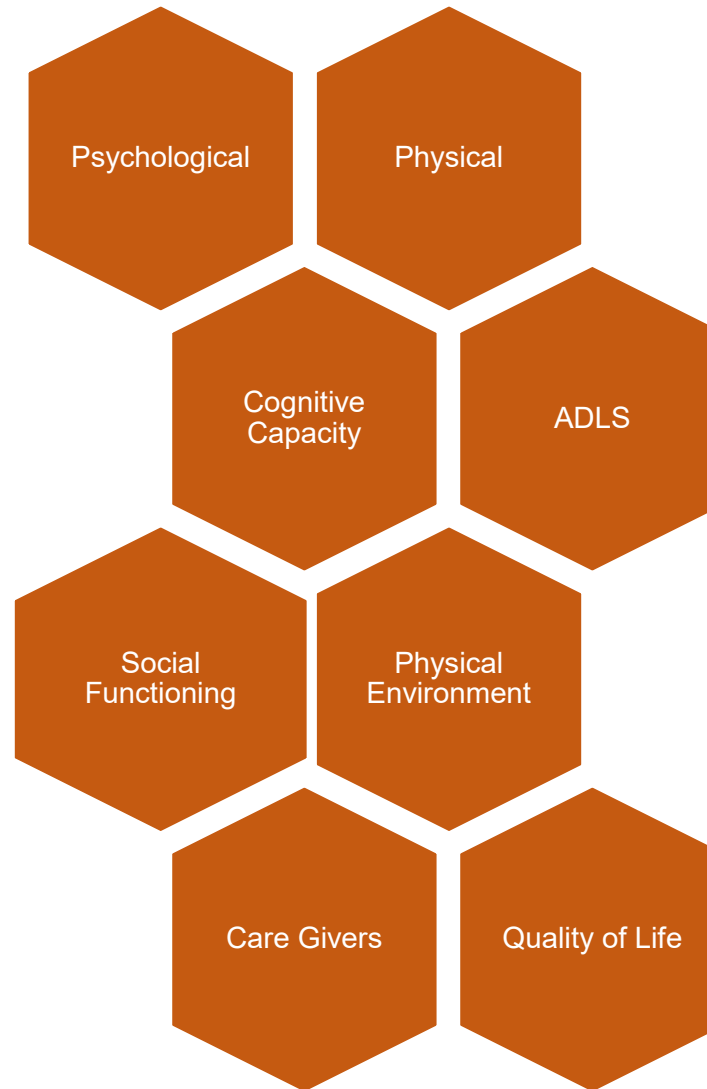
A large, solid orange shape with wavy, undulating edges, resembling a stylized wave or a piece of fabric. It is positioned on the left side of the slide.

UT PASC Program Overview

Opened in June 2020
Multidisciplinary Team
Part of Internal Medicine
Multiple providers
RN
Full Time SW
Dedicated Neurologist



Biopsychosocial Assessment for Chronic Illness





Assessment in Practice

Prior to Initial Visit

- Medical history, symptom severity, current level of functioning
- PROMIS Global 10- health functioning, physical health, mental health, social health, pain, fatigue, perceived quality of life
 - Social Determinants of Health Questioner
 - Based on Health Leads Social Needs
- Work, transportation, insurance, food, utilities, clothing, child care, phone, medicine/health care
 - Housing situation- stable, insecure, homeless



Initial Visit

- MOCA, PTSD-5, GAD-7, PHQ-9
- Provider visits last 60 min or more
- Full medical workup
- Social Work consult
- Enrollment in research projects

Treatment

- Specialty Care Referrals
- OT, PT, SLP
- Psychotherapy
- Medications
- Resources Provided

Follow Up

- Return to PASC clinic as indicated in 6-12 weeks
- Continue mental health treatment as needed
- Case management



Group Interventions

- Disease Self Management Workshop Series
- Art Group
- Information about connecting in Community (Facebook, Survivor Corps)

Ancillary Services

- Nutritionist
- Behavioral Health Clinical Pharmacist
- Neuropsychological Testing

Partnerships

- UT School of Law
- Design Institute for Health (Dell Medical School and College of Fine Arts)
- Ascension Seton

Living with PASC



Confusing Illness

Relapsing-remitting symptoms

Uncertain prognosis

Loss

Stigma

Accessing-navigating services

Being taken seriously by providers

Getting a diagnosis

Variation in standards of care

Therapeutic relationship with provider



Living with PASC

Financial problems
Loss of employment
Inability to care for loved ones or children
Unable to perform basic household
Food/ housing insecurity
Lack of knowledge or resources for this new condition
Long waits/denials for disability benefits
Inability to drive/access transportation
Underinsured, no health insurance



Living with PASC

“I am lazy and should work harder”

“No one understands what I am going through”

“Family and friends think I should be over this by now”

“I Cannot even figure out the simplest problem”

“I am a Terrible parent who can not care for my kids”

“Maybe this is all in my head”

“My medical providers do not believe me”

“ I am afraid to leave my house because fear getting Covid again”



Comorbid Psychiatric Conditions

- Significant psychiatric conditions that require treatment
 - Important to not rule out organic causes of symptoms
 - Not reinforce the idea that it is “all in your head”
- Susceptibility to covid associated with pre-existing condition
 - Worsening pre-existing mental illness post infection

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Liu L, et al. (2021) Mental and neurological disorders and risk of COVID-19 susceptibility, illness severity and mortality: A systematic review, meta-analysis and call for action. *EClinicalMedicine*. 2021 Oct;40:101111



Research on PASC and Mental Illness

n= 239

Months from Infection	PTSD	Anxiety	Depression
3	37.2%	35.6%	46.9%
6	26.8%	34.7%	40.6%

Research on PASC and Mental Illness

Pooled prevalence psychiatric disorders 59 studies n= 737, 901

Months from infection	PTSD	Anxiety	Depression	Sleep Disturbance
0	17.7%	16.2%	18.3%	13.5%
6	7.4%	15.4%	12.4%	12.3%



Research on PASC and Mental Illness

n=91,791 patients with covid

- Findings: Infected patients at risk for moderate depression,
 - Especially motoric symptoms and suicidality
- Risk increased as time passed due to consequence of acute illness
Not a typical depression- neurobiological factors play a role

Suicide risk and PASC

- Hard to differentiate between psychological and neurological affects making psychiatric presentation a challenge
- Depression, anxiety, PTSD, cognitive impairment, physical illness are all correlated with higher risk of suicidality
- Systemic inflammation including of the brain shown to worsen psychiatric disorders , especially depression
- Psychosocial factors, distress of chronic illness, worry infecting others, loss of income, career
- Assessment of suicide risk is important



Lack of Urgency on Research

- Those infected early have been suffering for 3 years or more
- Been dismissed as “this is in your head”
- No consensus on criteria for diagnosis
- NIH not fund any research on PASC until June 2021
- Major study awarded funds are only observational
- April 2022- funds for drug related clinical trials started
- Sufferers are losing patience and turning to “scam treatments”
- Primary care not prepared to treat PASC
- Need for National Institute for Post viral conditions

Social Work Interventions



- Case/care management
- Chronic disease self management
 - Caregiver support
- Address mental health concerns
 - Ensure Continuity of care
 - Advocacy
 - Resources
 - Coping with illness
 - Referral, linkage



Interventions For Fatigue

- CBT-I
- Sleep Hygiene
- Collaborate on mood issues
- Energy conservation, pacing, prioritizing
- Workplace accommodations, employment issues
 - Mobility aids



Interventions For Cognitive Impairment

- “ Brain Fog” Deficits in reasoning, problem solving, spatial planning, working memory, world retrieval and poor attention
- Multidisciplinary approach to care for impairments including Neuropsychology, Neurology, Speech Language Pathology
- Important to remember that patients have “brain fog” when conducting visits and providing information



Interventions Cognitive Impairment

- Address psychological issues
 - Deal with family and friends support over time
 - Cope with worry about work performance
- Distress over feeling judged, embarrassed for deficits
- Self acceptance, adjustment, compensatory strategies
 - MBSR, help with mental fatigue



Psychological Treatment

- Limited research, no evidence based therapy for PASC
- CBT -Chronic fatigue- Lacks high quality evidence
- CBT -Long covid- Only 10% improvement- no tangible gains

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Psychological Treatment

- ACT effective for depression and anxiety
 - Better emotional states
 - Psychological flexibility
- Moderate affects on covid related distress- promising psychotherapy

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Utilization of Outpatient services

- 8,724 individuals who received outpatient rehabilitation
- 43.3% were 40 years old or younger
- 54.8% were female, 58.2% were white, 17.9% were African American/Black, 2.1% were Asian, 13.0% were Hispanic,
- African Americans less likely to receive outpatient services
- Hispanic identified individuals highest rates of rehab services
- Recommendations: Importance of equal access to care, insurance, under referral, transportation, and racial basis

Hope and Chronic Illness

- Cultivation and maintaining hope is an effective tool to aid in enhanced quality of life in the face of chronic illness

How does this work?

Cognitive and effective part, generates positive feeling that can create upward shift in mood

Transformative response out of adversity that helps with more goal directed activity and feelings of agency



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Schiavon, C., Marchetti, E., Gurgel, L., Busnello, F., & Reppold, C. (2017). Optimism and Hope in Chronic Disease: A Systematic Review. *Frontiers in Psychology*, 7, 1-10.



“ Hope is not optimism, which expects things to turn out well, but something rooted in the conviction that there is good worth working for”

Irish Poet Seamus Heaney



Research on Hope and Chronic Illness

- Pessimism about illness leads to poorer health outcomes, more depression, and makes pain worse
- Increased life satisfaction for those with HIV and Spinal Cord injury who remained hopeful
- Hopelessness results in fewer endorphins and enkephalins released which makes pain worse
- Patients connection with religious faith and trust in doctor can help in recovery, therefore maintaining hope has a causative affect

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Hope and Social Work Practice

- Sense of hope central to practice of social work
- Helping clients envision a possible future can help with frustration, despair, trauma and adversity
- Cultivate hope through unconditional positive regard, active listening, empathy, understanding of the balance between hope and despair
- Not rush too fast into hopefulness
- Narrative, strength based, solution focused therapies helpful



Hope and Social Work Practice

- Balance between facts/ prognosis and space to hold hope
- Adjusting to changes in the future
- Help those with pain, emotional hardship, interpersonal conflict, financial difficulties
- Instill hope in others social workers must have source of hope for themselves



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