

# Accessing Benefits and Supports for Older Adults with Long COVID

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# Housekeeping

- All on mute. Use Questions function for substantive questions and for technical concerns.
- Problems getting on the webinar? Send an e-mail to [NCLER@acl.hhs.gov](mailto:NCLER@acl.hhs.gov).
- Written materials and a recording will be available at [NCLER.acl.gov](http://NCLER.acl.gov). See also the chat box for this web address.

# About NCLER

The National Center on Law and Elder Rights (NCLER) provides the legal services and aging and disability communities with the tools and resources they need to serve older adults with the greatest economic and social needs. A centralized, one-stop shop for legal assistance, NCLER provides Legal Training, Case Consultations, and Technical Assistance on Legal Systems Development. Justice in Aging administers the NCLER through a contract with the Administration for Community Living's Administration on Aging.

# About Bay Area Legal Aid

Bay Area Legal Aid (BayLegal) is the largest provider of free civil legal services in the San Francisco Bay Area, serving residents of San Francisco, Marin, Napa, Contra Costa, Alameda, San Mateo and Santa Clara counties.

BayLegal's mission is to provide meaningful access to the civil justice system through quality legal assistance regardless of a client's location, language, or disability.

# About Justice in Aging

Justice in Aging is a national organization that uses the power of law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources.

Since 1972 we've focused our efforts primarily on populations that have traditionally lacked legal protection such as women, people of color, LGBT individuals, and people with limited English proficiency.

# Key Lessons

1. What is long COVID and how are older adults and people with certain underlying conditions affected?
2. Coverage for treatment of COVID-19 generally encompasses treatment for long COVID, but access barriers to specialists exist
3. Long COVID and Social Security Disability: how does SSA evaluate COVID, how do you document the effects, and how do you effectively represent claimants with long COVID?
4. Additional issues and resources for those impacted by long COVID

# Long COVID Among Older Adults and Coverage of Treatment

# What is Long COVID?

- CDC: Post-COVID conditions (PCC) are a wide range of new, returning, or ongoing health problems that people experience after first being infected with the virus that causes COVID-19.
  - Alternatively, post-COVID symptoms lasting > 2 months
- Many names: long-haul or chronic COVID, post-acute COVID-19, etc.
  - Post-acute sequelae of SARS CoV-2 infection (PASC)—direct effects of the virus
  - Post-COVID conditions (PCC) umbrella term for both direct and indirect effects of the virus
- Effects and understanding may change over time, differ by variant and efficacy of vaccines and treatment
- Research
  - Distinguish acute COVID from Long COVID, [“COVID-19: from an acute to chronic disease? Potential long-term health consequences,” 12/20](#)
  - [Long COVID as a post-viral syndrome](#)
  - [“Characteristics and predictors of acute and chronic post-COVID syndrome,” 06/21](#)

# Common Symptoms of Long COVID

- Fatigue
- Post-exertional malaise (mental and physical)
- Respiratory, dyspnea (difficulty breathing or SOB)
- Chronic cough, chest pain
- Fast or irregular heart rate (palpitations)
- Myocarditis (inflammation of heart), lack of oxygen
- “Brain fog” or difficulty with concentration, memory
- Depression, Anxiety, PTSD
- Headaches, joint, and muscle pain
- Autonomic, neurological, or renal disorders

# Long COVID Among Older Adults

- 1 in 4 adults age 65+ who survive COVID are estimated to develop long-COVID
  - Other studies have estimated as high as 32%
  - The rate is 1 in 5 among all adults
- Higher risk for people who were severely ill from COVID but can occur after mild and asymptomatic cases
  - Underlying health inequities increase risk
- Older adults at greater risk for kidney failure, neurological conditions, and most mental health conditions

# Diagnosis & Treatment

- No test to diagnose and no treatments that specifically target long COVID
- Symptoms vary and often mimic and include other complex conditions
- Older adults may face more challenges getting diagnosed and treated
- Holistic approach and multidisciplinary teams are often necessary
- To make access to treatment equitable, federal leadership and investment, including through Medicare and Medicaid, will be important

# Medicare & Medicaid

- New ICD-10 diagnosis code for “Post COVID-19 condition, unspecified”
- In 2022, CMS expanded [Medicare](#) coverage for pulmonary rehabilitation services for Long COVID
- State [Medicaid](#) programs must cover treatments for COVID-19, as well as treatments and therapies for Long COVID
- Under Affordable Care Act essential health benefits, health plans generally cover diagnosis & treatment of COVID-19, including Long COVID
- Community-based resources also available through [ACL programs](#) (e.g., transportation, personal care, service coordination)

# Federal Response

- In 2021, Department of Health & Human Services and Department of Justice [issued guidance that long COVID can be a disability](#) under the Americans with Disabilities Act (ADA), Section 504 of the Rehabilitation Act of 1973 (Section 504), and Section 1557 of the Affordable Care Act
- In April, [White House announced “Whole of Government Approach to Prevent, Detect, Treat Long-COVID”](#)
- Forthcoming (August 2022):
  - Government-wide report on the Long-Term Effects of COVID-19
  - National Research Action Plan on Long COVID
  - COVID.gov will be updated with long COVID resources

# Long COVID and Social Security Disability

# Experts and Data

- I'm not an expert, but neither are most SSA ALJs and medical experts, or DDS medical consultants or consultative examiners
- We have a duty to keep up with the science and figure out how to best advocate for our clients, access appropriate diagnosis and treatment
- Use reliable sources of data and medical information (e.g., CDC, Johns Hopkins, SSA National Disability Forum, primary sources for studies)
  - [CDC Data Tracker](#)
  - [Johns Hopkins Data](#)

# SSA Guidance, EM 21032

- [Emergency Message 21032](#): “Evaluating Cases with Coronavirus Disease 2019 (COVID-19),” 04/06/2021
  - Limited to adults claims with allegation or diagnosis of COVID
  - Retention date 11/16/22 (expect updated guidance)
- SSA requires objective evidence of medically determinable impairment (MDI), severity, and duration.
  - Anti-body test is insufficient to establish MDI.
- Guidance references CDC data on Long COVID or post-COVID conditions
  - Long COVID more likely if unvaccinated, or had severe COVID, but can have long COVID even if vaccinated, mild acute case, or never even if tested positive for COVID \*may depend on variant (See, BA.5)

# Sequential Evaluation Process

- EM 21032 refers to sequential evaluation process

## 5 Step Sequential Disability Evaluation Process:

1) Is the claimant engaged in substantial gainful activity?

- If yes: not disabled. If no, proceed to step 2.

2) Does the claimant have a severe impairment?

- If no: not disabled. If yes, proceed to step 3.

3) Does the claimant have an impairment that meets or equals a listed impairment?

- If yes: disabled (process stops). If no, proceed to step 4.

4) Can the claimant return to their past relevant work?

- If yes: not disabled. If no, proceed to step 5.

5) Can the individual do any type of work that exists in significant numbers in the national economy?

- If yes: not disabled. If no: disabled (process stops).

# Documenting Long COVID

- Claimants may need more help accessing appropriate healthcare
- Telehealth might not yield objective evidence of a medically determinable impairment (MDI), or sufficient documentation of severity to be found disabled
- May need referral to experts (mental health, cardiology, pulmonary, neurological), long COVID clinics\*, and appropriate testing (e.g., PFT, cognitive testing)
- Increased need for medical source statements from treating and examining medical sources
- Consider lay witness opinions and claimant's subjective complaints (diary, calendar, declarations)

# Disability Advocacy Tips

- SSR 16-3p, Evaluation of Symptoms
- SSR 17-2p, Medical Equivalency
- SSR 14-1p, Evaluating Chronic Fatigue Syndrome
- SSR 12-2p, Evaluation of Fibromyalgia
- SSR 19-4p, Evaluating Primary Headache Disorders
- SSR 85-15, Capability to Do Other Work (evaluating solely non-exertional impairments)
- SSR 96-9p, Capability to Do Other Work (RFC less than the full range of sedentary)

# SSR 16-3p, Evaluation of Symptoms in Disability Claims

- Need for objective medical evidence of MDI
- Consider factors in 20 CFR §§404.1520c, 416.920c, in weighing medical evidence
- Consider other evidence in evaluation of symptoms, including subjective complaints, consistency with medical evidence, and factors in 20 CFR §§ 404.1529, 416.929 (e.g., daily activities)
- Determine functional limitations
- [Includes helpful language](#) to address gaps

# SSR 17-2p, Medical Equivalency

- Need an ME to find equivalency (or DDS MC or PC, or Appeals Council medical staff), or to infer an earlier onset date if not timely objective evidence
- ALJ or Appeals Council *may* ask for a medical expert, should be mandatory in complex cases
- ME opinion must be supported by the record, not conclusory
- Adjudicator articulation requirement
- Impairment or combination of impairments
- Argue equivalency, or “meets or equals” a listing, and request appropriate medical experts

# SSR 14-1p, Evaluating Chronic Fatigue Syndrome

- CDC: “a syndrome that causes prolonged fatigue lasting 6 months or more, resulting in a substantial reduction in previous levels of occupational, educational, social, or personal activities.”
- Lab findings required to establish CFS as a MDI:
  - Elevated antibodies to Epstein-Barr virus
  - Abnormal MRI brain scan
  - Neurally mediated hypotension as shown by testing
  - “Any other laboratory findings that are consistent with medically accepted clinical practice and are consistent with the other evidence in the case record (for example, an abnormal exercise stress test or abnormal sleep studies, appropriately evaluated and consistent with the other evidence in the case record).”
    - [Link to ruling](#)

# SSR 12-2p, Evaluation of Fibromyalgia

- Fibromyalgia is a common syndrome
- SSA must properly consider the person's symptoms when we decide whether the person has an MDI of Fibromyalgia
- SSA must ensure there is sufficient objective evidence to support a finding that the person's impairment(s) so limits the person's functional abilities that it precludes him or her from performing any substantial gainful activity.
- 1990 ACR Criteria for the Classification of Fibromyalgia – requires physical exam
  - [Link to ruling](#)

# SSR 19-4p, Evaluating Primary Headache Disorders

- “We are issuing this SSR to explain our policy on how we establish that a person has an MDI of a primary headache disorder and how we evaluate primary headache disorders in disability claims.
- 2018, the Headache Classification Committee of the International Headache Society published the third edition of the International Classification of Headache Disorders (ICHD-3).
- The ICHD-3 provides classification of headache disorders and diagnostic criteria for scientific, educational, and clinical use. We referred to the ICHD-3 criteria in developing this SSR.”

- [Link to ruling](#)

# SSR 85-15, Capability to Do Other Work (Non-Exertional Impairments, Limitations)

- The medical-vocational rules (grids) as a framework for evaluating solely non-exertional impairments
- The grids cannot direct a finding of disabled or not disabled if evidence of non-exertional impairment
- Identifies “basic mental demands of competitive, remunerative, unskilled work”
- “substantial loss of ability to meet any of these basic work-related activities would severely limit the potential occupational base” and justify a finding of disability
  - [Link to ruling](#)

# SSR 96-9p, Capability to Do Other Work (Physical RFC)

- Limit to “less than a full range of sedentary work does not necessarily equate with a decision of disabled.”
- Consider PRW and RFC
- Most helpful for individuals under age 50, but . . .
  - Grids likely direct finding of disabled for those over 50 or 55 who are limited to sedentary exertion, ***unless transferable skills or education provides for direct entry into skilled sedentary work***
- Guidelines for less than full range of sedentary work, erosion of the occupational base
  - [Link to Ruling](#)

# Areas for Advocacy

- Need for more detailed guidance, additional SSR or listings, for post-viral syndromes, autonomic disorders
- Restoration of treating source rule, appropriate weight to treating and examining medical sources, and actual experts, less reliance on consultative examiners
- Requiring medical experts in cases with evidence of long COVID or post-COVID syndrome, or more generally (need for experts to find equivalency or infer onset date in the absence of objective findings)
- Better training of ALJs, MEs, and CE providers on evaluation of chronic pain, fatigue, and mental health
- Better understanding of barriers to access treatment

# Resources to Address Additional Legal Issues

# Income Supports & Benefits

- Assess for eligibility for additional benefits or sources of income
  - [Veterans Benefits](#)
  - [Survivor's Benefits for LGBTQ Older Adults](#)
  - [Title II Auxiliary Benefits](#)
- Supplemental Nutrition Assistance Program (SNAP)
  - Learn More: [SNAP Basics](#)
- Screening Tools:
  - [Benefits Check-Up](#)
  - [SSA Benefit Eligibility Screening Tool](#)

# Consumer Protection

- Debt Collection
  - Learn More: [Strategies for Responding to Debt Collectors](#)
  - Learn More: [Medical Debt Rights & Protections \(CFPB\)](#)
- Scams & Fraud
  - Learn More: [Protecting Older Adults Against COVID-19 Related Scams and Obtaining Relief from Financial Distress](#)

# Housing: Rental Assistance

- Income-based public housing assesses income of residents on an annual basis.
  - May request an interim reexamination of rent as a result of “circumstances impacting adjusted annual income that occur between reexaminations.”
  - Learn More: [Legal Basics of Subsidized Housing Rents-Income, Formula-Based, and Tax Credit Properties](#)
- Emergency Rental Assistance Programs (ERAP)
  - Check for local and state rental assistance programs that may be able to pay back past due rent
  - Learn More: [Connecting Older Adults to ERAP](#)
- NCLER [Eviction Prevention Trainings](#)

# Housing: Mortgage Assistance

- Housing Assistance Fund
  - Learn More: [HAF: Navigating the Program Guidelines and Implementation Challenges](#)
- Loss Mitigation options depend on the loan servicer
  - Repayment Plans
  - Loan Modification
  - Forbearance
  - Refinance
  - Short Sale
- [Find HUD Approved Housing Counselors](#)
- [NCLER Mortgage Foreclosure Trainings](#)

# Access to Health Care

- Long-COVID or Post-COVID Care Centers (PCCCs)
  - Multidisciplinary teams from a range of specialties to address the issues of COVID-19 recovery
  - Holistic approach
  - 18 clinics established at Veterans Administration facilities
  - [Find a PCCC by State](#)
- [CDC webpage on Long-COVID and Post-COVID conditions](#)
- [Medicare Coverage](#)

# Information & Referrals

- [Disability Information and Assistance Line \(DIAL\)](#)
- Aging Services Network: [Elder Care Locator](#)
  - Area Agencies on Aging (AAAs)
  - Aging & Disability Resource Centers (ADRCs)
  - State Long-Term Care Ombudsman Programs
- [Centers for Independent Living \(CILs\)](#)
- [Legal Assistance](#)
- Learn More: [How ACL's Disability and Aging Networks Can Help People with Long COVID](#)

# Questions?

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# Case Consultations

Case consultation assistance is available for attorneys and professionals seeking more information to help older adults. Contact NCLER at [ConsultNCLER@acl.hhs.gov](mailto:ConsultNCLER@acl.hhs.gov).