



The Comprehensive Access to Resources and Education (CARE) for Long COVID Act (S.3726) Led by Senators Tim Kaine (D-VA), Ed Markey (D-MA), and Tammy Duckworth (D-IL)

Why do we need the CARE for Long COVID Act?

A significant number of COVID-19 survivors experience serious lingering symptoms, including neurological, cardiovascular, respiratory, and mental health symptoms, months after infection with the SARS-CoV-2 virus. [One systematic review](#) estimated more than half of survivors experience some form of post-acute sequelae of COVID-19 infection (PASC), commonly known as long COVID, six months after exposure to the virus.

With [over 75 million cases of COVID-19](#) recorded in the United States, long COVID has emerged as a complex and urgent public health concern. While initiatives exist at the [National Institutes of Health](#) (NIH) and the [Centers for Disease Control and Prevention](#) (CDC) to research the long-term effects of COVID-19, additional resources are needed to aid our understanding of the symptoms of long COVID, as well as reduce barriers to care and disparities in diagnosis and treatment.

As long COVID lingers, adults and children with long COVID require resources to navigate workplaces and schools, including support in accessing disability benefits if needed. The Biden Administration has taken the important first step of [recognizing long COVID as a disability](#), but we must do more to ensure that people have access to adequate social supports and accommodations or other resources as required by law.

What will the CARE for Long COVID Act do?

The CARE for Long COVID Act will:

- [Accelerate long COVID research](#) by authorizing the Patient-Centered Outcomes Research Institute (PCORI) to centralize and synthesize robust data-sets regarding patient experiences with long COVID for future research;
- [Improve understanding of long COVID treatment efficacy and disparities](#) by expanding the Chronic Conditions Data Warehouse research database at the Centers for Medicare and Medicaid Services and authorizing the Department of Health and Human Services to study and provide recommendations on improving the health care system's response to long COVID;
- [Educate long COVID patients and medical providers](#) through efforts at the CDC to develop and disseminate information on common symptoms, treatment, and other post-viral illnesses and conditions related to long COVID;
- [Facilitate interagency coordination to educate the public](#), including employers and schools, on the impact of long COVID and the rights associated with employment, disability status, and education for individuals with long COVID; and

- Develop partnerships between community-based organizations, social service providers, and legal assistance providers to help individuals with long COVID access needed services.

Supporting Organizations: American Academy of Physical Medicine and Rehabilitation, American Federation of State, County, and Municipal Employees (AFSCME), American Physical Therapy Association, Association for University Centers on Disabilities, Community Legal Services of Philadelphia, COVID-19 Longhailer Advocacy Project, International Association of Fire Fighters, Kennedy Krieger Institute, Long COVID Families, National Center for Health Research, National Organization of Social Security Claimants' Representatives (NOSSCR), Solve M.E., Survivor Corps, The Arc

The Comprehensive Access to Resources and Education (CARE) for Long COVID Act

Section by Section

SECTION 1. SHORT TITLE

This Act may be cited as the “Comprehensive Access to Resources and Education for Long COVID Act” or the “CARE for Long COVID Act”.

SECTION 2. AUTHORIZATION TO FUND RESEARCH OF THE LONG-TERM SYMPTOMS OF COVID-19 BY THE PATIENT-CENTERED OUTCOMES RESEARCH TRUST FUND.

- a) Directs the Patient-Centered Outcomes Research Trust Fund to fund activities related to the improvement of treatment and outcomes for individuals with PASC
- b) These activities include surveying existing patient registries to identify common data elements and definitions in order to promote appropriate data sharing and creating a patient registry for individuals with suspected or confirmed PASC that is culturally and linguistically appropriate and accessible to people with disabilities, collects demographic information, and disseminates information relevant to treatment of and policy around long COVID
- c) Requires that participation in the registry be voluntary and clarifies that all personal and health information in the registry is subject to applicable privacy protections
- d) Directs PCORI to submit an annual report to Congress and the President on the data, findings, and status of the registry
- e) Authorizes \$30 million for FY23 to carry out this section

SECTION 3. RESEARCH ON UNITED STATES HEALTH CARE SYSTEM'S RESPONSE TO PASC

- a) Instructs the Secretary of Health and Human Services, in coordination with the Agency for Healthcare Research and Quality, the NIH, and the CDC, to conduct and support research related to the health care system's response to long COVID, including:
 - 1) Expansion and efficacy of post-infectious disease treatment, with a focus on:
 - A) Identifying barriers to access to treatment for groups impacted by high rates of COVID-19;
 - B) Evaluating and identifying potential gaps that contribute to disparities in COVID-19 infection rates, severity and length of symptoms, and outcomes; and
 - C) Identifying trends associated with differences in diagnosis and treatment of long COVID and related post-viral illnesses and conditions by demographic factors
 - 2) Conducting and supporting research to:
 - A) Identify health care strategies that help mitigate disparities in COVID-19 infection rates, hospitalizations, severity and length of symptoms, secondary illnesses, and outcomes;
 - B) Identify health care-related factors contributing to such disparities; and

c) Provide recommendations on ensuring equity in diagnosis and access to quality post-infectious treatments

b) Authorizes \$15 million for FY23 to carry out this section

SECTION 4. EDUCATION AND DISSEMINATION OF INFORMATION ON PASC

a) Directs the CDC to develop and disseminate information on long COVID to the public, in plain language and in a manner that is accessible. This information shall include:

- 1) Awareness, incidence, and short- and long-term health effects associated with COVID-19 infection;
- 2) Illnesses related and often comorbid with long COVID; and
- 3) Availability of treatment options for long COVID and related post-viral illnesses and conditions

b) Instructs the CDC, working in consultation with representatives from communities impacted by long COVID and health care providers who treat these communities to develop and disseminate to health care providers information on long COVID, recommended assessment tools, and illnesses related and often comorbid with long COVID

c) Ensures that guidance on long COVID diagnostics, treatments, and care includes demographic factors and individuals with long COVID or related post-viral illnesses and conditions are empowered to participate in protocol development and outreach and education strategies

d) Allows for the dissemination of this information

e) Authorizes \$30 million for each year, FY23-FY25 to carry out this section

SECTION 5. INTERAGENCY COORDINATION ON PUBLIC ENGAGEMENT AND INFORMATION DISSEMINATION ON PASC

a) Directs the HHS Secretary to convene relevant agencies to develop information and resources on the impact of long COVID and related post-viral illness and conditions regarding rights associated with employment, disability status, and education

b) Instructs the Secretary to collaborate and consult with relevant agencies, communities and professions impacted by high COVID-19 rates

c) Directs these entities to develop:

- 1) Educational materials for school staff about long COVID and related post-viral illnesses and conditions with clear guidance on appropriate academic, social, and emotional supports and services, and the rights of students with disabilities;
- 2) Guidance for employers on the rights of people with disabilities related to long COVID and related post-viral illnesses and conditions; and
- 3) Guidance on long COVID and related post-viral illnesses and conditions as a disability, including recommendations to streamline the process of applying for benefits through the Social Security Administration and the Public Safety Officers' Benefits Program

d) Authorizes \$30 million for each year, FY23-FY25 to carry out this section

SECTION 6. RESEARCH WITH RESPECT TO MEDICAID COVERAGE OF LONG-TERM SYMPTOMS OF COVID-19

- a) Directs the HHS Secretary to expand the Chronic Conditions Data Warehouse research database of the Centers for Medicare & Medicaid Services (CMS) to collect data on items and services furnished to individuals enrolled in Medicaid or CHIP for the treatment of long COVID
- b) Authorizes \$3 million for FY22 to carry out this section

SECTION 7. PROGRAM TO SUPPORT LEGAL AND SOCIAL SERVICE ASSISTANCE FOR INDIVIDUALS WITH PASC

- a) Directs the Administration for Community Living to award grants for establishing or expanding medical-legal partnerships and increasing the availability of social supports to provide effective aid to individuals with long COVID or related post-viral illnesses and conditions in matters relating Social Security programs, housing, access to medical care, early intervention, specialized instruction and related services, low-income home energy assistance, employment supports, nutrition assistance, and other support services.
- b) Eligibility for Awards -
 - 1) To be eligible, organizations must be a State, a State protection and advocacy system, a nonprofit entity, a publicly funded organization not acting in a governmental capacity (such as a law school), an Indian Tribe or Tribal organization, an urban Indian organization, a territory, a health care provider serving populations impacted by COVID-19 or long COVID, underserved communities, or low-income patients, or an entity providing legal services;
 - 2) Priority is given to entities that certify in writing that any person providing legal assistance has demonstrated expertise in providing such assistance to people with disabilities
- c) These funds may be used to:
 - 1) Establish or expand medical-legal partnerships between community-based organizations, medical and social service providers, and legal assistance providers to help individuals with long COVID access or maintain social services;
 - 2) Establish or expand efforts to provide legal assistance for individuals with long COVID by organizations with a demonstrated history of providing direct legal or advocacy services on behalf of people with disabilities;
 - 3) Provide technical assistance around educating individuals with long COVID or parents caring for children with long COVID about rights related to accommodations in employment, education, or other matters as determined by the Secretary; and
 - 4) Employ staff or educate current staff on assisting individuals with long COVID in obtaining health care, social services, or legal services
- d) Directs grant awardees to collect and report data to the HHS Secretary
- e) Instructs the Secretary to submit an annual report to Congress detailing the number of individuals who sought services offered by grant recipients, the services provided, and a summary of activities conducted under the grant program
- f) Authorizes \$50 million for each year, FY23-FY27 to carry out this section and specifies that this funding will supplement and not supplant other Federal, state, and local funds

SECTION 8. DEFINITIONS

(1-3) Defines the terms Indian Tribe or Tribal organization, PASC, and urban Indian organization