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# CP Link project: Bridging disciplines to support adults with cerebral palsy to age well



Dr Erica Ranzato<sup>1</sup>, Emma Livingstone<sup>2</sup>, Miriam Creeger<sup>2</sup>, Dr Valerie Stevenson<sup>3</sup>, Prof. Karen Lowton<sup>4</sup>, Prof. Meriel Norris<sup>5</sup>, Prof. Cherry Kilbride<sup>5</sup>, Prof. Christina Victor<sup>5</sup>, Dr Kimberley Smith<sup>1</sup>

<sup>1</sup> University of Surrey; <sup>2</sup> UP - The Adult Cerebral Palsy Movement; <sup>3</sup> National Hospital for Neurology and Neurosurgery UCLH; <sup>4</sup> University of Sussex; <sup>5</sup> Brunel University of London.

## Cerebral Palsy

Cerebral Palsy (CP) is the most common lifelong physical disability in the UK, affecting over 130,000 adults. CP commonly occurs as a result of an injury to the brain, before, during or after birth. All people with CP experience disordered movement. However, the type and degree of functional disability experienced varies greatly between people. Existing research suggests that adults with CP face numerous physical, mental health, and social challenges as they age [1; 2].

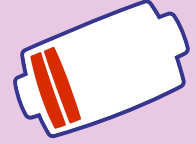
## Main objectives

1. Explore the ageing experience of adults with CP and determine how community resources are used by adults ageing with CP, and where they feel additional support is needed to promote their health and wellbeing.
2. Co-develop with UP the “Ageing with CP” training materials for the CP link worker who will deliver the CP link worker intervention.
3. Undertake a 1-year feasibility/pilot study of the CP link worker intervention with adults (aged 40+) living with CP in London.

## Ageing with CP



Increased risk of falls



Higher levels of fatigue



High rates of depression and anxiety



Loneliness and social isolation



Vascular issues



Increased joint and muscle pain



Long-term side effects due to medications or surgeries



Increased muscle spasm



Increased pain



Respiratory diseases

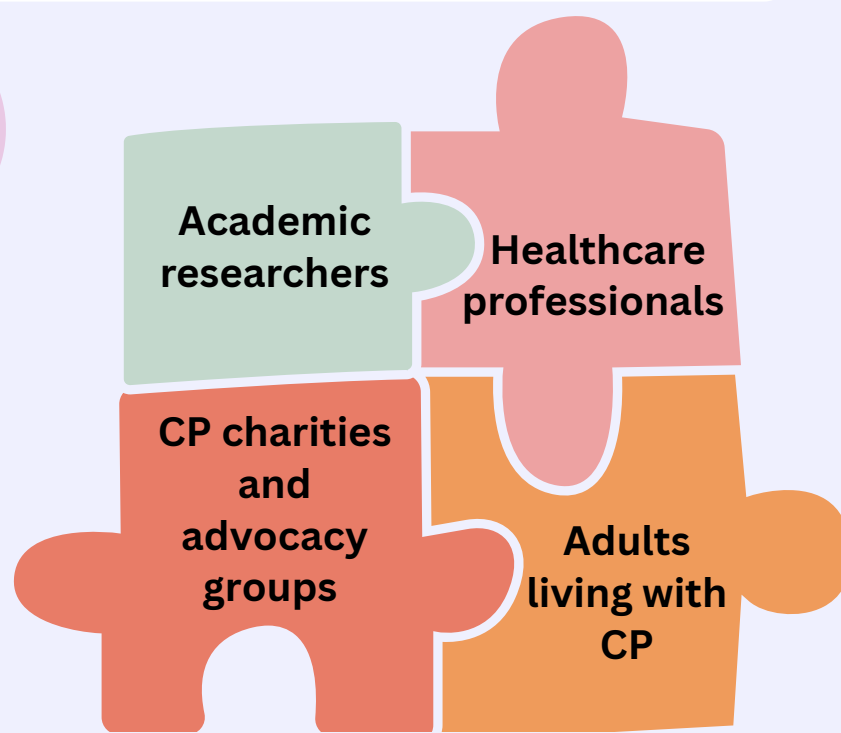


Discharged from specialist support services



Early-onset ageing-related issues

Our interdisciplinary team brings together academics from different universities based in UK and with diverse backgrounds including health sciences, psychology, sociology and disability studies. This allows us to explore the topic of supporting ageing with CP from multiple perspectives and to integrate diverse methodologies.



The UP charity has been a key partner from the outset, contributing to the project design and grant writing. They continue to support with recruitment and with the development of resources for the the CP link worker intervention.



The project involves collaboration with both advisory groups and co-production groups, each including people with lived experience of CP and healthcare professionals. The advisory groups offer continuous input across the project, while the co-production groups will engage in a series of online workshops focused on developing specific resources for the CP link worker.



We are collaborating with University College London Hospitals NHS Foundation Trust to recruit participants.

## Progress

- We have completed semi-structured interviews with 17 adults living with CP based in Greater London and aged 40 or older. We are now in the process of recruiting participants living with both CP and learning disabilities.
- We are developing the resources and training material for the CP link role and we aim to start the intervention in November 2025.



References: [1] Ryan et al. (2023). Prevalence and incidence of chronic conditions among adults with cerebral palsy: A systematic review and meta-analysis. Developmental medicine and child neurology, 65(9), 1174-1189. [2] Smith KJ, Peterson MD, O'Connell NE, Victor C, Liverani S, Anokye N, Ryan JM. (2019) Risk of depression and anxiety in adults with cerebral palsy. JAMA neurology. 76(3):294-300.