

SUPPORTING ADULTS WITH CEREBRAL PALSY TO AGE WELL: DEVELOPMENT AND PILOT OF A SPECIALISED LINK WORKER ROLE

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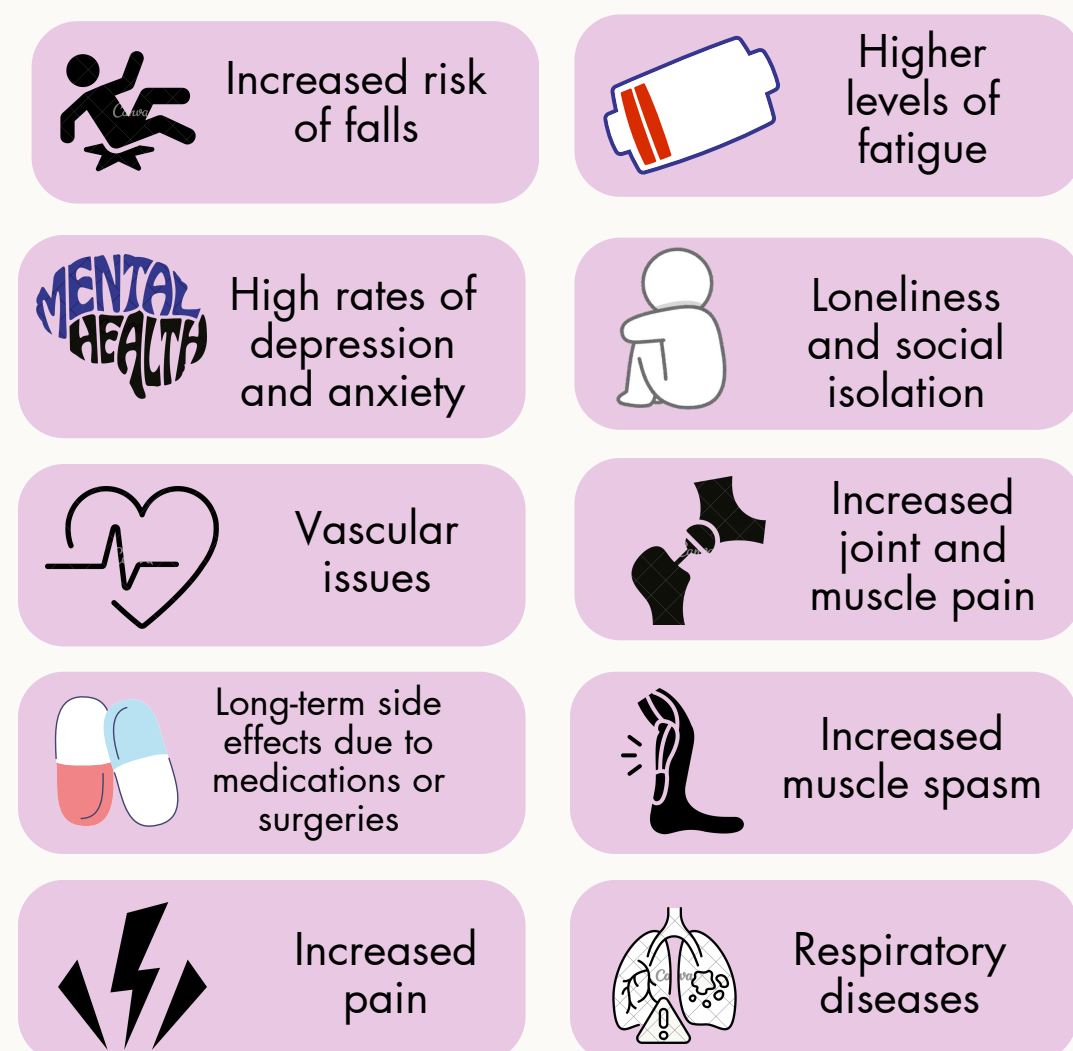
Cerebral Palsy (CP) is a lifelong condition, which commonly occurs as a result of an injury to the brain, before, during or after birth. All people with CP experience disordered movement. However, the type of movement disorder and the degree of functional disability experienced varies greatly between people.

There are 130,000 **adults** living with CP in the UK. Adults with cerebral palsy face a range of **physical, mental health, and social challenges** as they grow older. In addition, they are more likely to develop age-related issues earlier than the general population. However, once people with CP reach adulthood they are often discharged from specialised services and transitioned to non-specialised care, something that many people with CP describe as **“falling off a cliff”** [1].



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AGEING WITH CEREBRAL PALSY



SOCIAL PRESCRIBING

Social prescribing can be described as an intervention that signposts people to community organisations which provide **non-clinical support** - such as physical, emotional, practical, financial and spiritual support - and help to improve their wellbeing [2].

Social prescribing improves the outcomes for people by giving them more **choice** and **control** over their lives and an improved **sense of belonging** in their community. It also improves the awareness of, access to, and uptake of services available to individuals in their local communities, and it helps to improve the awareness and knowledge held by healthcare professionals of the non-clinical support available to their patients [3].

Existing research has demonstrated social prescribing interventions to be **effective** for a variety of different groups, such as those with mental health issues, long-term conditions, or who feel socially isolated [4].

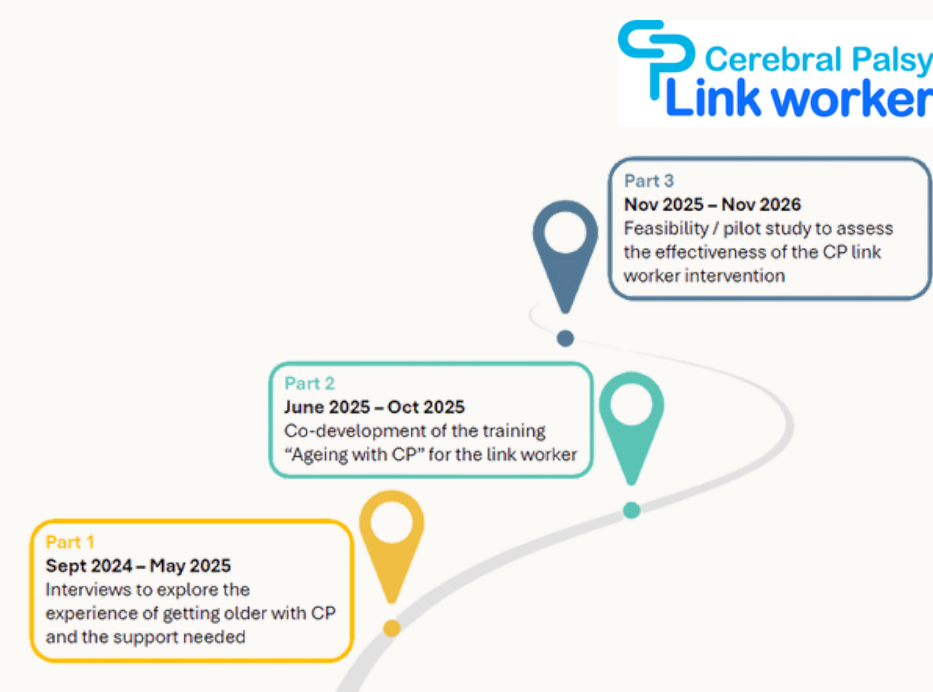
AIMS AND OBJECTIVES

The aim of this project is to co-develop and assess a specialised CP link worker role to support adults with CP to age well. We have three main objectives:

1. Explore the ageing experiences of adults with CP, including how ageing with CP impacts their physical, social, and mental well-being; examine how community resources are used and identify good practices, gaps in support, and areas of unmet needs of adults with CP.
2. Co-develop “Ageing with CP” training materials for the CP link worker with UP – The Adult Cerebral Palsy Movement.
3. Assess the feasibility and pilot a 1-year specialised CP link worker intervention.

PROGRESS AND NEXT STEPS

1. **Qualitative study.** We have completed semi-structured interviews with 17 adults living with CP, in Greater London and aged 40 or older. To date, participants span a wide age range (44–85 years), cover all GMFCS levels (I–V), and include two non-verbal individuals. We are in the process of recruiting participants with CP and learning disabilities.
2. **Co-production process.** The project involves both advisory groups and a 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.
3. **Feasibility and pilot study** for middle-aged and older adults living with CP in North Central London.



References

[1] Freeman, M., Stewart, D., Cunningham, C. & Gorter, J. (2019). Information needs of young people with cerebral palsy and their families during the transition to adulthood: a scoping review. *Journal of Transition Medicine*, 1(1); [2] The Social Prescribing Network. Report of the annual social prescribing network conference. (2016). London: University of Westminster, Wellcome Trust, & College of Medicine; [3] Enable. Evaluation of the Macmillan community link worker social prescribing scheme; [4] Bertotti, M., Frostick, C., Hutt, P., Sohanpal, R., & Carnes, D. (2018). A realist evaluation of social prescribing: an exploration into the context and mechanisms underpinning a pathway linking primary care with the voluntary sector. *Primary health care research & development*, 19(3), 232-245.



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