

LIVING HEALTHY LIVES: GROWING OLDER WITH CEREBRAL PALSY AND USE OF HEALTHCARE SERVICES ACROSS THE LIFE COURSE

POLICY BRIEF JULY 2023

This policy brief, based on research with adults with CP, outlines key considerations and recommendations to ensure adequate support and enable individuals with CP to lead fulfilling lives as they age.

Adults with cerebral palsy (CP) are a growing group, with a life expectancy similar to non-disabled contemporaries. Internationally the prevalence of CP ranges from 1.5 to more than 4 per 1000 live births. In the UK, the National Institute for Health and Care Excellence (NICE) estimates 2-3.5 per 1000 live births result in CP. Stable prevalence plus life expectancy, means that adults with CP are increasingly living into older adulthood. The World Health Organisation estimates there are 17 million adults with CP worldwide.



KEY RECOMMENDATIONS:

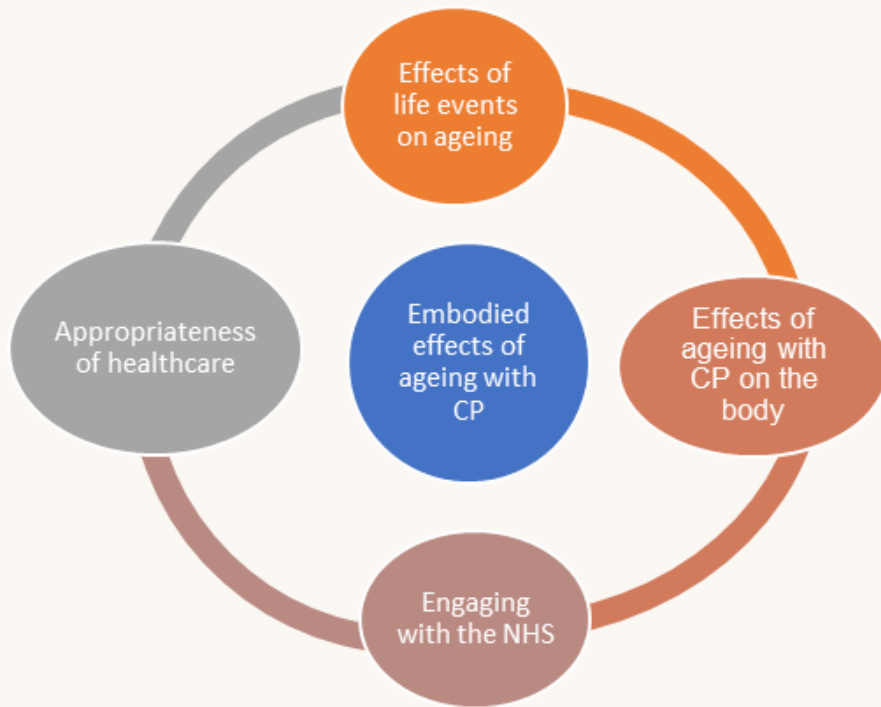
1. Set up a specialist adult Clinical CP service in every region of the country, available to adults ages 18 and above, with a multidisciplinary team of HCPs, to support physiological, psychological, gynaecological and general health needs across the life course. It would ensure continuity of care across the life course, from paediatric to geriatric care .
2. Ensure education and training, about CP across the life course, is embedded in medical and healthcare training at undergraduate, postgraduate and CPD levels; and clinical and clerical staff in primary and secondary care have regular disability equality training.
3. Make adjustments to healthcare environments, procedures and equipment across secondary and primary care settings to ensure people with CP receive effective and dignified care with proper funding and support.
4. Create and implement a CP clinical specialist role in hospitals to improve referral processes for individuals with CP, surpassing skeletal services and ensuring appropriate access to neuro services.

As people with CP age they experience physical and psychological changes across the life span, earlier than non-disabled age-matched peers. 1 in 4 live with multiple chronic condition. However, despite the extensive knowledge and rehabilitation available for children with CP, there is little knowledge and information about the lifelong effects of CP. Adults feel abandoned by the healthcare system as they are not having their needs met. This contributes to their higher risk of diseases such as diabetes and cancer.

The Study:

The Althea project was the first multi method study in the UK which aimed to understand the healthcare needs and experience of ageing for people with CP across their life-course. Through a national Online survey and life course interviews with adults with CP, information was collected to produce the four recommendations. These were validated by stakeholders at the project's multidisciplinary consensus event, held on May 19th 2023 at University of Nottingham. The overall findings of the project and consensus meeting highlighted the need for specialized CP services, improved education and training, integration of psychosocial needs, collaboration among professionals and accessible healthcare services.

Key Findings



"I actually got an acute illness...only diarrhoea... I spent three weeks in intensive care. Prior to me going into hospital I was still very independent... after I came out, I lost so much. I have lost so much independence, function, and it is purely down to the way that I was mistreated in hospital. And urm, it's the same hospital that I was born at, where they blundered my birth."
(Patrick - aged 51)

- People with CP experience ageing issues earlier in their lives.
- Young and middle-aged adults with CP can experience reduction in mobility and increase in falls.
- A range of technologies become more important in helping daily living.
- Knowledge and expertise of CP is scarce in adult health services, and thus impacts the quality of care received by adults with CP.
- Accelerated ageing issues and limitations in lifelong rehabilitation for adults with CP have implications for their ability to work, their relationships, their independence and opportunities for participation in society.
- Early ageing effects and lack of knowledge of CP as a lifelong condition can have psychological impacts for adults – depression, anxiety for example.
- There is a significant gap in knowledge, understanding and expertise of CP between child and adult healthcare provision.
- Lack of knowledge, about disability, and accessible resources can cause barriers for people with CP accessing good quality healthcare as they grow older.

Things that I was having no problem with suddenly became very heavy. My balance was going, I was falling over a lot. I was in a lot of pain, which seems to have progressed... I went on for about five or six years still working. Things gradually got worse. Saw a doctor, he said, "The only thing I can do is medically retire you." I didn't really want that, because mechanics was all I knew... (Bill - aged 61)

Conclusion:

This policy brief emphasizes the need to prioritize lifelong rehabilitation services for adults with CP. Doing so will contribute to the health and well-being of this growing population. It will also have long-term cost benefits via long-term reductions in hospital admissions, unemployment rates and long-term care.

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