
Campaigning for Better Adult Care for Cerebral Palsy

Why we're campaigning, and how you can help

The issue

Approximately 130,000 people in the UK live with cerebral palsy (CP). CP is a lifelong condition, and many adults with CP experience physical, emotional, and social challenges that can affect their health and wellbeing. Adults with CP are also more likely to develop other health conditions and to experience mental health difficulties such as anxiety and depression. These challenges may be linked to chronic pain, poor sleep, reduced mobility, social isolation, and barriers to getting the right support.

A gap in adult care

A key problem for many adults with CP is the lack of a clear adult care pathway. Children and young people often receive specialist support, but this support can reduce or stop when they become adults. Many people describe this change as "falling off a cliff". Without coordinated care, adults with CP may find it harder to manage their condition and get help early when problems arise.

This is compounded by a lack of visibility around the health and care needs of adults with CP, and by limited awareness among healthcare professionals and decision-makers that CP is a lifelong, childhood-onset condition. As a result, the needs of adults with CP are often overlooked in the health and social care system.

What we're campaigning for

We at UP -The Adult Cerebral Palsy Movement, together with our community are calling for a dedicated adult CP care pathway across the UK, based on the NICE guideline *Cerebral palsy in adults* (NG119). This pathway should include regular GP health reviews and access to coordinated services such as neuro-physiotherapy, speech and language therapy, occupational therapy, specialist CP services, community neuro teams, and mental health support.

Better adult services would help people with CP manage their condition, maintain independence, and take part fully in society. Regular reviews could also help identify physical and mental health concerns earlier, so that people receive the right support at the right time, contributing to the shift towards preventative care.

How we campaign

As a charity supporting adults with CP in the UK and advocating for better health and care provision, we encourage our advocates to speak up about their experiences of health and social care, including where support has been missing or difficult to access.

We encourage our advocates to reach out to their local Healthwatch to share their experience of services and support for cerebral palsy in their communities. Direct, local testimony like this helps address the lack of visibility described above and strengthens the case for change.

We welcome collaboration

We at UP-The Adult Cerebral Palsy Movement are happy to connect with Healthwatch to explore how we can help raise awareness and improve visibility of the health and social care needs of adults with CP at a local level. We would also welcome the opportunity to connect with local and regional decision-makers on health and social care issues, to discuss how a CP adult care pathway based on the NICE guideline (NG119) could be implemented in their area.

Contact UP

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