

# EXPERIENCES AND SOURCES OF SUPPORT FOR ADULTS WITH CEREBRAL PALSY AS THEY AGE

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## Background

- Cerebral palsy (CP) is the most common lifelong physical disability in the UK, affecting approximately 130,000 adults.
- Social support is a protective factor for physical and mental health and quality of life in older age [1], and an important facilitator of participation among people living with disabilities [2].
- This study explores the availability and types of social support among adults ageing with CP, focusing on older adults and including under-represented groups such as those with co-occurring learning disabilities (LD).

## Methods

- Semi-structured interviews were conducted between January and September 2025 face-to-face (n = 8), by telephone (n = 2), through online video-call (n = 10), or via email (n = 1).
- The interview guide was developed based on prior research on ageing with CP and in consultation with our advisory groups. The guide was piloted prior to use.
- Easy-read study documents were developed to support accessibility.
- Inclusion criteria: adults with CP ( $\geq 40$  years), living in Greater London, able to provide informed consent.
- Anonymised transcripts were imported into NVivo and analysed using reflexive thematic analysis [3].

## Findings

### Theme 1 - Receiving social support

All participants reported receiving some form of social support, either from formal or informal sources.

**Subtheme 1.1 - Informal support** from family members was most salient, with parents as key providers of emotional, practical, and financial support. Partners and adult children also offered advocacy support. Friends provided emotional and informational support. Support from strangers (often mobility-related) was often described as problematic.

**Subtheme 1.2 - Formal support** was accepted and embedded in daily routines for those with LD and those living in residential settings. In contrast, those without LD reported more limited experiences and more ambivalent views. Beyond practical and emotional aspects, formal support also had a social dimension, especially for those with LD and in residential settings.

[My friends] are the people maybe that I can talk to a bit about my stuff, not my family because I feel my family would get scared if they realised that there are some extra challenges now coming with age, already in your 40s. (Alice, 40-49, GMFCS 1-3)



I don't want our marriage to be put under incredibly- I don't want, you know, it to break up because of [my needs] (Zahra, 50-59, GMFCS 1-3)

## Participants

Demographic and health	N (22)
<b>Chronological Age</b>	
40-49	9
50-59	5
60-69	6
70+	2
<b>Gender</b>	
Male	9
Female	13
<b>Ethnicity</b>	
Asian	1
Black	2
Mixed	3
White	15
Not reported	1
<b>GMFCS level</b>	
1, 2, or 3	10
4 or 5	12
<b>Communication</b>	
Verbal, with no communication issues	14
Verbal, but people can have difficulties understanding me	5
Non-verbal	3
<b>Living arrangements</b>	
With family	8
With formal carer	2
Alone	7
Supported housing	5

### Theme 2: Costs of social support

**Subtheme 2.1 - Relational costs** made relationships more difficult and emotionally charged than they would otherwise have been. Relational costs arose from family members struggling to come to terms with participants' disability and evolving needs, boundary negotiations with family and friends, and misunderstandings with formal carers.

**Subtheme 2.2 - Financial costs** were explicitly mentioned by few participants, mainly when transitioning from informal to formal support. However, they were implicitly present across many accounts through references to having (or lacking) the resources to pay for support.

**Theme 3: Changes of social networks over time** were marked by reduced support from family and friends, leading to decreased informal support and, for some, greater reliance on formal support. These changes in some cases caused anxiety and worry.

Everybody always says have you got a personal assistant? No, I haven't because I want to do things myself. Even when I went back to work, one of the managers said maybe you need a personal assistant, not realising that that is my worst fear to now really. I want to do everything myself and not feel that I have to depend on anybody else but I am depending on people but they are family. But to actually have to go and pay somebody to do different tasks, it's a big step for me (Helen, 60-69, GMFCS 1-3)



My mum's 79 and my dad's 82, and you feel they're getting older. I don't know how long they will live, I'm thinking I'm living by myself. My brother might move out of London, my sister might move out of London. Who have I got? I ain't got no-one, and that network is gone, and that's always playing on my mind. (Raj, 50-59, GMFCS 1-3)



## Discussion

- Experiences of receiving support in older adulthood involved managing relationships and negotiating expectations and boundaries, including balancing reliance on support with societal expectations of independence. These experiences were often associated with relational and emotional costs.
- Social support spanned multiple dimensions (practical, social, emotional, informational, and advocacy) and sources, which were not interchangeable.
- Changes in social networks raised concerns about the future and the sustainability of support.