

Living Healthy Lives: Exploring effects of growing older with cerebral palsy and use of healthcare services across the life course (ALTHEA)

Participant worksheet

Recommendation 1: Provision Recommendation

Set up a specialist Clinical CP service in every region of the country available to people with CP ages 18 and above, with a multidisciplinary team of HCPs who can support and help manage their fluctuating physiological, mental and psychological health needs across the life course. As part of establishing the clinics, a clinical speciality in CP across the life course is needed.

Key points

- 1a. Be led by a clinical specialist in CP across the life course.
- 1b. Offer service users regular rehabilitation therapy, (including physiotherapy, hydrotherapy, speech and language) and counselling with specialist workers.
- 1c. Advise on self-management strategies for fatigue or pain
- 1d. Act as a specialist resource for other health specialities (e.g. Cancer, maternity) who will treat people with CP as part of their wider healthcare needs
- 1e. The multidisciplinary team will have expertise in treating CP as a lifelong condition.
- 1f. Where appropriate provide preventative routine healthcare checks to people with CP or advise on their provision in other healthcare settings.
- 1g. Referral to occur via self-referral or a GP

Recommendation 2: Infrastructure Recommendation

Changes to facilities and healthcare environments across clinical and primary care settings are needed to ensure people with CP and other disabled people receive effective and dignified care. Such adaptations will be of benefit to a range of disabled people using healthcare.

Key points

- 2a. Disability access assessments of healthcare facilities and environments to identify current limitations in provision.
- 2b. Adaptations to equipment used across healthcare to be able to be used safely and comfortably by people with CP (for example breast scanning technology, hospital beds, MRI scanners etc.).
- 2c. Changes in the working practices and training involved in the provision of services to ensure they are responsive to the needs of people with CP, for examples issues related to spasticity, uncontrolled movements or communication difficulties.

2d. Using the expertise and knowledge of people with CP and other disabled people in the re-design of such facilities.

Recommendation 3: Education and Training Recommendation

Education and training is central to ensuring all those working across healthcare treat people with CP appropriately and with an understanding of both their clinical needs and the challenges they face as disabled people in society. Changes are required across medical training, workplace training and continuous professional training to ensure those working in healthcare provide effective care and support for people with CP.

Key points

- 3a. Disability equality training to be embedded in all areas of education and training for all staff who work with people with CP across primary and secondary healthcare settings.
- 3b. Disability equality training to come from a rights-based perspective, emphasising the social production of disability and the need for person centred care that ensures people with CP and other disabled people make decisions about their treatments and their lives.
- 3c. Education and training of all staff who work with people with CP to incorporate a life course perspective that understands the interrelationship between how the body changes across the life course and the impacts of living in a disablist society.
- 3d. The development of resources that support the above approaches for use in education and training and which have been developed with the involvement of people with CP.