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The everydayness of falling: consequences and management for adults with Cerebral Palsy across the life course

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Dr Hannah Harvey

A quick guide to Cerebral Palsy in adults

for health professionals

CP results from **BRAIN DAMAGE** around the time of birth. The brain damage does not get worse



HOWEVER adults with CP age faster than the non-disabled

because

the body works harder



organs tire

+ early neurological deterioration



musculoskeletal systems deteriorate at an accelerated rate

THIS MEANS

CP is a **LIFELONG** condition

IMPACTS
JOBS EATING HOBBIES
FREEDOM SEX LIVES
RELATIONSHIPS

Women with CP experience hormonal changes at adolescence and menopause much earlier

Many health professionals don't know that hormonal based medication and contraception can aggravate the impact of CP.

What you can do in practice



ACCOMMODATE
Make appropriate changes to ensure equitable access to primary and secondary healthcare



LISTEN AND HEAR

BE FLEXIBLE

GET TRAINED



Take what is said **SERIOUSLY**



PREVENT

Ensure regular and accessible preventative health checks as patients with CP age.

FUNCTIONAL LOSS

PAIN

DIFFICULTY SWALLOWING

FATIGUE

FRACTURES

LOSS OF BALANCE





Background

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- Falls and the risk of falling as a global public health concern (*World Health Organisation*)
- Adults with CP experience approx 5 times more falls than average person (incl. falling from standing, walking or wheelchair)
- Incidence of falling with CP is higher than other common neurological conditions such as Stroke, Parkinsons, or Multiple Sclerosis
- People who have CP have premature ageing of their bodies
- Dearth of knowledge and appropriate falls management provision, leading to premature deterioration in walking, balance, and strength for adults with CP
- Most falls prevention services are aimed at people over 65 years of age

Methodology

- Life course approach to health emphasises a social and temporal perspective, and the value of looking across stages of an individual's life to identify emerging patterns of health and disease.
- It recognizes how a person's health behaviours and lifestyle choices are shaped by their social and cultural environment and relationships over biological time and historical time (WHO, 2017).
- Permits an exploration of embodied effects of ageing over time; impacts on social and economic participation, changes in life choices and responsibilities; and access to and utilisation and quality of health care.



Recruitment & Interviews

- Sample – 26 adults with CP based in UK with capacity to consent
- Recruitment: Scope UK online community; private CP FaceBook groups, Twitter, Snowballing techniques
- Digital interviews: Email, Facebook Messenger, Zoom
- Interview questions:
 - Have you experienced an increase in falls since you were a teenager?
 - What have been the physical and mental health consequences of your falls/near-falls?
 - What has helped you to manage and prevent falls/falling?
 - Do you know of any mobility aids that could help you now or in the future?
 - If you don't currently use these, could you discuss why?
 - How have falls/fear of falling shaped your life activities, choices and opportunities?



Digital Methods To Increase⁷ Public Involvement

- Funders of health and social research are looking for:
 - Evidence of public involvement and societal impacts
 - Good practice to ensure that meaningful patient and public involvement is embedded within every research design
- Digital methods enables disabled people to be involved as research participants and advisors by:
 - Flexibility to participants in terms of time and space
 - Involvement across different geographical locations without the practical barriers
 - Providing an anonymous distance between researchers and participants (more likely to feel comfortable to disclose private and sensitive stories)
- Inclusive research design adheres to Art.21 of United Nations Convention on Rights of Persons with Disabilities

RESULTS

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(1) Limiting what to do and where to go

I have trouble doing anything too much, so like I can walk and I do stuff indoors, but I can't do too much before I start falling over which is alright indoors because I bounce pretty well, but, you know, outside, that's a bit more dodgy...Probably a couple of times a day, but I lose my balance more than that. So like near misses are a lot more than the actual falls...Have lost confidence to do things, so now limit what I do to make it manageable to prevent falls (JK, 50)

(2) Losing autonomy and independence

I'm very aware that I'm a lot more like bent forward and so I had a lot more falls because of that. And I think it's affecting my confidence, so - I am using my chair a lot more in the home It affects me going to friends' houses that have no wheelchair access. I feel awkward relying on physical assistance eg holding hands. (Rose, 31)

3) Managing falls and adapting practice

You know, because they (doctors) were saying, you know, “Your pain isn’t going to get better; it’s going to get worse. You’re going to fall more. As you get older, you’re probably going to break something,” you know. (Erin, 32)

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. (Bill, 61)

I have indeed been told, ‘I’m too young’ for the local falls service and they have several times when I’ve been referred been very unhelpful and actually quite rude. Definitely not designed for or clued up on conditions such as CP. Purely aimed at elderly. (JK, 50)

Self management, negotiating disabling barriers, getting on with life

I am planning a lot more than I ever used to (and I used to think I planned a lot in the past). I make sure that I have plenty of time to get to places, and I plan the entrances to buildings more carefully than I ever needed to. I am also using the furniture and the environment to help me move and get around... I feel like I have to rely on my partner a lot more than I would like to. (Chloe, 26)

Concluding Points

- Adults with CP are falling at an earlier age than the general public
- Falls can:
 - change how people with CP live their lives
 - change how they interact with friends, families and work colleagues
 - cause severe physical and psychosocial damage.
- Taking a life course approach can:
 - helps us learn about the dynamic nature of someone's health over time
 - help health and social care services support people with CP to remain socially active and productive across their lives
- Current falls prevention services do not meet the needs of adults with CP

Implications

- Rehabilitation services have helped other populations reduce falls rates through maintaining strength and balance. Is this applicable for people with CP
- Use of assistive technologies could be seen as a marker of difference and dependence
- Would specialist prevention rehabilitation services be appropriate for people with cerebral palsy and how do we make sure relevant mobility devices and assistive technologies are available to prevent falls
- Maintaining social participation and quality of life is essential in any falls prevention intervention.



Next steps:

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**Falling In The Lives Of Adults With Cerebral Palsy:
Taking Action To Prevent, Manage, And Support
Through The Life Course.**

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