

# Taking a Lifelong Perspective on Cerebral Palsy: Challenges and Opportunities

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CP Conference, Norway March 2024

**“Children with Cerebral Palsy grow up  
to be adults with Cerebral Palsy”**

# Taking a Lifelong Perspective on Cerebral Palsy: Challenges and Opportunities

1. My Story
2. What we know about Cerebral Palsy
3. Understanding Cerebral Palsy as a lifelong condition
4. How a third sector organisation, like UP, supports the community

# My Story

- Lack of accessible and coordinated care for adults with CP is a major barrier.
- Misdiagnoses/diagnostic overshadowing and age-based restrictions highlighted systemic challenges.
- Self-advocacy and exploring alternative options are crucial for managing your own health.
- Importance of personalized and holistic approaches to CP care.
- Adults with CP face unique challenges that require specialist knowledge and care.
- Need for an MDT that has an understanding of Cerebral Palsy
- Need for extended rehabilitation after surgical procedures/or life event/fall for someone with neurological condition
- Consider impact of intervention on the rest of the body e.g. skin integrity, leg pain, long term crutch use
- Knowledge about Cerebral Palsy AND how aging impacts disability
- Not everything is because of Cerebral Palsy, but CP may be having an impact on its presentation



# What I have learnt

- **Knowledge is power**
- **Speak up**
- **Professionals**
- **Develop healthy habits**
- **Challenge internal ableism**

We need information and support to understand our condition, problem solve and how CP impacts ageing

Advocate for yourself and for others, know when and who to seek help from and don't take no for an answer

Don't need to be experts but need to be open to learning and accessible at time of need

Understand the best ways to support yourself and integrate that into your daily routine

Use aids / tools to help yourself. These are not symbols of failure but aid participation



# The consequences

Requiring life-impacting surgery

No support or understanding from the medical community

Needing to come terms with functional change in ability

Questioning life choices

Dealing with guilt



Low self-esteem and anxiety

Disempowered

No positive association with exercise or knowledge of how to help myself

Isolated from the community and having never met anyone else with CP before

# Adults with Cerebral Palsy

A community of 130,000 adults living with CP, the largest group in the UK living with a lifelong condition.

Comparable in size to those with Multiple Sclerosis and Parkinson's Disease, yet without the same resources.

No coordinated, specialist medical care and services fall short of NICE guidelines.

Impact is unnecessary pain, reduced quality of life, avoidable medical problems and increased mental health issues.

# The community tell us...

- Fatigue
- Pain
- Sleep
- Declining mobility
- Managing functional decline
- Poor mental health and anxiety

Which lead to issues with wider participation e.g. social relationships, in the workplace, travel, hobbies etc



# This is backed up by the research

- 65% of adults have pain
- 40% of adults have limited knee mobility
- 33% of adults have limited hip mobility
- Among ambulatory adults, 56% reported to perceive a decline in walking function or capacity over time
- Proportion of adults in remunerative employment is 39%; it's 56% in samples of adults without ID

*van Gorp et al. Epidemiology of cerebral palsy in adulthood: a systematic review and meta-analysis of the most frequently studied outcomes. Arch Phys Med Rehabil. 2020;101(6):1041-1052.*

*Ryan et al. Prevalence and incidence of chronic conditions among adults with cerebral palsy: a systematic review and meta-analysis. Dev Med Child Neurol. 2023;doi:10.1111/dmcr.15526*

# Physical health

- Prevalence of hypertension, ischemic heart disease, heart failure, stroke are higher in adults with CP than adults without CP
- Prevalence of asthma is higher in adults with CP than adults without CP
- Prevalence of liver disease is higher in adults with CP than adults without CP
- Prevalence of osteoarthritis and osteoporosis are higher in adults with CP than adults without CP
- Prevalence of chronic kidney disease is higher in adults with CP than adults without CP
- Prevalence of epilepsy is higher in adults with CP than adults without CP

*van Gorp et al. Epidemiology of cerebral palsy in adulthood: a systematic review and meta-analysis of the most frequently studied outcomes. Arch Phys Med Rehabil. 2020;101(6):1041-1052.*

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# Mental health

- Prevalence of anxiety, depression, psychotic disorders are higher in adults with CP than adults without CP
  - Adults with CP are more disadvantaged in healthcare system
  - This has impact on the individual and may perpetuate the health and functional decline
  - Barrier to optimal healthcare are felt to put them at more risk of low mood, anxiety and depression
  - Worsening physical health reduces participation, physical engagement in self-management and can learnt helplessness
  - There are questions about whether there is an organic cause to mental health amongst the community

*van Gorp et al. Epidemiology of cerebral palsy in adulthood: a systematic review and meta-analysis of the most frequently studied outcomes. Arch Phys Med Rehabil. 2020;101(6):1041-1052.*

*Ryan et al. Prevalence and incidence of chronic conditions among adults with cerebral palsy: a systematic review and meta-analysis. Dev Med Child Neurol. 2023;doi:10.1111/dmcn.15526*

# Screening tools

- Many women from the community find it difficult to access appropriate support for their Mammograms and Cervical smears
- Morphology, composition of muscle/ fat ratio is different in Adults with CP
- BMI monitoring may not be reliable for this population due the higher levels of visceral fat
- Adults with CP have higher rates of metabolic syndrome, cardiovascular disease and stroke and this could be related to excess body fat but also linked to lower levels of fitness and activity

# National Institute of Clinical Excellence (NICE)

## Quality Standards

### Statement 1

Adults with cerebral palsy are referred to a multidisciplinary team if their ability to carry out usual daily activities deteriorates or may be affected by a procedure.

### Statement 2

Adults with cerebral palsy who have complex needs have an annual review.

### Statement 3

Adults with cerebral palsy who want support to live independently are referred to a professional with expertise in independent living.

### Statement 4

Adults with cerebral palsy who want support to work are referred to a professional with expertise in vocational skills and independent living.

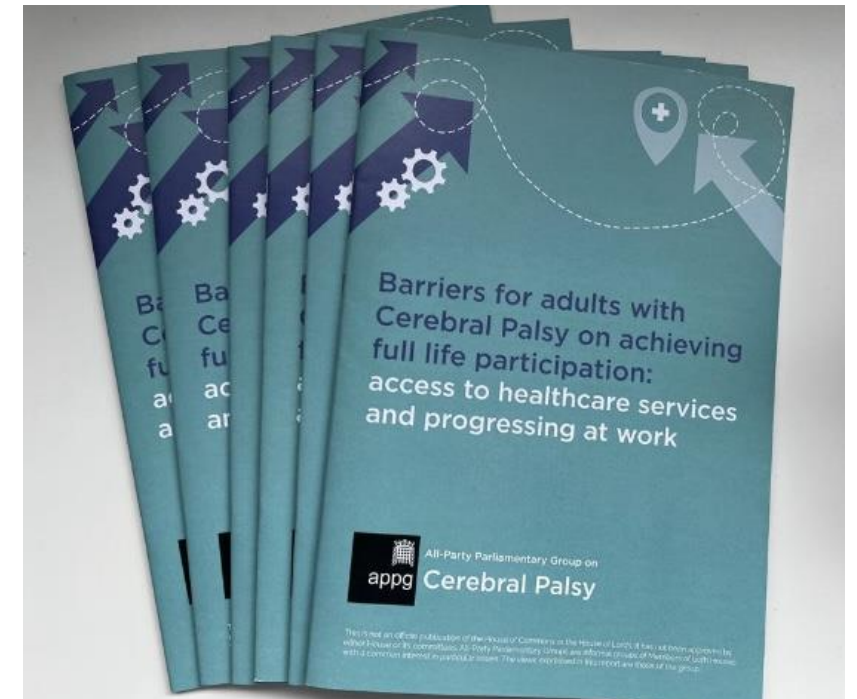
### Statement 5

Adults with cerebral palsy who have communication difficulties are referred to speech and language therapy services to assess their need for intervention

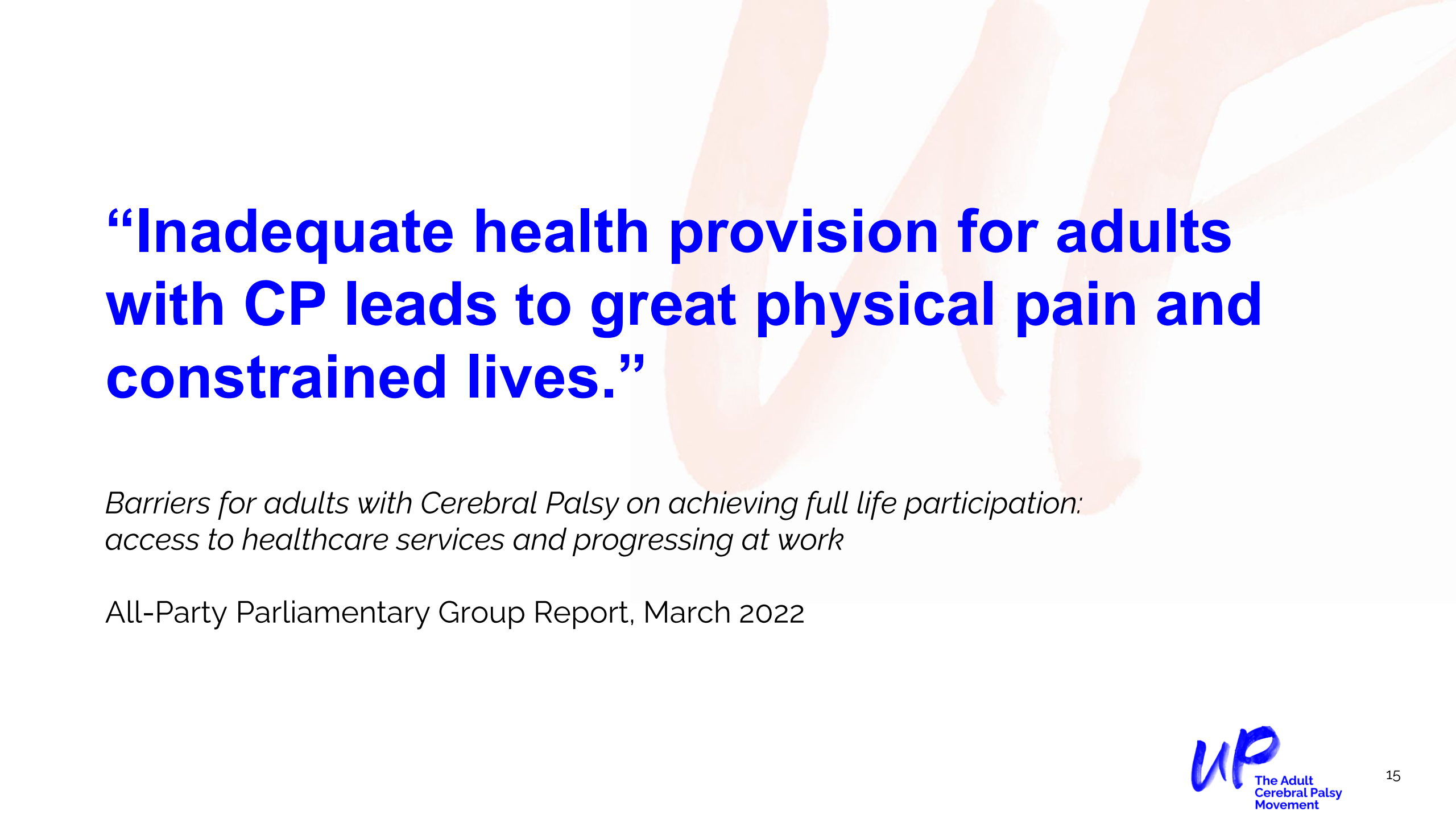
# All Party Parliamentary Group on CP

## Summary of key recommendations

- 1** NHS England, social care, education, and employment specialists must agree a national service specification for adult Cerebral Palsy to be used to commission dedicated specialist services based on the needs of local populations within the 42 new Integrated Care System areas.
- 2** To support GPs in identifying adults with Cerebral Palsy, the UK-wide Quality and Outcomes Framework (QOF) must be extended to incorporate the creation of general practice-level Cerebral Palsy registers along the lines of the expansion of QOF to learning disabilities. Once identified, adults living with Cerebral Palsy must receive annual medical reviews, whilst improved coding of medical records will support GPs in identifying patients in need of support.
- 3** Training for those working in general medicine, general practice and nursing must specifically cover adults with Cerebral Palsy from an entry level upwards.
- 4** Each Integrated Care System (ICS) area will be required to undertake a gap analysis of existing Cerebral Palsy services for adults against NICE guidance and use the results to inform and guide their local commissioning decisions.
- 5** The Department of Health and Social Care and the Department for Work and Pensions must ringfence funding to ICSs to enable them to develop specialist services and for these services to work in partnership with the working health program at a local level to support individuals on health grounds, as well as accessing and staying in employment.







**“Inadequate health provision for adults with CP leads to great physical pain and constrained lives.”**

*Barriers for adults with Cerebral Palsy on achieving full life participation:  
access to healthcare services and progressing at work*

All-Party Parliamentary Group Report, March 2022

**"90% of children with Cerebral Palsy reach adulthood and find themselves at a cliff-edge, without the support they had relied upon for their first 18 years of life."**

*Barriers for adults with Cerebral Palsy on achieving full life participation:  
access to healthcare services and progressing at work*

All-Party Parliamentary Group Report, March 2022

# Overlapping needs

Individuals with Cerebral Palsy have needs that overlap the following areas:

## Health Care – Social care – Vocational – Social participation

Physical health issues can exacerbate social and mental health for adults with CP. Issues such as loneliness, social isolation, social exclusion and mental illness are all commonly reported in this population.

These complex physical, social, and mental health issues point to the need for specialised support. In childhood people with CP are often supported by specialist teams. However, once people reach adulthood they are often discharged from these services and transitioned to non-specialised care that many people with CP describe as *falling off a cliff*.

At this point, it is a GP rather than a specialist clinician who becomes their main point of contact and healthcare support. As such, there is a need to look to innovative ways to support this population within the community.

# This is what good looks like

1. Clinical pathways with someone responsible for this at ICB level
2. Primary & Secondary Care – Able to identify those with CP and offer appropriate advice, support and onward referral
3. Annual Reviews – CPIP extension
4. CP Nurse/Advocate



## WE'RE CHANGING THE WAY PEOPLE THINK ABOUT CEREBRAL PALSY.

Cerebral Palsy affects 130,000 adults in the UK. It presents in childhood, and at that stage, is rightly given coordinated care. Then at 18, you are no longer under paediatric services, and the support structure disappears. Cerebral Palsy is a lifelong condition, yet the way healthcare is provided to adults with CP is as if the condition has miraculously disappeared.

Our movement is about positively making the changes in ourselves, and in society, so that we can live our best lives.



It is rooted in our belief in our own power, standing up for ourselves and our rights, and combatting ignorance, prejudice and indifference. We also help to educate the medical profession so they can give informed advice, and also be aware of where they can draw on additional resources of information.

Please get involved with our work by visiting our website.

[upmovement.org.uk](http://upmovement.org.uk)

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**UP**  
The Adult  
Cerebral Palsy  
Movement

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Cerebral Palsy  
Movement

CP as a  
childhood  
condition



CP as a  
childonset  
condition

Adults with CP present with

- Physical decline
- Risk factors for co-morbidities
- Poor mental health
- Reduced participation



**If we agree that we want full life participation for our children – then what happens in childhood matters.**



# Equipping our children for adulthood



1. Information is Key
2. Building Skills:
3. Healthy Habits
4. Success is Participation
5. Signposting
6. Role models

# Equipping our children for adulthood

## Information is Key

- Understand your type of CP and how to manage it effectively.
- Discuss birth and early development to build self-awareness.
- Transition planning should start around age 14.



# Transition website



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## Transition >

[Process of Transition](#)

[Advice to Parents](#)

[Independence Skills](#)

[Self-Advocacy](#)

[Making Decisions](#)



### Transition

The transition between child and adult healthcare for young people with Cerebral Palsy can be challenging in several ways. We look at these challenges, and suggest ways of approaching them.

# Equipping our children for adulthood

## Building Skills:

- Practice independence, self-advocacy, and decision-making.
- Seek opportunities to learn and grow through activities and experiences.
- Encourage open communication and asking for help when needed.



# Equipping our children for adulthood

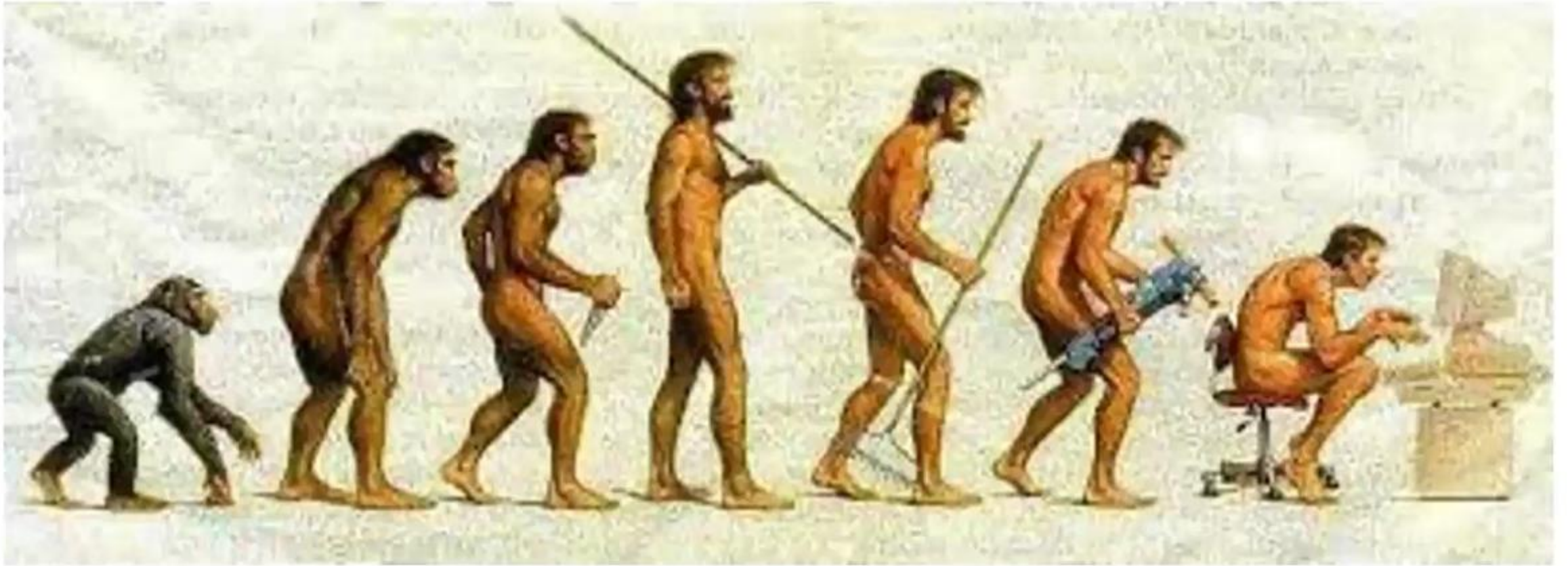
## Healthy Habits

- Develop a love for physical activity early on.
- Find sports and activities you enjoy and participate regularly.
- Exercise helps manage pain, improves mood, and fosters social connections.





# Dangers of Sedentary Behavior





# Healthy habits

We need to reduce the risks of sedentary behavior.

- Positive experience of exercise
- Finding an activity that is fun and sociable
- Family pursuit- that is integrated into everyday life
- Exercise is for “me too” – cardiovascular and strength training
- Mental Health impacting physical health and visa versa



# Equipping our children for adulthood

## Success is Participation

- Embrace assistive devices to participate more fully in life.
- Don't let fear of failure limit your activities and experiences.
- Focus on enjoying life and being involved with loved ones







**Mobility aids increase participation and support inclusion**

# Equipping our children for adulthood

## Signposting

- Seek support from organizations specializing in disability and CP.
- Utilize resources available throughout different life stages.
- Connect with others with CP for shared experiences and inspiration.



# Midweek matters

We provide support each week to the community, through our Midweek Matters virtual meetings.

Topics ranging from adaptive fashion to parenting with Cerebral Palsy to mental health.

There's also digital engagement through our social media channels and website, which offer lots of content and advice for our community and their families.



# Equipping our children for adulthood

## Role Models

- You are not alone! Connect with others with CP for support and guidance.
- Sharing experiences and seeing others succeed empowers and motivates.
- Believe in your potential and strive for your own definition of success.





# Adults with CP need

- Knowledge and skills
- Support
- Signposting
- Services





## Live Well >

[Be Your Own Advocate](#)

[Fatigue](#)

[Mobility](#)

[Mental Health](#)

[Travel](#)

[Parenting](#)

[Eating, Drinking & Swallowing](#)

[Pain](#)

[Sleep](#)

[Being Active](#)

[Communication](#)

[Fashion](#)

[Hobbies & Passions](#)

[FAQs](#)



### Live Well

Living well with Cerebral Palsy is about not letting these challenges stop you living the fullest, most satisfying life you can. Sometimes that isn't so easy. Hopefully, what you'll find in these pages are ways to start winning more of those battles.

# What good looks like

## Health and Social Care

- Easy access to community services e.g. Falls teams, Community Neuro teams, wider MDT support with rehabilitation to prevent deterioration and manage risk
- Clear Pathways to access appropriate support from services like gastroenterology, respiratory, orthopaedics, gynaecology to manage co-morbidities
- Annual reviews for holistic management
- CP Nurse/Advocate to help joined up care and navigate complicated system and understand own condition – Provide easy access to timely advice and support

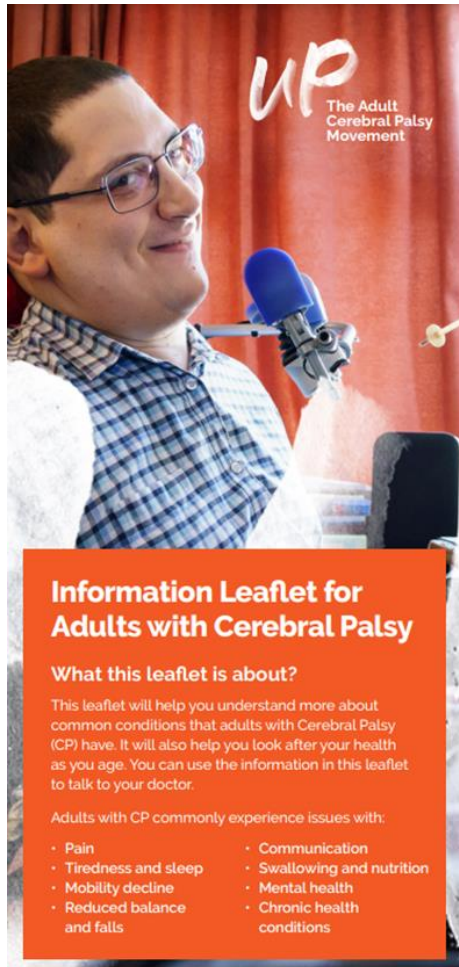
# What good looks like

## Health and Social Care

- Well planned and supported transition
- Clear care pathways equitable with other long-term conditions
- Knowledgeable professionals who recognise CP as a long-term condition
- Social prescribing/Support and education to live well with CP
- Specialist services for those at GMFCS 4 & 5 and for all at certain times e.g. post-surgery, decline, change

# Community resources

## GP Leaflet



## Annual Self-check list

**UP The Adult Cerebral Palsy Movement**

**SUMMARY OF ANNUAL SELF CHECK**

Below are the areas you have filled out on the Questionnaire.  
**Tick 2-3 boxes you would like to discuss with your GP and why?** This will assist you in having a focussed conversation and move forward together with your GP.

Date \_\_\_\_\_

Medical Support  \_\_\_\_\_

Medical history  \_\_\_\_\_

Physical activity  \_\_\_\_\_

Pain  \_\_\_\_\_

Fatigue  \_\_\_\_\_

Mobility  \_\_\_\_\_

Falls  \_\_\_\_\_

Sleep  \_\_\_\_\_

Mental health  \_\_\_\_\_

Men's Health / Women's health  \_\_\_\_\_

Relationships & Social Life  \_\_\_\_\_

**TIPS FOR PREPARING FOR YOUR GP APPOINTMENT**

- Take a pencil and pen with you to the appointment.
- Write down the issue that you want to discuss beforehand.
- Ask the GP if you can record the conversation.
- Book a double appointment with your GP to discuss anything in detail (if possible).
- Take someone with you to help listen to all the information.
- Discuss any assistance needed for your examination beforehand.
- Ring your GP practice beforehand to book in-person, video or telephone appointment as needed.
- Ring your GP practice before the appointment to check physical accessibility to attend service (e.g. wheelchair access, disability toilets, examination tables, and ramps).

## Health checklist

**TRANSITIONS**  
 Healthcare for adults with cerebral palsy

**Health Summary**

This health summary belongs to \_\_\_\_\_

**Before you start:**

- Read the whole summary to understand the questions under each section
- Complete the summary over time and in stages
- You might find it helpful to gather the information you need before filling in the summary
- Ask for support to complete the summary, for example from parents and health professionals
- Keep the summary in a safe place
- Consider bringing the summary with you to appointments with new health professionals
- Add to the summary over time so it remains up-to-date.
- It may be helpful to update at key times in your life such as being discharged from a health service, attending a new health service, attending a new education setting or starting a new job

About me	2	Pain	12
About my cerebral palsy	4	Other medical conditions	13
Gross Motor Function Classification System (GMFCS)	5	Allergies	15
Manual Ability Classification System (MACS)	7	Vaccines - Teenager / Adult	15
Eating and Drinking Ability Classification System (EDACS)	8	Vaccines - Baby / Child	16
International Dysphagia Diet Standardisation Initiative (IDDSI)	9	Equipment	17
Communication Function Classification System (CFCFS)	10	History of orthopaedic surgery	19
Scoliosis	11	History of other surgery	20
Epilepsy	11	History of other hospitalisations	21
Fatigue	11	History of spasticity management	23
		Other medications	25
		Any other medical history	26
		Contact details	27

# Advocating

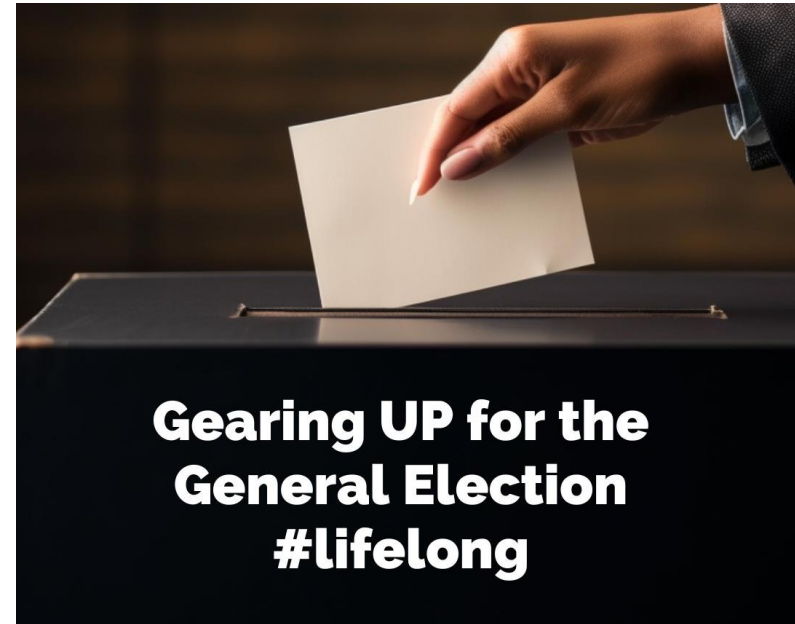
Service Mapping

**Support Well**

## **Find Your Community Neuro Team**

This is a tool for doctors to be able to look up the details of the relevant Community Health Team for their patient with Cerebral Palsy, and then to make a referral. Patients may wish to direct their GP to this page.

Policy - Our Manifesto





**Thank you.**

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