Beskrivning av cerebral pares

CPUP-dagarna 2026

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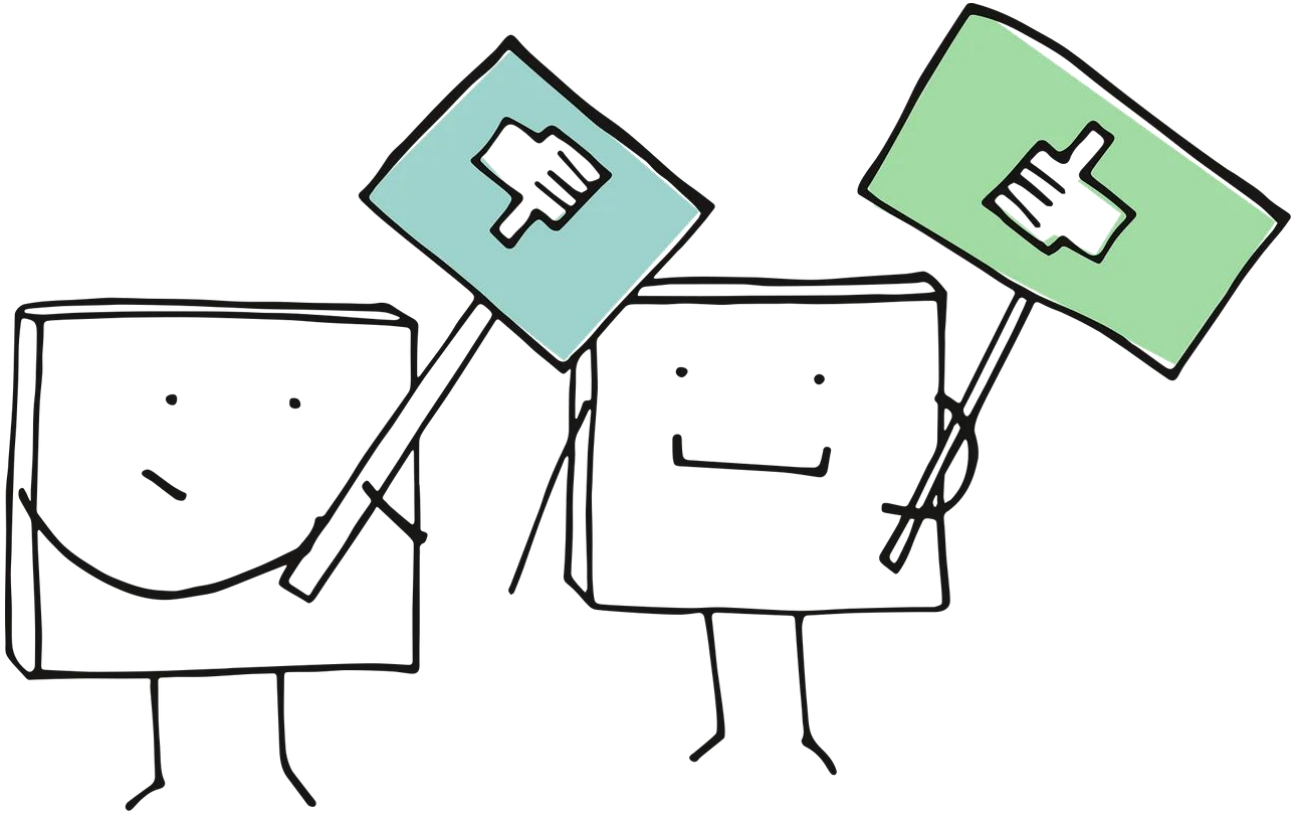
UPPFÖLJNINGSPROGRAM FÖR CEREBRAL PARES

Gamla definitioner och den uppdaterade beskrivningen av cerebral pares



Utveckling av begreppet cerebral pares

- Klinisk observation
- Neurologisk beskrivning
- Operationell diagnos, kriterier för epidemiologi
- Multidimensionell beskrivning av ett livslångt utvecklingsneurologiskt tillstånd som integrerar funktion, delaktighet, genetik och lived experience

Evolution of the Definition of Cerebral Palsy (1843–2026)

From early clinical description to an operational, multidimensional neurodevelopmental condition

1 — 1843

Little WJ
The Lancet

"Spastic rigidity of the muscular system in infants and young children, with subsequent difficulties in standing and walking."

First systematic clinical description of spastic motor disorders in early childhood; emphasized early onset and non-progressive course.

2 — 1955

Balf CL, Ingram TTS
British Medical Journal

"Cerebral palsy is a descriptive term applied to a group of motor disorders of young children, in whom full function of one or more limbs is prevented by paresis, involuntary movement, or incoordination."

Introduced a neurological concept of CP as a group of motor disorders in children; excluded progressive and transient disorders; proposed neurological classification.

3 — 1959

The Little Club
Cerebral Palsy Bulletin

"A persisting qualitative motor disorder appearing before the age of three years, due to a non-progressive interference with development of the brain."

Added key elements: persistence, non-progressiveness, developmental brain disturbance, and onset before 3 years of age.

4 — 1964

Bax MCO
Dev Med Child Neurol

"A disorder of movement and posture due to a defect or lesion of the immature brain."

Provided a concise, internationally applicable definition; emphasized movement and posture and the immature brain as underlying substrate.

5 — 1992

Mutch L, Alberman E, Cans C et al.
Dev Med Child Neurol

"An umbrella term covering a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of its development."

Highlighted heterogeneity and "often changing" course; reinforced early developmental origin and the non-progressive nature.

6 — 1998

Badawi N, Watson L, Petterson B et al.
Dev Med Child Neurol

"Cerebral palsy is a term of convenience applied to a group of motor impairments caused by non-progressive brain injury or malformation during the early stages of development."

Emphasized CP as a construct used for surveillance and research; need for standardization to monitor trends and compare populations.

7 — 2000

SCPE Collaborative Group
Dev Med Child Neurol

Five core elements:

1. Disorder of movement and posture
2. Non-progressive
3. Arising in the early stages of development
4. Not due to other conditions
5. (Epidemiological) stability over time

International consensus on five epidemiological core elements for CP; provided a harmonized definition for surveillance across Europe.

8 — 2007

Cans C, Dolk H, Platt MJ et al. (SCPE)
Dev Med Child Neurol

"A group of permanent disorders of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain."

Emphasized permanence and activity limitation; confirmed early developmental origin; operational definition for SCPE registers.

9 — 2018

Schiariti V, Fowler E, Brandenburg JE et al.
Dev Med Child Neurol

Operationalized the 2007 SCPE five-core-element definition for use in research. Developed CP-specific Common Data Elements (CDEs) to standardize data collection in clinical research.

Created a common data language (CDEs) for CP research to improve study efficiency, data quality and comparability across studies.

10 — 2025

Dan B, Rosenbaum P, Carr L et al.
Dev Med Child Neurol

"An early-onset, lifelong neurodevelopmental condition that affects movement and posture, and activity limitation."

Conceptual shift: CP as a lifelong neurodevelopmental condition; recognized heterogeneity, participation and life-course perspective.

11 — 2026

Jiang W, Zhu D, Tang X et al.
BMJ Paediatrics Open

Three diagnostic pillars:

1. Brain injury from embryonic period through age 3
2. No regression of motor milestones through age 5
3. Genetic factors integral to pathogenesis; may classify as "CP due to genetic variation"

Operationalized diagnostic criteria with explicit age boundaries and integration of genetics into the CP definition and classification.

12 — 2026+

Ongoing evolution
Future directions

- Further refinement with emerging evidence
- Greater inclusion of lived experience
- Harmonization across global contexts
- Focus on participation, inclusion and quality of life

CP definition and classification will continue to evolve with advances in science, society and global collaboration.

Overall evolution: From early clinical observation → to a neurological description → to operational epidemiological criteria → to a multidimensional, life-course neurodevelopmental condition that integrates function, participation, genetics and lived experience.

National Spastics Society

4th International Study group Child Neurology and Cerebral Palsy

Oxford 1964

4 **1964**

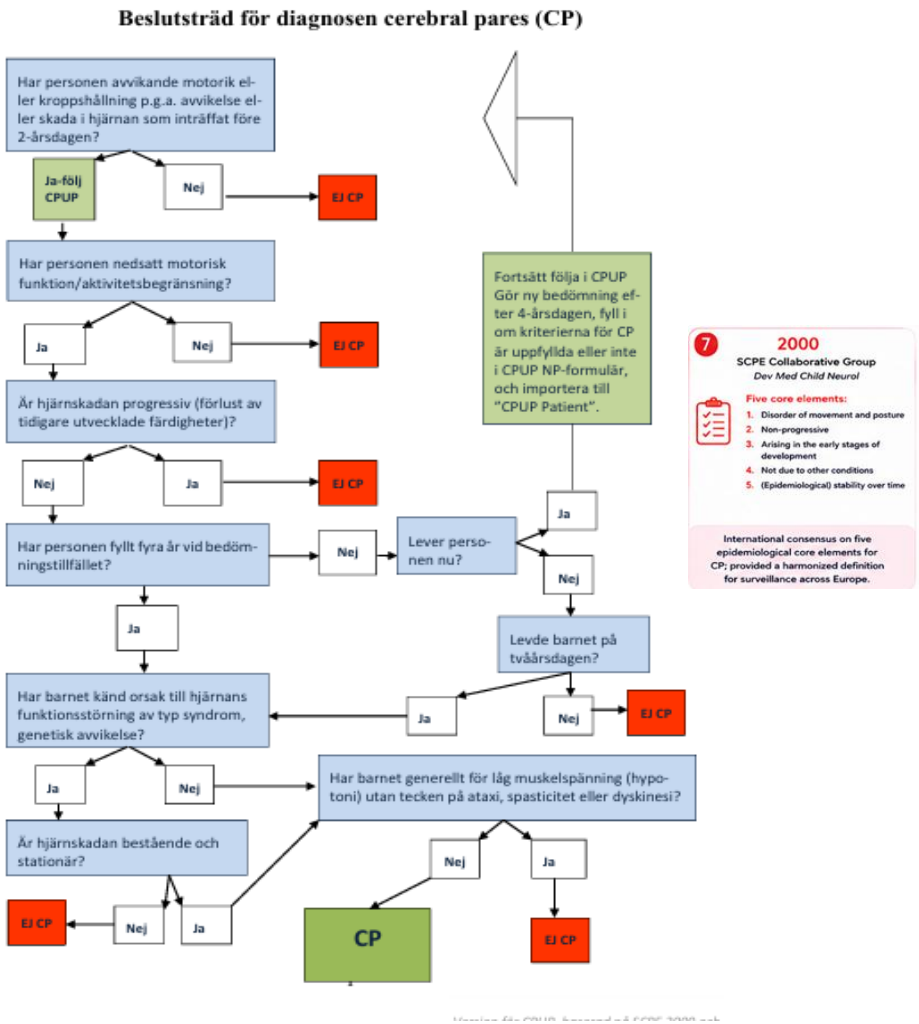
Bax MCO

Dev Med Child Neurol

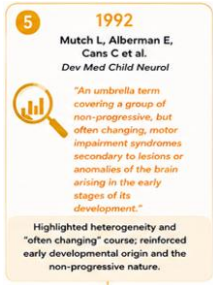
"A disorder of movement and posture due to a defect or lesion of the immature brain."

Provided a concise, internationally applicable definition; emphasized movement and posture and the immature brain as underlying substrate.

Vad använder vi i Sverige?



Mutch L, Alberman E, Hagberg B, Kodama K, Perat MV: Cerebral palsy epidemiology: where are we now and where are we going?. Dev Med Child Neurol. 1992, 34: 547-551.



Cans Prevalence and characteristics of children with cerebral palsy in Europe. Dev Med Child Neurol. 2002 Sep;44(9):633-40. PMID: 12227618.

Rosenbaum P, Paneth N, Leviton A, Goldstein M, Bax M, Damiano D, Dan B, Jacobsson B. A report: the definition and classification of cerebral palsy April 2006. Dev Med Child Neurol Suppl. 2007 Feb;109:8-14. Erratum in: Dev Med Child Neurol. 2007 Jun;49(6):480.

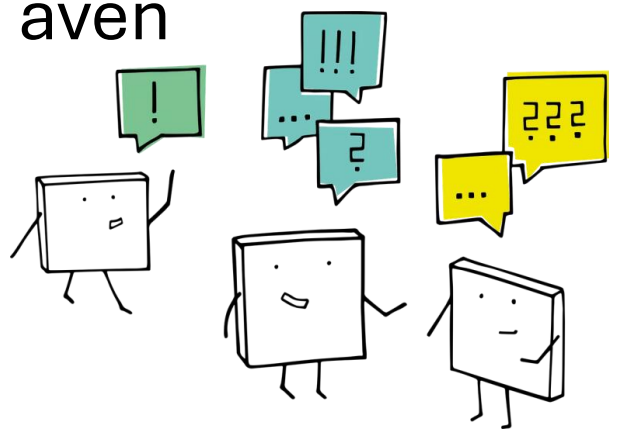
Arbetet bakom den uppdaterade beskrivningen av cerebral pares

- Denna definition ville man uppdatera:
- *Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbance of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder. (Rosenbaum 2007)*

Ett 40-tal grupper och organisationer globalt, plus enskilda personer som bidrog i processen.

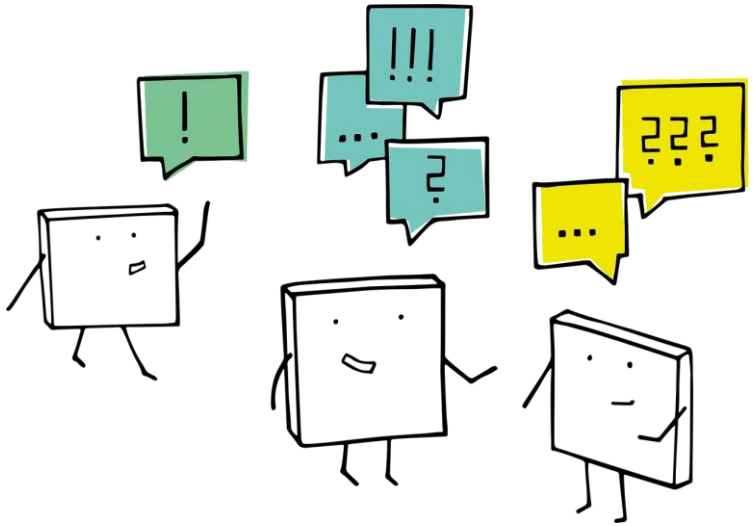
Enighet

- Begreppet cerebral pares ska vara kvar, inklusive förkortningen CP
- Beskrivningen ska betona livserfarenheter hos personer med CP och de olika utmaningar som finns
- Att se CP utifrån funktion och social delaktighet snarare än som motorisk nedsättning
- Livslångt tillstånd
- Beskrivningen ska vara relevant för alla omgivningar, även områden/länder med begränsade resurser



Oenighet

- Ska det vara en definition eller en beskrivning?
- Mätbarhet, diagnostik och behandling?
- Åldersgräns för orsak?
- Inkludera mer än motorisk nedsättning i beskrivningen?
- Är CP-typer viktigt?
- Hypoton CP?
- Ordval…



Den nya beskrivningen av cerebral pares

- Cerebral palsy (CP) is an early-onset lifelong neurodevelopmental condition characterized by limitations in activity due to impaired development of movement and posture, manifesting as spasticity, dystonia, choreoathetosis, and/or ataxia.
- It results from maldevelopment attributed to dysplasia of or injury to the fetal or infant brain that is not degenerative, although the manifestations may change with age.
- The **phenotype** of CP is complex and heterogeneous, with each person experiencing a unique presentation.
- In addition to motor dysfunction, people with CP frequently encounter primary and secondary impairments across various areas of development and functioning, which can significantly impact their participation in daily life.

Ur den nya beskrivningen av CP

Phenotype

- This refers to the characterization of observable features that can relate to clinical knowledge and serve its methodology. Careful phenomenological observation of the phenotype is the only way to make a clinical diagnosis of CP (there are no pathognomonic features), and it provides a base for pathophysiological reasoning to tentatively explain observed features by known physiology and, where applicable, gene function.

Funktionsnedsättningar

Primary

- directly from the same aetiology as the one causing the motor manifestations.
- epilepsy can be seen as a manifestation of cortical dysplasia or injury.
- visual impairment, which can be attributed to white matter injury along the thalamo- occipital radiations

Secondary

- consequences of motor impairment or activity limitations that restrict learning and perceptual developmental experiences

New description of cerebral palsy

- Cerebral palsy (CP) is an early-onset lifelong neurodevelopmental condition characterized by limitations in activity due to impaired development of movement and posture, manifesting as spasticity, dystonia, choreoathetosis, and/or ataxia. It results from maldevelopment attributed to dysplasia of or injury to the fetal or infant brain that is not degenerative, although the manifestations may change with age. The phenotype of CP is complex and heterogeneous, with each person experiencing a unique presentation. In addition to motor dysfunction, people with CP frequently encounter primary and secondary impairments across various areas of development and functioning, which can significantly impact their participation in daily life.

Google translate…

Cerebral pares (CP) är ett tidigt debuterande livslångt utvecklingsneurologiskt tillstånd som kännetecknas av begränsningar i aktivitet på grund av försämrad utveckling av rörelse och hållning, vilket visar sig som spasticitet, dystoni, koreoatetos och/eller ataxi.

Det är ett resultat av störningar utvecklingen som tillskrivs dysplasi i eller skada på fostrets eller spädbarnets hjärna som inte är degenerativ, även om manifestationerna kan förändras med åldern.

Fenotypen av CP är komplex och heterogen, där varje person upplever en unik presentation. Förutom motorisk dysfunktion har personer med CP ofta primära och sekundära funktionsnedsättningar inom olika utvecklings- och funktionsområden, vilket avsevärt kan påverka deras delaktighet i det dagliga livet.

Plain language description

People living with cerebral palsy have a complex physical disability that makes their muscles unusually stiff and affects their movements. Cerebral palsy is caused by early damage to a part of the brain, which does not get worse in itself but whose consequences become more severe over time. Each person with cerebral palsy is unique and, while all have some degree of physical disability, many face additional learning, communication, visual, or other challenges.

With the right resources, therapies, and support from family, people with cerebral palsy can thrive and live fulfilling lives.

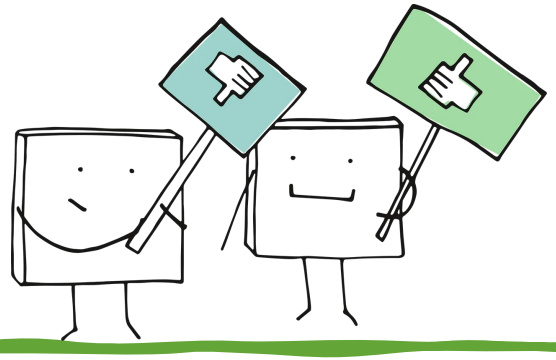
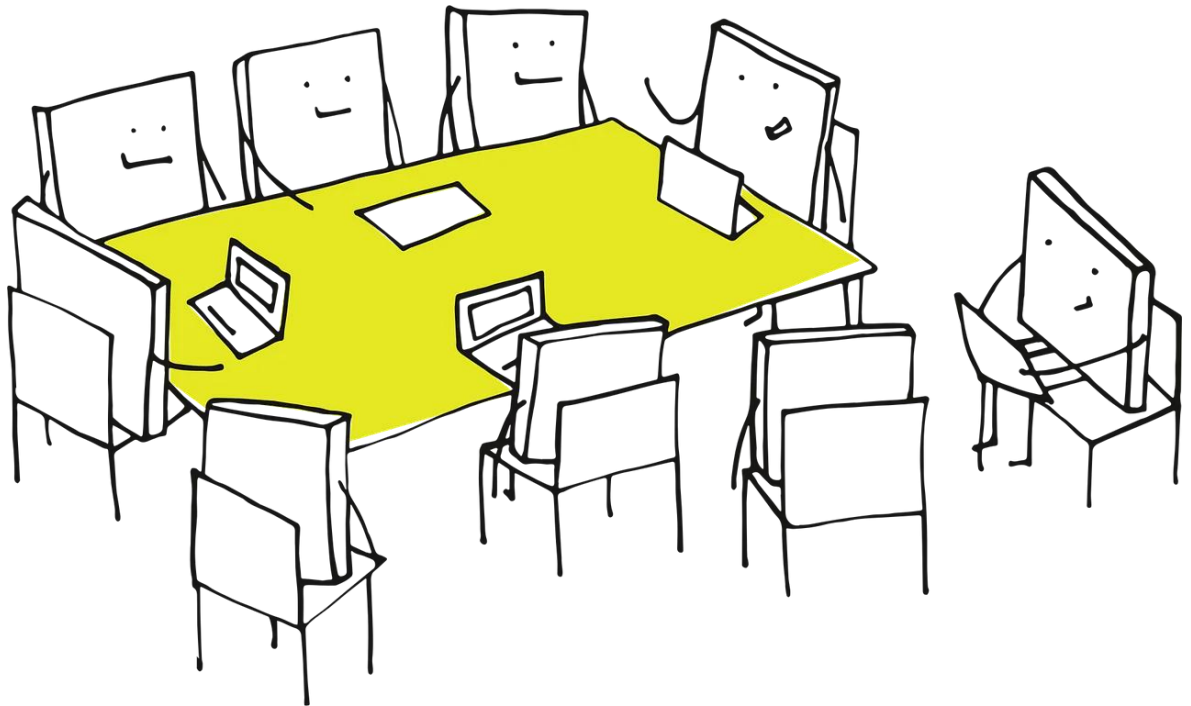
Google translate…

- Personer som lever med cerebral pares har en komplex fysisk funktionsnedsättning som gör deras muskler ovanligt stela och påverkar deras rörelser. Cerebral pares orsakas av tidig skada på en del av hjärnan, vilket inte förvärras i sig självt men vars konsekvenser blir allvarligare med tiden. Varje person med cerebral pares är unik och även om alla har någon grad av fysisk funktionsnedsättning, möter många ytterligare utmaningar vad gäller inlärning, kommunikation, syn eller andra problem.
- Med rätt resurser, behandlingar och stöd från familjen kan personer med cerebral pares blomstra och leva meningsfulla liv.

Kortversionen…

Cerebral palsy is a heterogeneous neurodevelopmental condition beginning in early life, caused by a non-degenerative brain disturbance that affects motor abilities and often other aspects of functioning across the lifespan

Blir det någon skillnad?



- För personer med cerebral pares?
- För professionerna?