

# elsass fonden

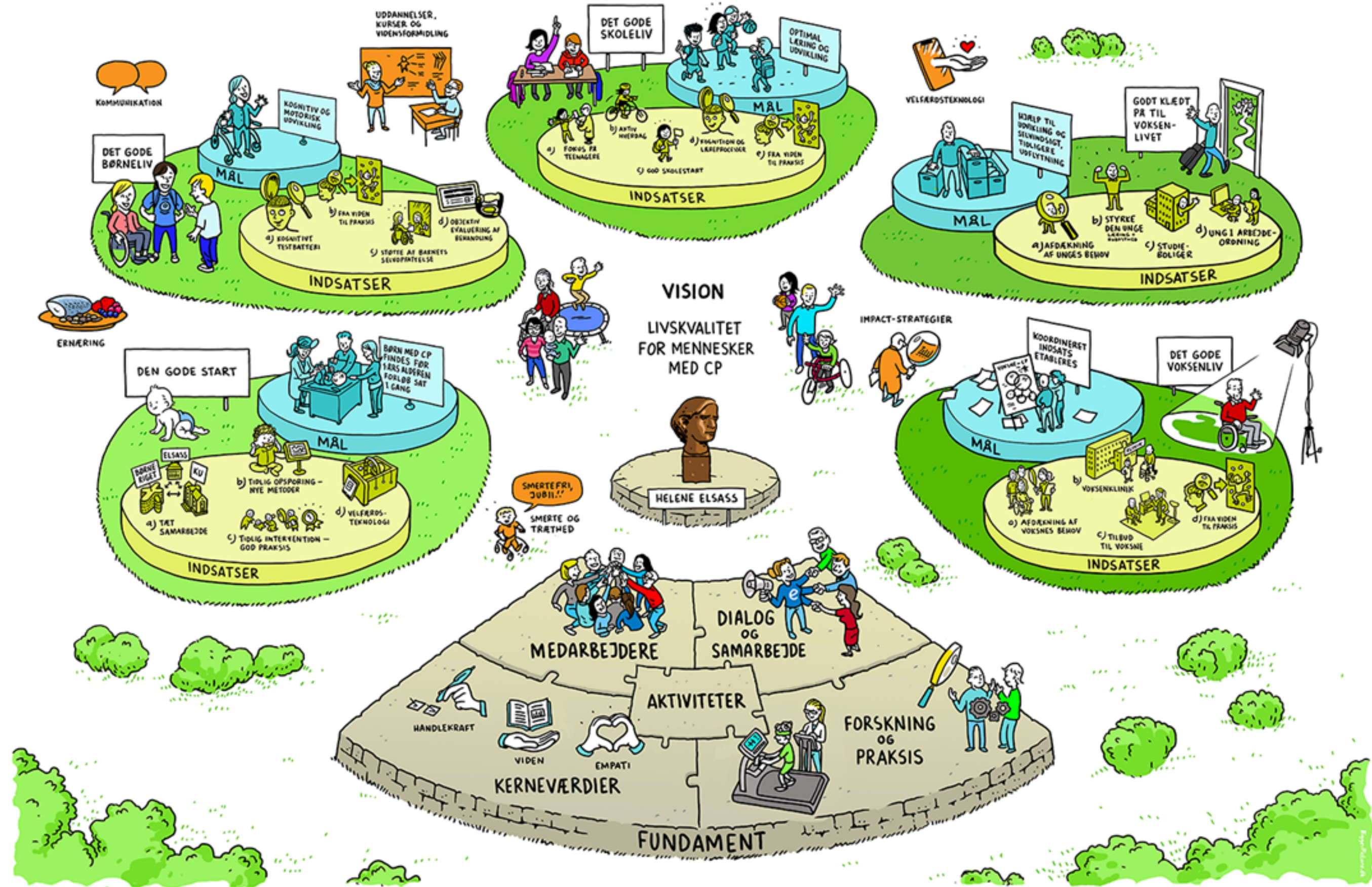
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# Livsrejsen

Strategi 2019-2025





# Ny administrerende direktør

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- Jacob Hübertz







## Uglemose, Charlottenlund

Elsass Fonden købte Uglemose i 2004 og foretog en nænsom modernisering, hvor man blandt andet tilføjede en ny fløjbygning med handicapvenlige lejligheder til kursister.

## Elsass Vest, Kolding

Åbningen af Elsass Vest i november 2023 markerede mange års ambition om at være mere fysisk tilgængelig for mennesker med CP i Vestdanmark. I dag har fonden fire medarbejdere ansat i Kolding.









# Status - 2023

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- **Personlige legater**

**1301 stk. 15. mio. DKK**

- **Forskningslegater**

**11 stk. 9,8 mio. DKK**

- **Projektlegater**

**135 stk. 79 mio. DKK**

# Jubilæumslegat

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I anledningen af Elsass Fondens 50-års jubilæum åbnes der op for en særlig pulje af legatmidler. Puljen er målrettet sociale initiativer til gavn for mennesker med CP i hele Danmark.

- Involverer mindst 5 mennesker med CP og/eller pårørende
- Understøtter aktiv deltagelse og socialt samvær
- Er nytænkende og kreativ
- Understøtter fællesskaber – om muligt gerne blivende
- Forankres i en eller flere foreninger, klubber, organisationer eller lignende og gerne i et samarbejde på tværs (kræver CVR-nummer at ansøge)
- Ikke overstiger 100.000 kr.

Deadline for ansøgning  
den 7.11.2024





# Podcast i samarbejde med CP DK

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# Tour de Elsass

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# Oversættelser - i proces

Forbedring af fysisk funktion hos børn og unge med CP: Internationale anbefalinger for klinisk praksis

DEVELOPMENTAL MEDICINE & CHILD NEUROLOGY

CLINICAL PRACTICE GUIDE

## Interventions to improve physical function for children and young people with cerebral palsy: international clinical practice guideline

MICHELLE JACKMAN<sup>1,2</sup> | LEANNE SAKZEWSKI<sup>1</sup> | CATHERINE MORGAN<sup>3</sup> | ROSLYN N BOYD<sup>1</sup> | SUE E BRENNAN<sup>4</sup> | KATHERINE LANGDON<sup>5</sup> | RACHEL A M TOOVEY<sup>6</sup> | SUSAN GREAVES<sup>7</sup> | MEGAN THORLEY<sup>8</sup> | IONA NOVAK<sup>3,9</sup>

### Interventions to improve functional outcomes in cerebral palsy BEST PRACTICE PRINCIPLES

When working with children and young people with cerebral palsy who have functional goals, the following best practice principles are recommended, with the aim of maximising functional outcomes.

- Client chosen goals should be set**  
Intervention should begin with understanding what is important to the child's goals that focus on improving the child's participation in those activities. Go meaningful and achievable within a short timeframe. A written copy of goal goals should be measured at the beginning and at end of the intervention.
- Factors limiting goal achievement should be determined**  
Clinicians should observe the child attempting the goal to determine factor achievement. This may include a discussion about when and where the child the activity, and consideration of aspects of the task and environment that
- Intervention should include direct practice of the whole goal**  
Active practice of the child's goal should be the focus of intervention, rather underlying impairments. This includes the clinician taking a 'hands-off' appr feedback to support the child to successfully carry out their goal.
- Intervention should be enjoyable and motivating for the child**  
Intervention should be enjoyable and motivating for the child and challenge improves. Interventions that are painful or distressing should be modified ; interventions be considered.
- Practice of goals should occur within the home and community**  
Achievement of the goal is more likely to be carried over into every day life real life environments. When this is not possible, intervention should be ad reflects the environments and resources relevant to the child's goals.
- Parent-delivered intervention is a key component of all intervention**  
Clinicians should provide information and coach families to be actively engi intervention. A structured home program adapted to suit each individual, o support and reviews will maximise practice outside of therapy sessions.
- Children and parents should be empowered to make decisions**  
Clinicians should share their knowledge with families and provide up to dat families to make informed decisions about interventions. Clinicians should child and recommend only feasible, effective interventions that are support
- A high enough dose of practice should be planned for goal achievement**  
It is important to consider how much practice will be needed to achieve go families to plan for how the amount of practice needed can be achieved. Ce require a higher dose of practice and it is important to consider this when i
- A team approach should be used**  
A team approach (with the child and family as part of the team) to setting g planning is recommended. Clinicians/providers communicating effectively ; common goals can reduce the pressure on families.

### Interventions to improve functional outcomes in cerebral palsy SETTING FUNCTIONAL GOALS Guidelines for clinicians working with children and young people

Setting meaningful goals is best practice when working with children and young cerebral palsy. Intervention should begin with setting client-centred, functiona the focus of intervention.

#### GOALS SHOULD BE ...

##### CHOSEN BY THE CLIENT

Time should be spent understanding what is important to the child, and set that focus on improving the child's ability to participate in activities that ar them. If the child is unable to identify or articulate their own goals, familie encouraged to set goals considering the child's preferences and interests. If do not identify goals, therapists may support goals that focus on improving

##### FUNCTIONAL

Functional goals are goals that reflect real-life tasks such as the ability to g put a t-shirt on or ride a bike. Functional goals are not goals that focus on u impairments such as improving strength, sensory processing or joint range. to break down long-term goals into smaller, more achievable functional go

##### SPECIFIC

Goals should be specific, measurable, achievable, realistic and timely (SMART) well-defined, incremented according to the child's ability and progress. A re within which goals may be achieved should be set. A plan for how the goals important consideration when setting achievable goals.

##### SET AS A TEAM

When children are engaged with multiple health professionals it is importa plan for intervention as a team, with the child and family as active member Setting a small number of team goals (2-4) means that practice can be targe and the child and family are less likely to feel overwhelmed with the numb recommendations being made.

##### AFTER GOALS HAVE BEEN SET ...

- A plan for how the goals may be achieved should be collaboratively set with the child and family
- A copy of the goals should be given to the family. This should include the timeframe within which goals will be reviewed
- Goals should be measured at the beginning and the end of the intervention, using tools such as the Canadian Occupational Performance Measure or Goal Attainment Scale. Goals should be reviewed regularly to ensure they remain relevant to changes in the child's preferences and abilities.

### Interventions to improve functional outcomes in cerebral palsy EMPOWERING CHILDREN AND FAMILIES Guidelines for clinicians working with children and young people with CP

When working with children and young people with cerebral palsy, it is important for clinicians to connect with families, consider individual needs and preferences and empower families to feel that they have the skills and knowledge to support their child.

#### CONNECT

Building a collaborative relationship with children and families is key to ef intervention. Families know their child better than anyone else and should experts in their child's care.

Listening, understanding individual family needs and preferences, and bui collaborative relationship leads to families being more likely to follow thro recommendations, which in turn leads to better outcomes for the child.

#### SHARE KNOWLEDGE & EVIDENCE

Clinicians should proactively provide children and families with up to date evidence and intervention options to enable families to make informed decisions about which intervention best suits their child and family. Interventions that research suggests are not suitable for the child, based on their age, ability or diagnosis should be discouraged, as should interventions that have been shown to be ineffective.

Families of younger children may appreciate information regarding developmental and pr trajectories in children with cerebral palsy. This information should be delivered using pos that focusses on the potential of the child.

Information can be overwhelming for some families. Adapt the amount of information you according to what suits the individual child and family.

#### EMPOWER SELF PRACTICE

Practice at home has been shown to be the most effective way to achiev families are provided with knowledge, resources and ongoing support. C seek to ensure families are confident practicing goals outside of the the including assisting families to access any services and equipment they r Clinicians can use a coaching approach to empower children and familie can face new challenges and attempt new goals, without necessarily rely support this process.

#### ADAPT TO INDIVIDUAL NEEDS & PREFERENCES

Intervention should focus on direct practice of the child's goals. A plan for how and when practice can happen should be made collaboratively with the child and family to ensure the plan is feasible and acceptable to the child and family. How much practice is needed will vary depending on the child and the complexity of the goal.

Intervention should be enjoyable and motivating for the child and challenging enough that the child improves. Interventions that are painful or distressing should be modified and alternative interventions be considered.

### Interventions to improve functional outcomes in cerebral palsy KEY STEPS TO EFFECTIVE INTERVENTION Guidelines for clinicians working with children and young people with CP

When a child or young person with cerebral palsy has a functional goal, there are a number of steps that are recommended for clinicians to carry out in order to maximise outcomes.

- SET CLIENT CENTRED GOALS**  
The first step in best practice intervention is to set goals that are meaningful to the child. Goals should be related to real life activities. Goals should be realistic and achievable within a short timeframe (they may work towards longer term goals). Direct practice of these goals should then be the focus of the intervention, rather than attempting to address underlying impairments or skills.
- OBSERVE CHILD CARRYING OUT GOAL**  
Clinicians should observe the child attempting the goal to determine factors limiting goal achievement. This may include a discussion about when and where the child needs to or wants to participate in the activity. There may be aspects of how the child is carrying out the task, or components of the task or environment that can be addressed to facilitate goal achievement.
- PRACTISE THE WHOLE GOAL**  
Therapy is most likely to lead to goal achievement when the focus of the intervention is direct practise of the goal, rather than addressing underlying impairments. If practice of the whole goal is not possible, part task practise can be undertaken in order to work towards practise of the whole goal.
- PRACTICE IN REAL LIFE SETTINGS**  
Practise of the goals should occur within the child's home and/or community as there are important factors within different contexts that impact on our ability to carry out a task. This is likely to lead to the child being more confident and capable of carrying out the goal outside of the clinical setting. When practice within the child's environment is not possible, practice should occur within a setting, and using resources, that simulates the child's real life as much as possible.
- PLAN FOR ENOUGH PRACTICE**  
Research tells us that we need to practise a task many times in order to be proficient and confident. Once the child has an agreed strategy for carrying out their goal, clinicians and families should make a plan for when and where practice can happen, to ensure enough practice is undertaken for the child to achieve their goal. A home program, which reflects the child's goals and agreed plan can support this process.

### Interventions to improve function in cerebral palsy BEST PRACTICE PRINCIPLES Information for young people and families

The following recommendations have been developed by an international panel of clinicians to highlight best practice principles for children or young people with cerebral palsy who have functional goals. This information sheet aims to provide you with ideas based on current research. These ideas can be discussed with the clinicians who are supporting yourself or your child to achieve your goals.



#### SETTING GOALS THAT ARE IMPORTANT TO YOU

Intervention should always begin with clinicians asking children, young people and families what is most important to them, and setting therapy goals based around these priorities.

Functional goals are related to real-life tasks and activities (such as getting dressed and riding a bike), rather than focussing on underlying movements or impairments (such as increasing elbow range of motion).

Small, achievable goals should be set and all members of the team should have a copy of the goals so that everyone is working towards common goals.

A maximum of three goals is recommended at any one time, so that practice is achievable and children and families are not overwhelmed by trying to work on everything at one time.

#### PRACTICING THE WHOLE GOAL WITHIN REAL LIFE

When a child or young person has a functional goal, research tells us that the most effective way to achieve that goal is to practice the whole goal, rather than working on underlying movements or skills. For long term goals, this may mean setting smaller, achievable goals that work towards the long term goal.

Practicing goals within real life contexts, such as at home or school, and practicing with the equipment or objects that the child uses everyday leads to greater success

Practice outside of therapy is hard work for families, but in order for goals to be achieved, practice needs to occur more regularly than just during therapy sessions.

Talk to your team about how much practice is likely to be needed. Together, come up with a plan for when and where this practice can realistically happen for your family. Consider supports that may be able to help with this plan, such as friends, siblings, school or extended family members.



#### WORKING TOGETHER AS PART OF A TEAM



Clinicians should share their knowledge about evidence-based intervention options that are appropriate for you/your child based on their abilities and goals. This will enable you to make informed decisions about which intervention suits you best. Some interventions may not be appropriate for you/your child at that time, and clinicians can help you understand why that is. Families should be given choices and flexibility around services.

Clinicians working with you/your child should collaborate as a team, with your family included as an integral part of the team.

Clinicians communicating effectively around current priorities and intervention plans can ensure everyone is working towards common goals and reduce the burden on families around coordinating services.

Artiklen kan findes med fri adgang Informationsark kan findes frit tilgængeligt på engelsk her: <https://cerebralpalsy.org.au/cerebral-palsy/guidelines-to-improve-function-in-cerebral-palsy/>

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# Oversættelser - i proces

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*Eating and Drinking Ability Classification System - MiniEDACS*





# Tilbud

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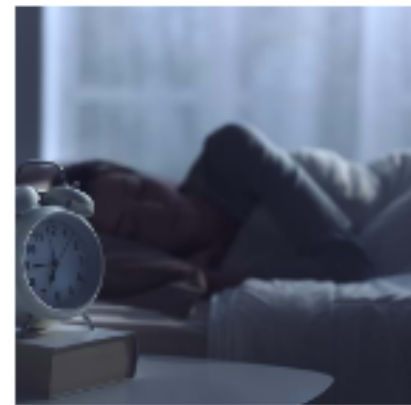
## Faglig sparring (online)

TILMELDING ÅBEN

Arbejder du med børn og unge med cerebral parese? Få sparring om det, som fylder i dit arbejde.

LÆS MERE ›

31  
OKT  
2024



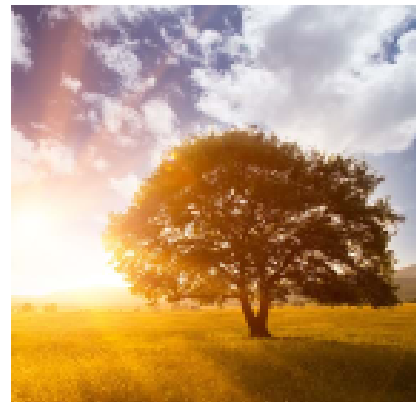
## Webinar: Vågn op til vigtigheden af søvn

TILMELDING ÅBEN

Lær, hvorfor søvnhåndtering spiller en stor rolle i rehabiliteringen af mennesker med CP.

LÆS MERE ›

21  
SEP  
2024



## Kursus i mental sundhed og meditation

TILMELDING LUKKET

Oplever du stress i hverdagen? Deltag i et videnskabeligt baseret online-kursus til forældre med børn med cerebral parese.

LÆS MERE ›

18  
MAR  
2024



## Mestring af forælderrollen (løbende optag)

TILMELDING ÅBEN

Er du forælder til et barn med CP i alderen 10 mdr. til og med 4 år? Så kan du tilmelde dig et mindre psykologforløb.

LÆS MERE ›



# Pre- og post-natal detektion af cerebral parese: Ethiske implikationer og overvejelser

## International (non-consensus) symposium

### Spørgeskema

- Fagfolk/forskere
- Forældre
- Mennesker der lever med CP 18+

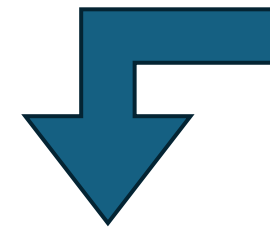
Temaer med størst uenighed vil danne grundlaget for spørgsmål til fokusgrupperne.



### Fokusgrupper

- Fagfolk/forskere
- Forældre
- Mennesker der lever med CP 18+

Skal give en kvalitativ forståelse af spørgeskema besvarelserne.



### Internationalt (non-konsensus) symposium 27. – 28. januar 2025

#### Temaer

- Weighing the risks of harm in the NICU
- Early diagnosis or early prediction? How much to say when we are not certain?
- Dealing with false positives in an age of AI and screening
- New therapies. To do, or not to do? Do they work?
- Identifying risk factors in the mother and the fetus
- Prenatal treatment
- Voices of the parents and people living with CP



# Etiske aspekter af: Tidlig diagnostik af CP før og efter fødslen samt tidlig indsats

Til jer der **lever med CP** og er over 18 år, **forældre** til børn og voksne med CP samt **fagfolk/forskere** der arbejder med børn eller voksne med CP.

Hjælp os med at blive klogere!

Internationalt har der de seneste år været fokus på at nedsætte diagnosticeringsalderen for børn i risiko for CP. Nye teknologier har gjort det muligt at opspore fund, der kan være medvirkende til CP (også kaldt risikofaktorer) allerede før fødslen. Derfor er der i dag et større behov for at blive klogere på de etiske problemstillinger og dilemmaer, som knytter sig til diagnostik af CP og den tidlige indsats.

På den baggrund har Elsass Fonden igangsat en spørgeskemaundersøgelse, hvor vi har brug for jeres besvarelser. Det er ikke en forudsætning, at du tidligere har beskæftiget dig med diagnosticering af CP, tidlige indsatser eller med etik. Vi ønsker os en bred forståelse og indsigt i dine tanker om emnet. Spørgeskemaet kan færdiggøres på ca. 10-15 minutter - alt efter hvor lang betænkningstid, man har brug for.



# Etiske aspekter af: Tidlig diagnostik af CP før og efter fødslen samt tidlig indsats

For:

Mennesker der lever med CP.

<https://www.survey-xact.dk/LinkCollector?key=TYFXEU58UP35>



For:

Forældre til børn og voksne med CP.

<https://www.survey-xact.dk/LinkCollector?key=CPVYK6ELUN9N>



For:

Klinikere og forskere der arbejder med mennesker med CP eller forsker i diagnosen.

<https://www.survey-xact.dk/LinkCollector?key=M5R72Z77U2C5>





# Tak for jeres tid