



‘Together against tension.’

INVOLVING PARENTS IN THE CARE OF PERSONS WITH CP

KATLEEN DETLOFF

PARENT INITIATIVES

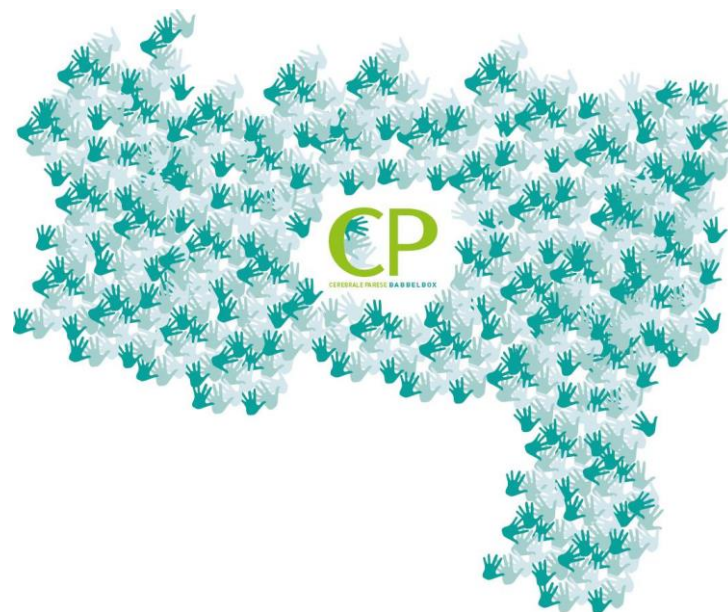
IEvzw/CPinfo

Katleen Detloff



CP Babelbox

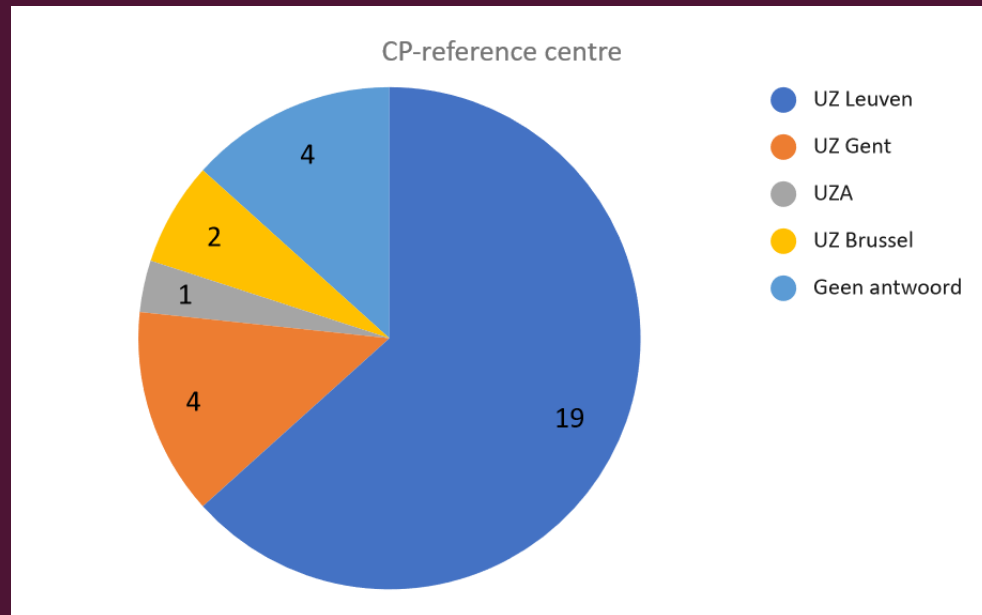
Yannic Verhaest/Katleen Detloff



CP Oudercafé

Mia Maes





SURVEY

- Survey CP Babelbox
- 8 questions
- 30 respondents
- Not all questions have been answered

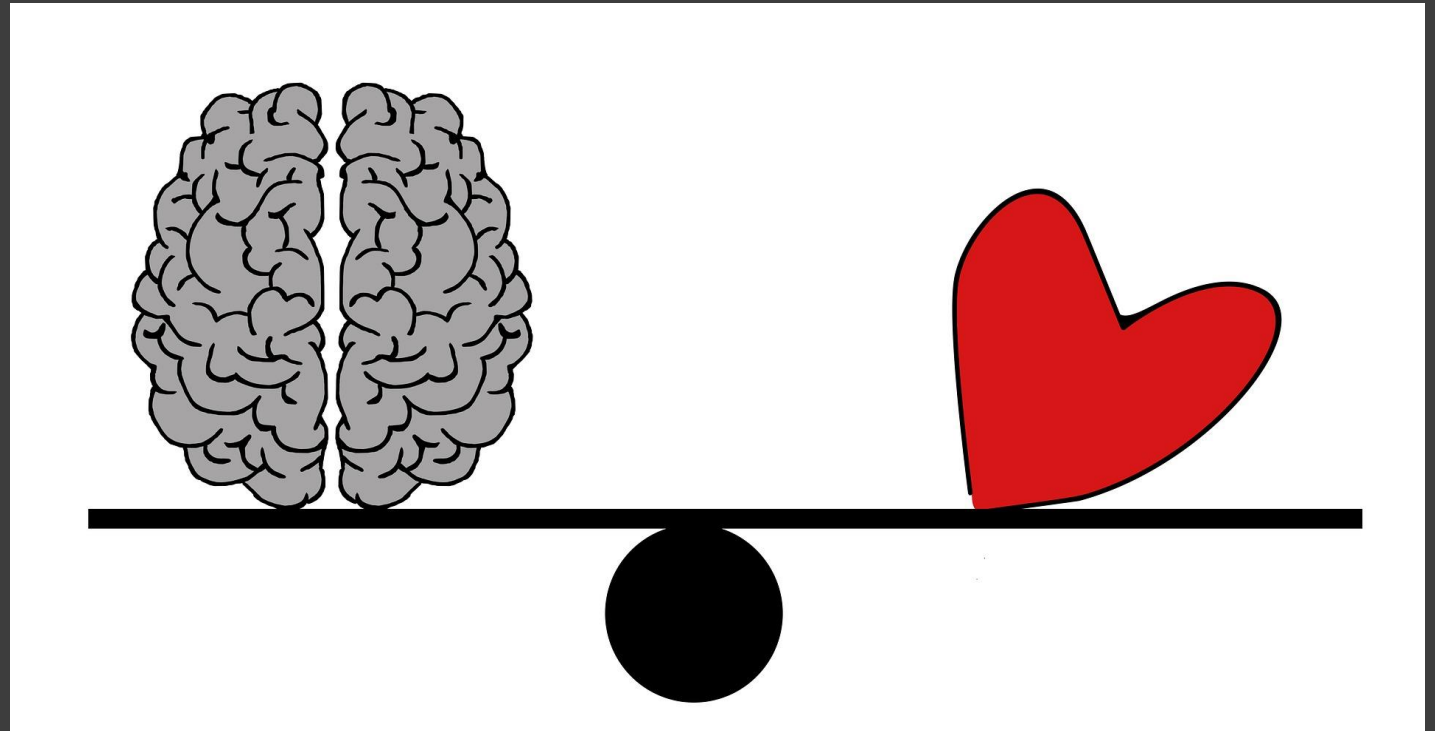


INTERVIEW I - KIM

HAVING A CHILD WITH CP, WHAT DOES IT MEAN?



TENSION I



INFORMATION

Parents are in
need for
information

Parents can offer
information
about their child.

INFORMATION

- Parents are in need for:
 - **Information about CP**
 - **Information where to find help with questions, emotions,...**
 - Contact with other parents
 - Administrative help (VAPH, Team ZOE,...)

INFORMATION

Giving information is always tailor-made.

What are the needs?

Proactively provide information

- Refer to websites with information
- Refer to peers / fellow sufferers
- Make sure parents and children have a single point of contact

Open for help/expertise, looking for the best!

INFORMATION

- Parents can offer:
 - Information about their child, know their child the best
 - Knowledge about their family situation.
 - Have information from other care givers (school, family, therapists,...)

Open for help/expertise, looking for the best!



INTERVIEW 2 – SIGRID

WHAT WERE THE TOUGH MOMENTS FOR YOU AS A PARENT?



TENSION 2



RESILIENCE

What is the expectation for the child?

Where is the bar set?

How do you assess the family's
resilience?

RESILIENCE

CP – complex condition – request for help is broad.

- Parents are busy fitting the child's care into family life.
- Parents have their own values/priorities about raising children. They may have very different views on how high they set the bar for their children.

Parents think and act very differently. Talk honestly about everyone's side of the story.

Recognize that parents often have many other questions besides questions about their child's health status.

RESILIENCE

Not only the care, but also the daily fight.

Fight for recognition, acceptance, understanding, inclusion, well-being, administrative burden.

Sometimes parents are vulnerable, overburdened, overprotective,...

Support them as much as possible.

High need practical and emotional support with the aim of adapting to the special situation and finding a balance.

Attention to self-care, well-being. Create a team to keep on caring for the child.

They have to do it!

RESILIENCE

As a child, you largely undergo what is imposed on you/what your parents and/or others decide for you. You have little control or little to say in it yourself or you don't consciously think about it yet. As a child, you take all experiences, both the good and the bad, with you into your subconscious. Between the ages of 0 and 7, you absorb everything from your environment like a sponge and only later on you begin to form your own convictions step by step. These beliefs determine how you initially view yourself, others and the world around you. Later, if necessary, you can start working with yourself.

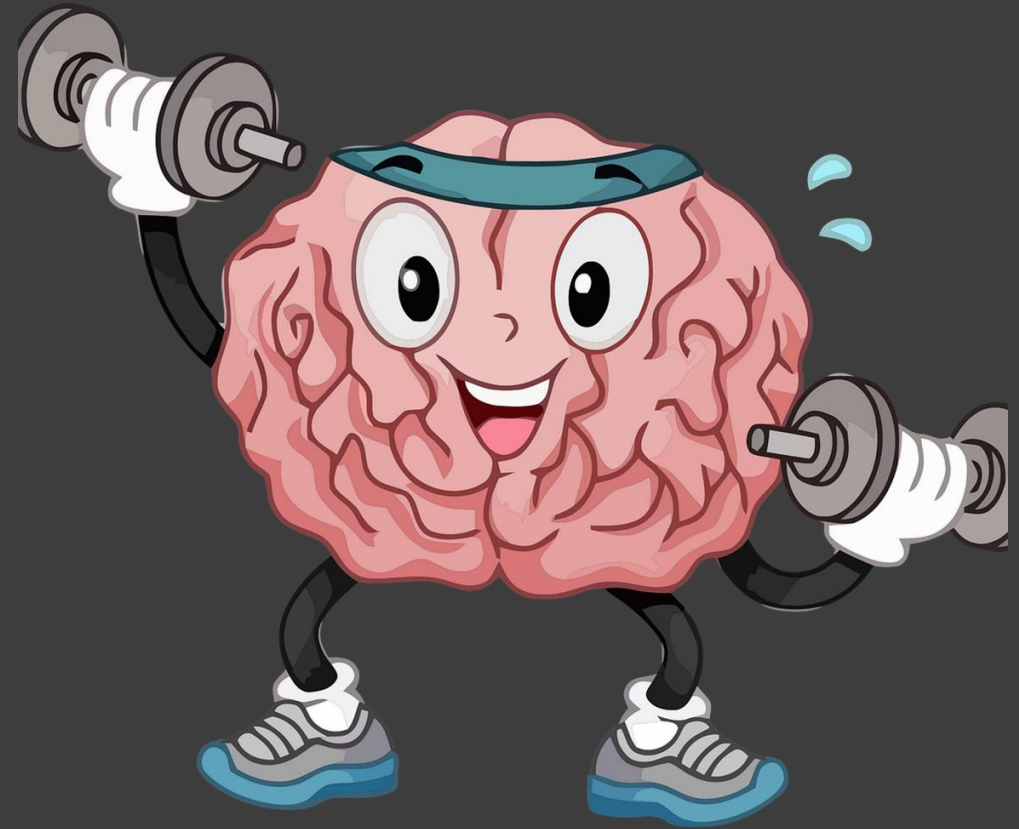


INTERVIEW 3

TO THE CONSULTATION... A PERSONAL EXPERIENCE



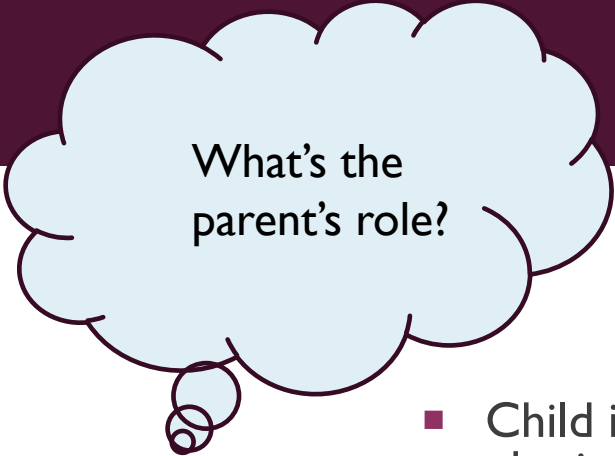
TENSION 3



MULTI- CONSULTATION

How do you ensure that all information comes together to approach the child from all the necessary disciplines?

MULTIDISCIPLINARY CONSULTATION



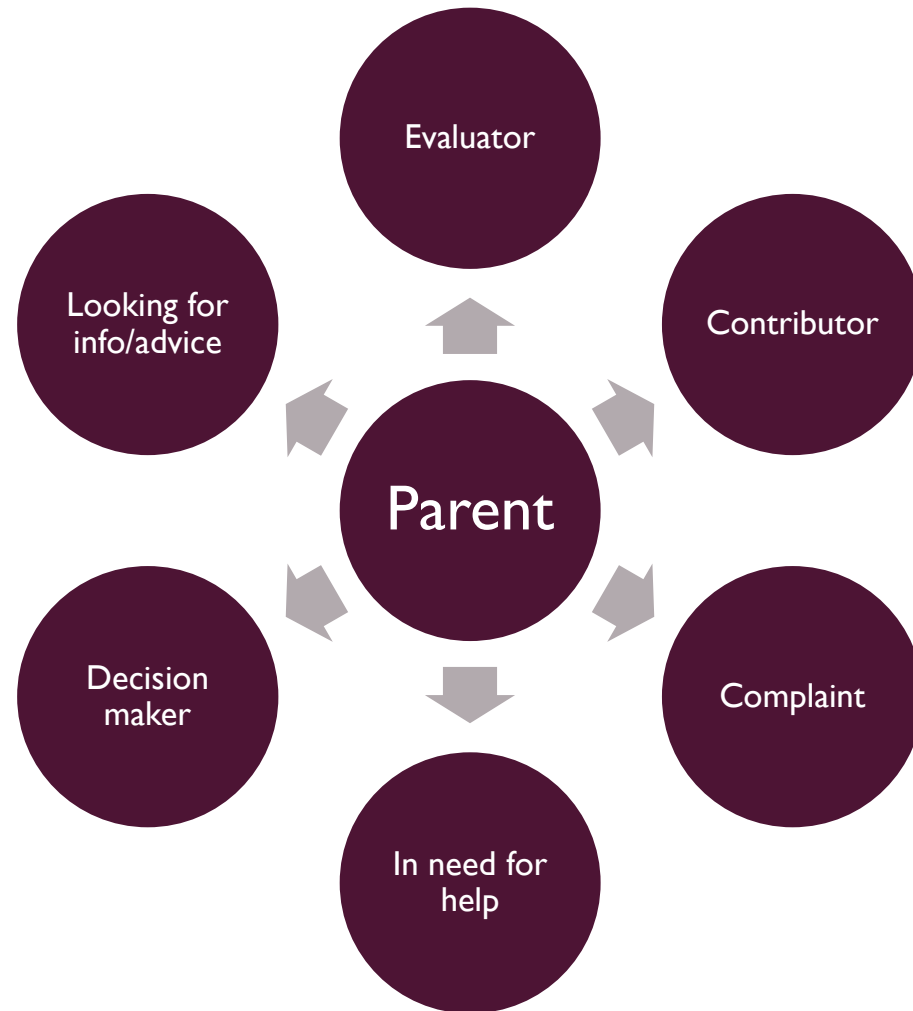
What's the
parent's role?

- Child is seen in CP-reference centre
→ Multidisciplinary follow-up
- COS
- Medical file

- Child is seen by other care givers (logopedist, physiotherapist, home support, school, boarding school,...)
- Often parents are involved in multidisciplinary follow-up meeting.
 - At school (Teacher, CLB, care teacher, class support,...)
 - BuBaO/BUSO (Teacher, therapists, social assistant, nurse,...)

Open discussion, explore options

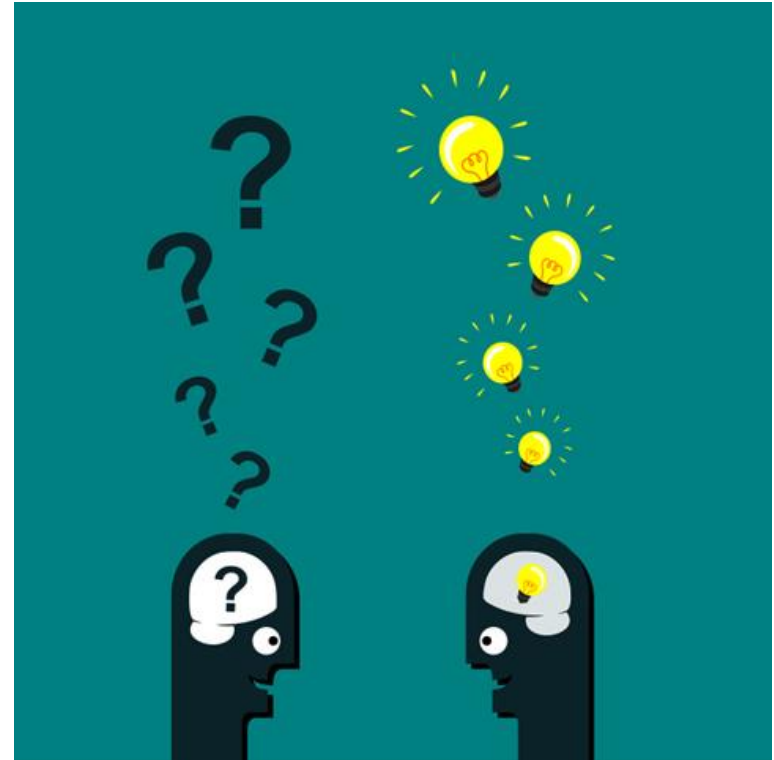
WHAT'S THE PARENT ROLE?



WHAT CAN HELP?

Preparation

- Goal of the consultation
- Who will examine the child? Sequence?
- What are the ideas / concerns / expectations?
- Questionnaires, email on beforehand
- Dossier / paperwork



WHAT CAN HELP?

Consultation

- Be prepared, be accurate
- Transparency
- Efficiency – gather around one table?
- What is feasible / what makes sense?
Alternatives?
- Speak expectations
- Be realistic - avoid disappointment
- Think in possibilities, not limitations
- Child-friendly setting, custom language
- Child always present?
- Long-term vision, what do we want to achieve together?
- Refer if needed
- Conclusion – agree on next steps

WHAT CAN HELP?

Follow-up

- Give info to parents who they can contact with remaining questions
- Follow-up on open questions
- Provide additional information on what has been discussed (folder, website,...)
- Provide correct and adequate medical letters
- Plan new appointment



SUMMARY

Well-informed parents, are more confident, more resilient and better able to think along about their child's treatment. Listen to parent's / patient's needs.

Assess child's progression versus quality of life.

Provide practical and emotional support with the aim of adapting to the special situation and finding a balance. Create a team to keep on caring for the child.

Professionals from different disciplines and parents should work together to develop a comprehensive understanding of a child's needs and strengths . Develop a shared understanding of the child's goals and priorities.

Effective communication and documentation are essential in ensuring that all information is shared between professionals and disciplines.

FUTURE?



TIPS FROM PARENTS

- **Gewoon en anders?!** geestelijke gezondheidszorg bij mensen met een beperking.

Winy Ang, Sofie Bettens, Ilse Hardy, Lieve Kiebooms, Marleen Pirotte, Veerle Verboven

- **Oog voor jou** wat ouders en professionals van kinderen met een (lichamelijke) beperking moeten weten, durven en doen.

Minke Verdonk

- **Gedrag en Emotie bij kinderen met cerebrale parese**

Tinka Bröring-Starre