

Working in families with a child with JNCL

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Juvenile Neuronal Ceroid Lipofuscinosis (JNCL)

- Formerly called Batten-Spielmeyer-Vogt
- A degenerative condition that affects all the areas of functioning:
 - vision
 - motor system
 - speech and language
 - cognitive function

We often see:

- behavioral problems and psychiatric symptoms
- epileptic symptoms

Children with JNCL have a limited life expectation.

Home based counseling in a family with a child with JNCL

- These are families that I have been counseling for many years
- During the counseling a relationship of trust with the family is created
- These are families in a very special situation
- These are families that touch me very deeply
- I feel a certain embarrassment towards these families

Very important are:

- Continuity of the care provided
- Offering proximity
- An honest answer
- Respect for the pathway the parents want to go

The period of diagnosis

- First diagnosis - second diagnosis
- The moment that the diagnosis JNCL is communicated to the parents
- The information needed from the doctors
- How to share this information

After the diagnosis: life in the family of a child with JNCL

- The diagnosis often means an end to the uncertainty
- Certainty is quickly replaced by new uncertainties
- ‘It seems as if there is no life anymore’ – ‘there is nothing more to live for’

- Bringing things into perspective:
'experience life as it is at that certain moment in time'
- Coming to an understanding about the coping strategies of the parents
- Keeping life valuable

- Children feel that they are following a special pathway
- The interaction with the environment:
 - what parents want to tell to whom
 - wanting to rely on resources
- Parents face a special task – they have to make special decisions

After a residential admission

The importance of continuity: very meaningful that the home based counsellor stays involved.

Working together at:

- How parents can take care of themselves and each other
- How parents deal with the continuous process of decreasing abilities of their child

- How parents can continue to communicate with their environment when the problems become more and more visible.

Next to the attention to continuity it is important to create the necessary conditions for the parents so they can build a bond of trust with the new setting.