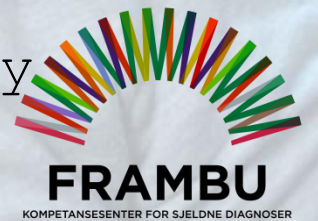


# Parents communication with a child with Juvenile Neuronal Ceroid Lipofucinosi about the diagnosis

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# Background

A person wearing a white t-shirt, light-colored trousers, and white sneakers is walking on a city street. They are using a white cane with a red tip. The background is a blurred city street with other pedestrians.

Juvenil Nevronal Ceroid Lipoficinosis (JNCL)

Norwegian laws and guidelines

Tell or not to tell

# Aims



To describe how parents communicate with their children about JNCL throughout the illness trajectory

To describe the reflections and justifications the communication choices is based upon

# Method

Semi structured interviews with 13 parents (4 fathers) of children with JNCL

Nine children in phase 3 (6-17), two in phase 4 and two in phase 5

Transcribed verbatim and analyzed with reflective thematic analysis

A close-up photograph of a woman with long dark hair, wearing a red top, kissing a young boy on the cheek. The boy is wearing a tan jacket and has a slight smile. The background is blurred, showing what appears to be a white vehicle. The text is overlaid on the image.

## Results - parental practice

*"What do you need my love, to cope  
with life  
right now?"*

# Basic understanding to empower

## **Avoid guilt**

*«We told about genetics quite early (...) That it wasn't her, but mum and dad's fault»*

## **Protect self-image**

*"I said 'You are a good skier', you know how its done. But your legs don't work anymore because of the disease'"*

## **Increase compliance**

*«I told her it's common with epilepsy, and that that medication would prevent her from having seisures»*

# About the present or the future?

## **Tell or not tell**

*«We agreed that we wouldn't tell her. She was never to know. We were to support her were she was, but never tell her about how it would become»*

## **When it appeared**

*«The strategy is to explain when things appear. With absolute honesty about things that are relevant here and now. Not about things that will happen»*

## **Answer questions**

*«If he ever asks 'did she have the same disease?' I will answer yes. If he asks 'did she die from it?' I will answer yes. If he asks 'will I die from it?' I will answer yes».*

## **Hope in words**

*"We decided to say everything, but not 'this and this will happen'. We said you may get problems with speaking and walking"*

## **Hope in religion**

*«You are going to go to heaven before us, and we will meet again there. And you will meet grandma and grandpa»*



# Communication in daily interaction

## **Seize the moments**

*«In bed in the evening he opened up. I sat with him a lot, listening to his thoughts like 'What if I fall off the latter on my way to heaven?」»*

## **Buy time**

*«Sometimes I have to say 'I need to talk with dad about that before I answer you' and then it's like 'ok, how do we answer this?」»*

*«(...) a book where they wrote or drew questions. They knew that whatever was in that book would be answered at the hospital. It provided us time to think»*



## **Results** - reflections and justifications

*Navigating through dilemmas*

Old enough and still well enough

What does a seven year old think of disease in general and how much information can be processed at a time?

At what age and illness stage are they able to search for information by themselves?

At what age and illness stage are they able to understand and ask questions?

# Protect and still give autonomy

## **Need based**

*"It's all about what you need to cope with life here and now. What is needed for you to wake up in the morning and think that there is a reason to get up"*

## **Normalize**

*"I want to talk about him, not his illness. No joy in life comes out of talking about the illness"*

## **Individualize**

*"He needed to talk about things (...). He was philosophical (...)"*. *"She was concerned about being just like other girls her age"*

# Informing others - a resource and a risk

## **Secrecy**

*«We did not tell her so we did not tell many others either.  
(...) We were always afraid that someone would talk in front of  
a child, who in turn would tell our child»*

## **Ailienation**

*«We told them...Otherwise he would end up as that strange blind  
boy. Right?»*

## **Social support**

*«It's a smart thing to ally with others. Someone that may  
talk with your child if they do not want to talk to you»*

## **Research as a push factor**

*«Ok, here are something (research) we need to participate in, to help in the process of finding a cure»*

*"You cannot expose your child (in media to get more research funding) and say that "he has this" without the child knowing"*

# A huge responsibility and lack of support

## **Betrayal**

*«They promised us help. We took the step and told the children everything and it ended well. But their promise did not mean anything as we have not been able to reach them since»*

## **Coercion**

*«The physician was so angry with me because I did not tell my daughter that she was going to die. He said it was her right»*

## **Peer pressure**

*«It hurts when people say 'this is the way you should do it'. It's scary to say that 'we have done differently, the exact opposite of you. And that was right way as well'»*


# Conclusion

The communication dilemma is not as simple as «sharing or not sharing»

Don't just give advice - get involved in the process!

A nuanced approach, minding aspects of the disease, personality, family environment, culture and context is important





Thank you!

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