

Rare Diseases Denmark



**Navigators helps
PLWRD manage**

Project manager Stephanie Jøker Nielsen, Rare Diseases Denmark



The project

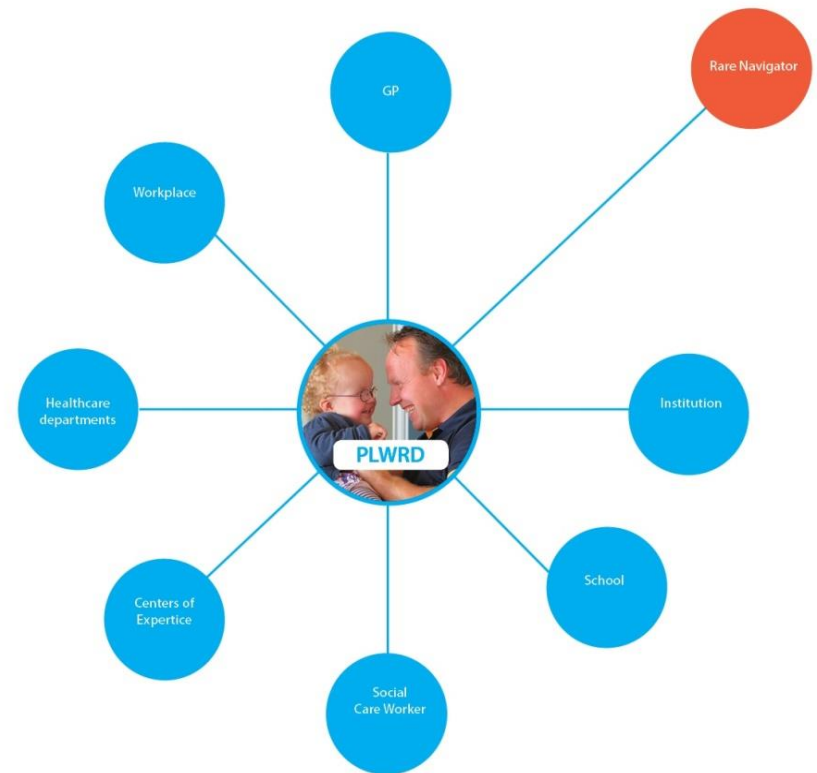
- A project in the process (2015 – 2017)
- A grant from the Danish Health Authority (DHA) to 1 NGO and 3 municipalities aiming to promote health literacy in the most vulnerable patients based on voluntarism
- Evaluation:
 - RDD evaluates the impact of receiving support from a Navigator
 - External evaluation from DHA





Why PLWRD?

- Studies shows that PLWRD gets more challenged and becomes vulnerable
- The systems becomes more standardized
 - Calls on structured support
 - to fill in the gaps
 - prevent patients from falling into cracks





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The model



- US model developed in the eighties
 - Proven successful by the Danish Cancer Society
- Adjust the model to become suitable for PLWRD
 - Corps of Navigators - voluntary action
 - Structured and systemized support to PLWRD
 - Rekrutting patients
 - Match making
 - Navigation



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Karina



”Being a Navigator is like being the captain on a container ship. It requires overview and navigation skills in high seas and calm waters to help PLWRD through, without them getting seasick. I could have used support from a navigator when my children and husband got diagnosed with tuberous sclerosis. Based on my experience I want to make that difference for another family”

Tells Karina who is one of Rare Diseases Denmark’s 18 navigators.



The corps of navigators

- Recruitment of volunteers through our member societies
- Training and continuously support to Navigators
 - As a group
 - Individually
- Competences
 - Personal experience and competences
 - Professional skills

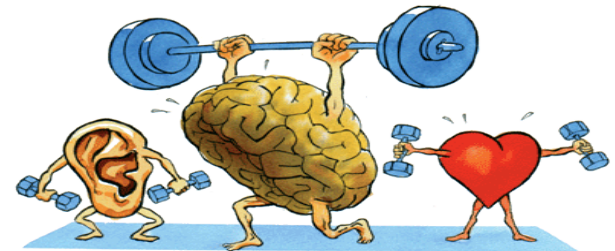


The overall principle is helping PLWRD to help themselves



The personal skills

- Personal experience navigating the healthcare system
- Personal skills such as empathy, structuring and vigor
- The ability to take care of themselves in the balance between personal issues and those needing navigation





The more professional skills

- Knowledge about:
 - Where to seek information
 - How to help PLWRD to structure and systemize
 - How to help PLWRD to help themselves

“Taking charge of is also, taking away charge and responsibility”





The task

- Is to support PLWRD through voluntary action and participate in the important effort to support PLWRDs in the process of:
 - Acknowledging their personal situation
 - Creating an overview of options
 - Encouraging health literacy and support compliance





Where we “find” the patients

- In RDDs patient associations
- Centers of Expertise for Rare Diseases
- The genetics departments at the 5 regional hospitals
- Network of Ultra Rare Diseases(NURD)





Match making

- Matching patient and navigator
 - Taking into account:
 - The specific skills of the Navigator
 - The geographics
- The first meeting
 - Matching expectations and structuring the cooperation





Lessons learned so far...

- The voluntarism perspective
 - Works out as a supplement, but more is needed
 - Making public authorities perform their best...
- Recruiting and training volunteers. RDD is far better than the municipalities!
 - Navigators
 - Patients looking for support
- Other
 - What kind of navigator support?
 - Implementation after project?





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Patient to patient



“I support a woman with an ultra-rare disease. She has lost confidence in the social- and health-care systems. She no longer dares to ask for the social support and the treatments she needs to live a good life. As a patient myself and a social worker I am supporting her to take responsibility for her own life. She is so brave and is slowly gaining back confidence”

Tells Rune who is one of Rare Diseases Denmark's 18 navigators.



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Thank you for your attention

Do not hesitate to call or write me for more detailed information

Stephanie Jøker Nielsen

Email: sjn@sjaeldnediagnoser.dk

Telephone: +45 21 71 61 97