

# Navigating the transition to adult healthcare for rare diseases

A project designed and piloted by Rare Diseases Sweden together with and for our young members

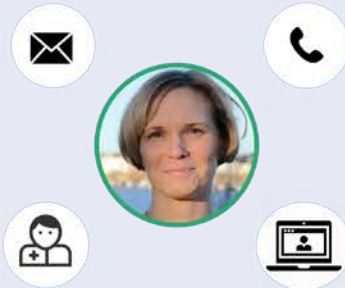
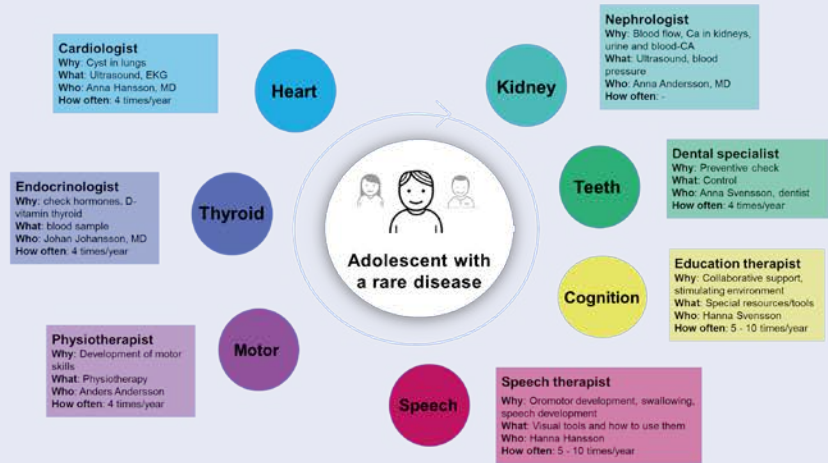
**Problem:** Adolescents face large challenges when growing up. Having a rare disease or other chronic diagnosis further demands organization of one's extensive and fragmented healthcare from one day to the next. Extensive implementation of person centered healthcare could considerably improve the situation for those adolescents and their relatives.

Rare Diseases Sweden has, together with our members and a service design team, developed and tested a new job profile, a coordinator. The aim was to instill trust and support adolescents in their transition between healthcare systems and towards independence. Another intention was to help adolescents in their everyday life and in developing an understanding of their diagnosis.



## Remedy: Person centered coordination in a fragmented healthcare system

**A coordinator** met 8 adolescents during 4 months around the age of 18, without parents. During 5 personal or digital meetings, a trustful relationship was built and relevant questions regarding everyday life, the individual diagnosis and the healthcare system were discussed, leading to increased independence.



**The care map** was the most important tool for coordination of healthcare transition. A clear visualization of all individual care contacts advanced each adolescent's understanding of its own position in the fragmented and specialized Swedish healthcare system.

## Result: Successful person centered healthcare transitions

### Adolescents

- Eight of ten adolescents participated regularly
- Got increased knowledge about diagnosis and care contacts
- Got to talk about important individual everyday life questions

### Relatives report

- That adolescents showed increased independence (33%)
- Their own future worries reduced (57%)
- Their feeling of trust and security increased (84%)

"Yes, I think my coordinator meetings help me to better manage myself in the future."



"My coordinator meetings were the first appointments I took on my own."



"I became more independent. I was nervous at first but now I know that I can take my appointments alone."



**Rare Diseases Sweden** is an association for individuals with a rare disease, gathering about 14500 members from 60 member associations. As an interest organization we strive for public attention for rare diseases, we influence politicians and policymakers, nursing staff and societal influencers and we drive own work on improvement.

### Contact

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