



Help yourself!

Rare tips for better meetings with the healthcare system

A project designed and piloted by Rare Diseases Sweden together with and for PLWRD



Problem: People living with rare diseases (PLWRD) face countless challenges in their encounters with the healthcare system, like lack of knowledge, of access to professional experts, and of coordination and collaboration between highly specialized parts of the healthcare system. This was shown in our member survey (ref 1).

Remedy: Rare Diseases Sweden has in a two years project and in collaboration with our members, developed solutions that can be used by all PLWRDs, without prior knowledge.

Tools for improved healthcare visits, more continuity and coordination, tips for finding experts and careplan templates are provided on a new webpage (fig 1, ref 2).



Fig 1: Screenshot och länk (QR-code) of our new webpage presenting rare tips for better healthcare meetings for PLWRD.

Step 1 - Identify problems

We collected experiences and narratives from our members via social media and during membership meetings. In a workshop we identified the following five most common and most relevant problem areas.

1. Healthcare visits
2. Lack of continuity
3. Lack of coordination
4. Lack of careplan
5. Lack of experts

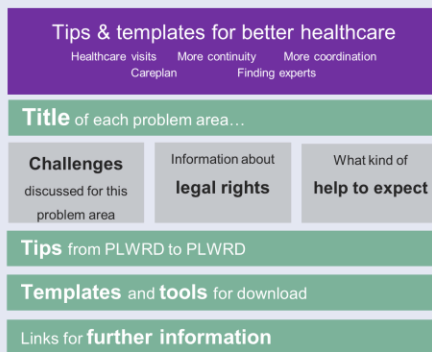


Fig 2: Structure of our new webpage (fig 1, ref 2).

Step 2 - Provide solutions

For each problem area, we discussed promising solutions and developed, tested, and drafted individual tools, together with our members (fig 3 – 6). The results in form of easily understandable tips and templates were formulated and are presented together with information about the Swedish healthcare system on a new webpage (fig 1 – 2). Below you find four examples with QR codes for direct download.

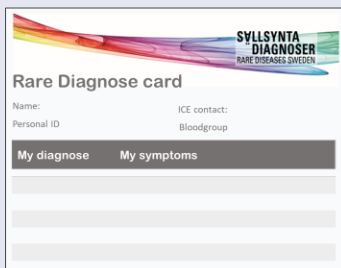


Fig 3: Rare diagnose card to sum up your most important diagnose/s and symptoms. Have with you in case of emergency and inform your MP before visit.

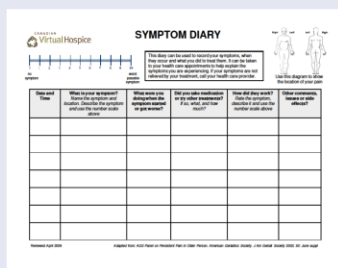


Fig 4: Journal your symptom diary between MP visits. Locate and evaluate on a prototype scale and model.

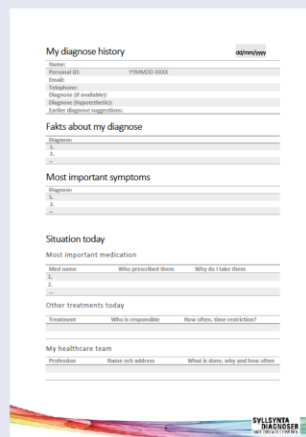


Fig 5: Draft your individual careplan.

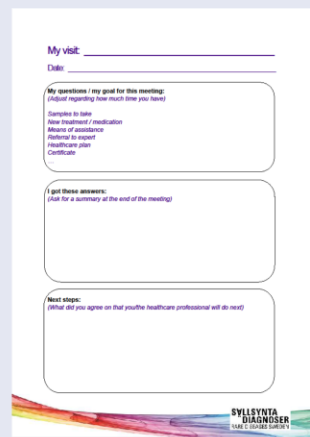
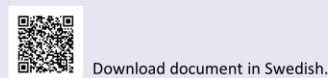


Fig 6: Prepare your healthcare visit.



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Conclusion: In addition to advanced patient education programs, even simple tools to structure individual everyday challenges are important for empowering the individual, and thereby strengthen the Rare Disease community.

Reference 1: Rare Diseases Sweden member survey



Reference 2: Rare Diseases Sweden webpage



“vardtips”

Rare Diseases Sweden

is an association for individuals with a rare disease, gathering about 16.000 members from 65 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.

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