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).

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

**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).

**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).](image)

**Tips & templates for better healthcare**
- Healthcare visits
- More continuity
- More coordination
- Careplan
- Finding experts

**Title of each problem area…**
- Challenges discussed for this problem area
- Information about legal rights
- What kind of help to expect

**Tips from PLWRD to PLWRD**

**Templates and tools for download**
Links for further information

![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.](image)

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

![Fig 5: Draft your individual careplan.](image)

**Fig 6:** Prepare your healthcare visit.

**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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