

Additional file 1: Patient preparatory tool

Patient brochure

Dear Mr, Mrs

You will soon have an appointment with the doctor in the hospital. Would you like to fill in this brochure at home and take it with you to the appointment?

The doctor has
medical knowledge

You have knowledge of
your personal situation



Together, we can decide what is
best for you!



These questions help the doctor to understand your personal situation

1. What does your **day** usually look like?

 Activities

 Social contacts

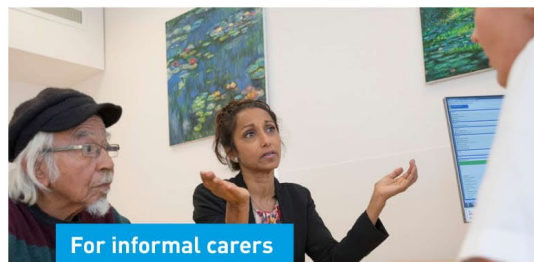
2. How would you **rate your life** at this moment ? (0-10)

3. What needs to happen to **raise** this grade a point?

4. What would you like to **discuss** with the doctor?

You can ask these questions when you visit the doctor!

- Are there any other options other than the treatment or research you mention?
- What are the advantages and disadvantages of the different treatment options?
- What do these advantages and disadvantages mean for my daily life?
- What do these advantages and disadvantages mean for my other diseases?



For informal carers

The doctor is also interested in how it is going for informal caregivers (the partner, daughter, son, family member or friend) because their work is important and they must continue to sustain their health.

That is why the doctor will also ask about the health of the informal caregiver. When we think about health we think about how the caregiver is doing physically, mentally and emotionally.

As a carer I feel like I am: