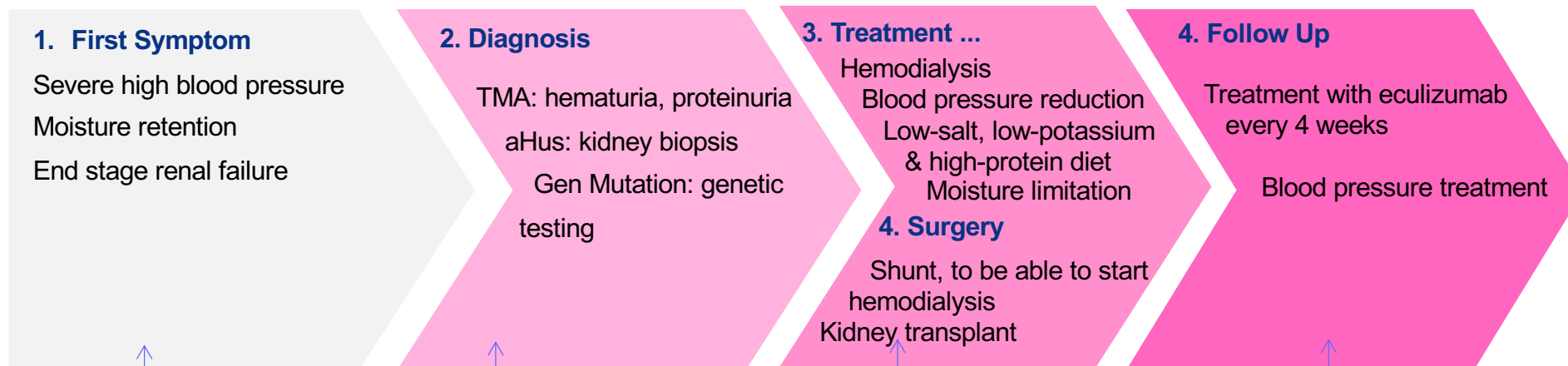
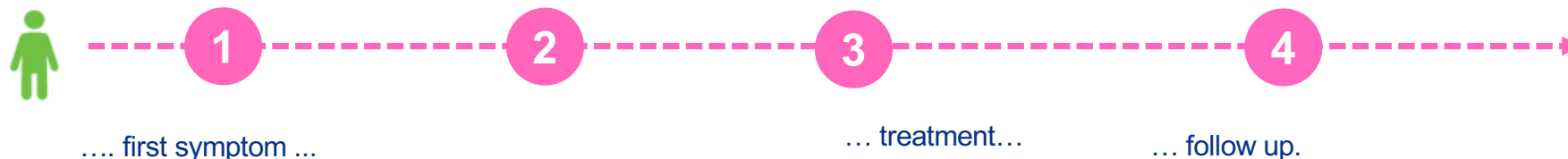


Atypical Hemolytic Uremic Syndrome (aHUS) Patient Journey



Needs:

- Information
- Dialysis
- Drugs to reduce high blood pressure

Needs: Information about treatment options. Liaison to patient organization/ other patients. Information about the rare disease and genetic counseling.

- **Ideally:** Well informed patient
- Complete understanding of disease and consequences for life

Needs: Information about alternative treatment options (transplantation in combination with your rare disease) Discuss dialysis options Information about chance of success and start treatment eculizumab (if available, due to extreme high costs)

Ideally: Guidance by a dietician, on a regular basis
Good working shunt

Needs: Start and stop criteria. Information on the forehead that blood pressure treatment remains necessary, even after transplant

- Ideally:**
- Individualized treatment with eculizumab, with approval of Health Minister and funded by health insurance
 - Alternative in food instead of drugs