Toolkit 1:

For Patients (Adults Living with vWD)

1. Understanding vWD

von Willebrand Disease (vWD) is the most common inherited bleeding disorder. It occurs when the body does not make enough von Willebrand factor (vWF) — a protein that helps blood clot — or when the vWF does not work properly.

Types of vWD:

- Type 1: Mild, most common.
- Type 2: Moderate; several subtypes (2A, 2B, 2M, 2N).
- Type 3: Severe, very rare.

2. Signs & Symptoms

- Easy bruising
- Nosebleeds that are difficult to stop
- Prolonged bleeding after cuts, dental work, or surgery
- Heavy or long menstrual periods
- Prolonged bleeding after childbirth
- Rare: bleeding into joints or muscles (usually in severe cases)

3. Treatment Options

- Desmopressin (DDAVP): Helps the body release more vWF.
- Factor Replacement Therapy: Infusions of vWF or factor VIII concentrate for moderate to severe cases.
- Antifibrinolytic Medications: Such as tranexamic acid; these help stabilize blood clots.
- Hormonal Therapy: Can help women manage heavy menstrual bleeding.

4. Daily Living & Safety Tips

- Always wear a medical alert bracelet or carry a wallet card.
- Inform doctors and dentists before any procedure.
- Avoid aspirin or NSAIDs (unless prescribed) since they thin blood.
- Choose safe activities: walking, yoga, and swimming are encouraged; avoid high-contact sports like football or boxing.
- Keep a bleed log to track patterns and treatment effectiveness.
- Plan ahead for travel or surgery by talking to your care team.

5. Tools Included

- Bleed Log (track date, location, severity, treatment, outcome)
- Medication & Treatment Tracker (record date, dose, reason, side effects)
- Emergency Wallet Card (to carry at all times)