

Patient talk: Logistics of care and aftercare

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“ You don’t know what you don’t know ”



Bridging the Gap

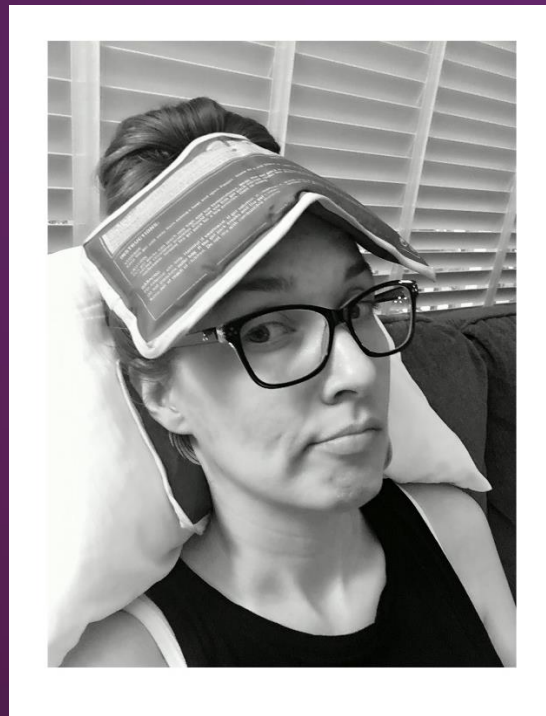


My story: *onset*

- Normal brain MRI
- Misdiagnosis
- Delayed diagnosis



My story: *spinal CSF leak care*



- Brain & spine imaging read as normal
- Improvement from non-targeted EBP
- Rebound high pressure & complications



My story: *re-leaking*



- Devastating setback
- More severe symptoms
- Uncertainty



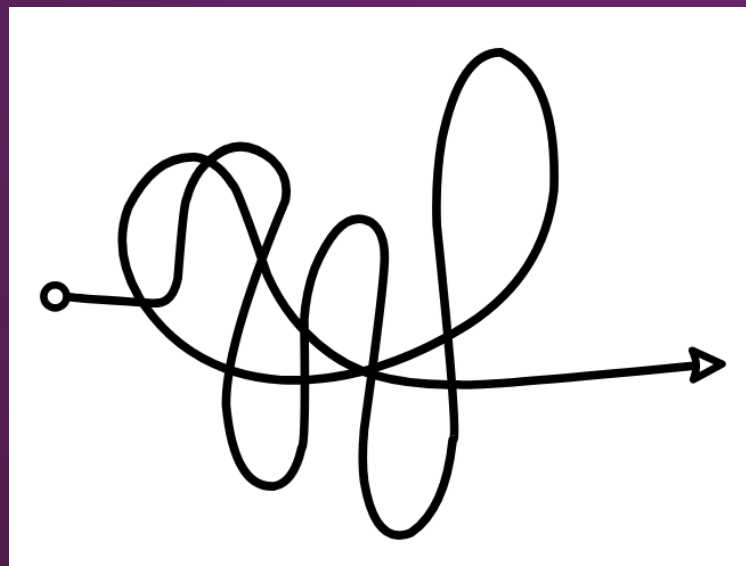


My story: *leak found!*

- Leak **FINALLY** located
- Fibrin patch
- Surgery



My story: *recovery*



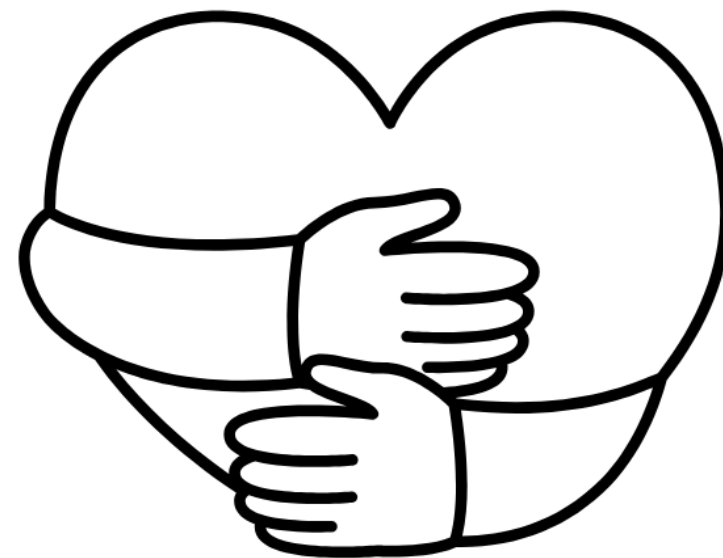
- Patient, healing takes time
- Helpful physician to navigate complications
- Progress continues



Strategies for managing leak life, care, and recovery



Coping through the challenges

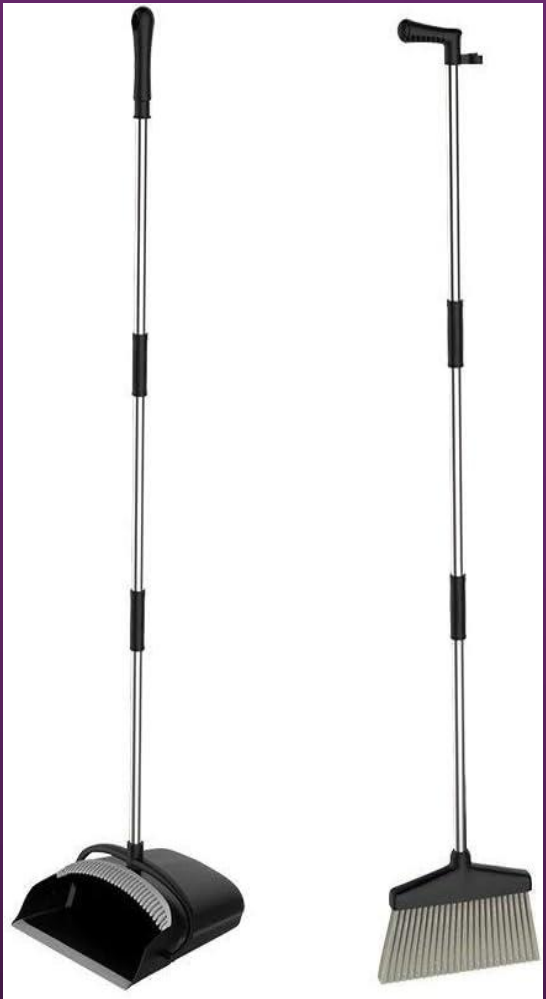
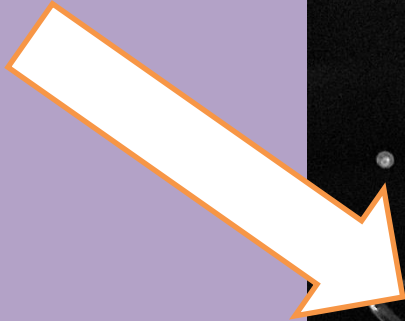


Day to day challenges:

- Plan ahead
- Set up environment
- Embrace routine
- Prioritize symptoms & needs
- Accept limitations
- Be creative, open minded, & patient



Modifications to my environment



Navigating medical care



Navigating medical care: *record keeping*

Document

- Daily trends
- Symptoms
- Medications & supplements
- Care team
- Timeline



Request Copies

- After visit summaries
- Discharge instructions
- Imaging reports
- Imaging



Navigating medical care: *preparing for procedures*

Discuss with my physician

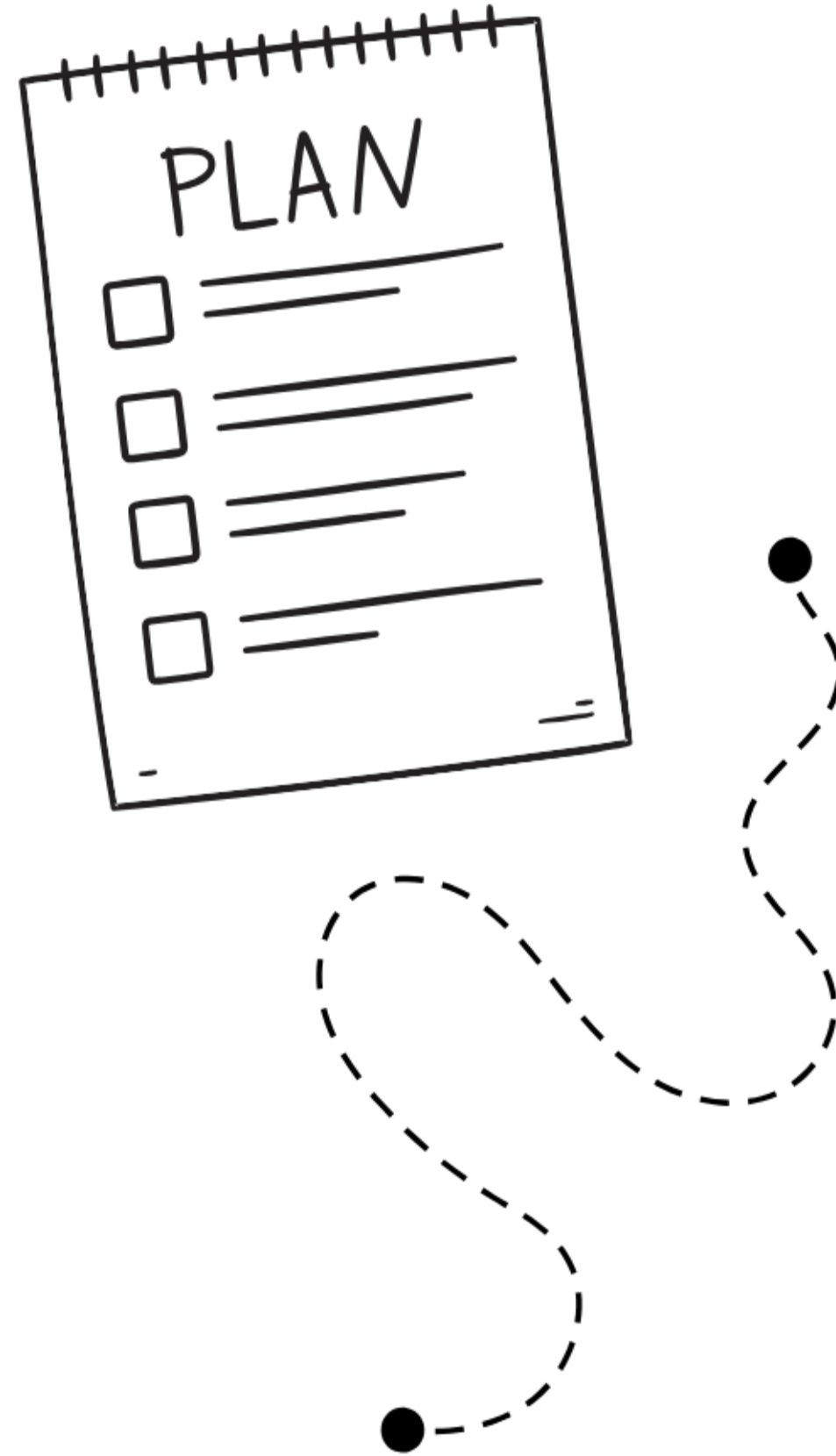
- Procedure details
- Immediate recovery/discharge plan
- Post-procedure guidance
- Other questions/comments



Tips for procedural appointments:

- Plan ahead
- Ask questions
- Contact patient relations for onsite assistance
- Update care team
- Prepare companion/advocate
- Prepare environment for recovery
- Dress accordingly
- Follow all the instructions
- Prioritize nutrition and sleep before/after
- Practice log roll ahead of time
- Have plan to avoid constipation
- Breathe





Navigating medical care: *travel tips*

- Ground transportation
- Air travel
- Lodging

Thank you