



PATIENT ADVOCACY CHECKLIST

Medical appointments can be overwhelming. Use this checklist to organize your thoughts and ensure your voice is heard.

1. Preparation: Gathering Your Map

- ☐ Request copies of your most recent MRI images on a disc.
- ☐ Write down your 'Top 3' most debilitating symptoms.
- ☐ Create a simple 1-page summary of your medical history.
- ☐ Bring a notebook and pen (or a recording device, if allowed).
- ☐ Bring a 'Support Partner' to be your second set of ears.

2. The Compass: Questions to Ask

- ☐ What type of Chiari do I have (Type 0, 1, 1.5, etc.)?
- ☐ Do my MRI scans show a syrinx (fluid cyst)?
- ☐ Have we ruled out related conditions like Ehlers-Danlos (EDS)?
- ☐ Is surgery necessary right now, or is 'watchful waiting' safe?
- ☐ If surgery is recommended: What specific technique do you use?
- ☐ What are the risks if I choose to do nothing?

3. The Megaphone: Communication Tips

- ☐ State your goal early: 'I need to know if my fatigue is related.'
- ☐ Use the 'Repeat Back' method: 'So, what I hear you saying is...'
- ☐ If you don't understand a term, ask for a plain-English definition.
- ☐ Ask about the 'Plan B': 'If this doesn't work, what is next?'

4. Notes & Action Items
