



Self-Advocacy Series
Medical Appointment Agenda

Empowered patients receive higher quality care

Welcome

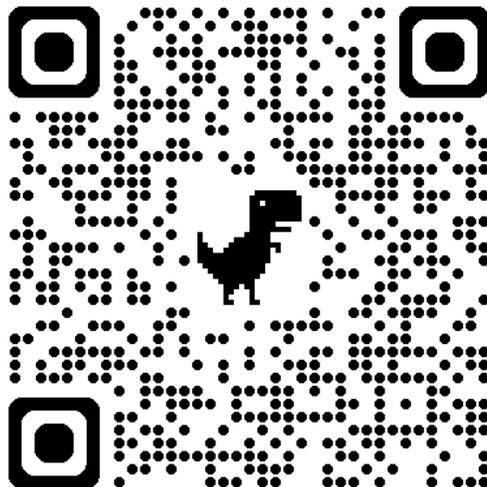
Agendas help you to work effectively and efficiently with your care team.

Help your doctor to help you.

Three parts to the agenda.

Treatment Goals – Issues/Updates/Questions – Treatment Options/Recommendations

Training Video Link



Appointment Agenda - Template Instructions

Treatment Goals

Define for your doctor what your priorities are. This can be very different for different people. What matters to you? What do you want to get out of treatment? What do you need to be happy and satisfied with life? What are you willing to risk achieving your goals? What do you want to be certain to avoid in terms of adverse effects?

Updates/Issues/Questions

Write out the symptoms, issues, and side effects that you are having. Write a list of your questions. NF/SWN involves many body systems. Include a holistic review of what is going on with your body.

Focus on what you think is most important for this visit. Provide more information when seeing a provider for the first time. Only give updates/changes to an existing provider.

Treatment

Review treatment options – let the doctor know what you are doing now and seek input on what to do next. Ask about **ALL options**, not just the one the doctor recommends. Ask the doctor to explain why the recommended option is better than other choices. Ensure that it is your goals, risk tolerance, and preferences that drive the decision about your treatment.

Neurofibromatosis - Surgery

Treatment goals:

1. Learn to live independently.
2. Engage in the physical activities I enjoy (golf, boxing, etc.)
3. Work at my job
4. Pursue photography as a potential career (preserving vision).

Issues/Questions

I want to be sure I understand.

1. Is the tumor being removed a plexiform neurofibroma?
2. Why are we taking one tumor out and not both?
3. Could this tumor be a problem in the future if we do not take it out?
4. Could the tumor come back if we take it out?

Treatment Options/Recommendations

I want to be sure I understand.

1. What are the risks of the surgery?
 - a. Nerve damage/numbness. What does this mean?
2. How long will the recovery be?
3. How long until I can resume physical activities like golfing and skiing?

Treatment goals:

1. Live independently with my fiancé.
2. Find a new support system and social network in new city.
3. Succeed in my career (nurse).
4. Manage pain from tumors that interfere with work and recreation.
5. Make plans to start a family.

Issues/Updates/Questions

1. Mild non-dystrophic scoliosis (see imaging)
 - a. Stable. No changes in the last 2 years
 - b. Managing with PT exercises and therapeutic massage
 - c. Monitoring annually or as needed if change.
2. Cardiovascular
 - a. Mitral valve prolapse
 - b. Cardiologist recommends monitoring only. Appointments every 12 months.
3. **Plan to start a family (in five years)**
 - a. Considering IVF to ensure do not pass on NF to children (if funds permit).
 - b. **What impact would pregnancy have on NF issues?**
4. **Status of Peripheral Neurofibromas?**
 - a. Review imaging. Are they growing/changing?
 - b. Pain from pNFs in leg and neck getting more bothersome. Can interfere with activities.
 - c. Concerned about progression to MPNST
 - d. **What are treatment options?**
 - e. **Concerned about pregnancy impact on pNFs and treatment.**
5. **Cutaneous Neurofibromas** (have 12)
 - a. Intermittent itching. Use antihistamine to manage.
 - b. **Concerned about pregnancy impact on cNFs.**

Treatment

1. ***Need a new NF care team in new city. Recommendations?***
2. ***Family planning***
 - a. *Referral to Genetic counseling.*
 - b. *Recommendations for the impact of pregnancy on symptoms and treatment options.*
3. ***Recommendation for treating pNFs?***
4. ***Other Recommendations?***

Treatment goals:

1. Extend quality of life.

1. Remain functional and able to work and engage in preferred activities.

2. Extend length of life

1. Better to get less tx benefit and preserve QOL with any tx

Issues/Updates/Questions

6. Miscellaneous

- a. Iron WNL
- b. TSH slightly high recently 5.989
- c. LDL consistently high 119
- d. Vit D deficiency consistent – note NF1 related.
- e. PSA WNL but increasing to 2.71 with Hx of increase size of prostate.
- f. A1c-Glucose WNL

7. **Note recent dx Osteopenia** (see DEXA report)

- a. **Specific recommendations related to NF1?**

8. **Cardiovascular**

- a. Removal of pulmonic valve at age 6 months.
- b. Regurgitation fraction current = 52%
- c. Right ventricle enlarged - end-diastolic volume = 208ml or 119ml/sq-m
- d. O2 levels typically = 95-100%. Occasionally lower (91%).
- e. Average HR = 90. Sometime 120s without significant exercise. Premature atrial and ventricular contractions noted. One incident of 10 beat SVT noted.
- f. Left anterior fascicular block and right bundle branch block noted on EKG.
- g. **Cardiologist assessment = that these issues would not cause erythrocytosis.**
- h. **Install artificial pulmonic valve scheduled for May 2025**

9. **Status of Erythrocytosis**

- a. No incidents of thrombosis.
- b. Recent mild anomalies in leukocytes
- c. **Consistent increase in erythrocytosis over time**

Date	RBC	HGB	HCT
12-19-23	6.44	18.4	54.9
11-10-22	6.39	18.2	52.8
09-22-21	6.04	17.2	50.5

- d. **Hematologist assessment - related to the heart issue.**
- e. **Any possible (rare) link to NF1?**

Treatment

5. Heart valve installation date May 2025

- a. *Advisable to determine the cause of erythrocytosis prior to surgery?*
- b. *Anything NF1 specific to relay to cardiac surgery team?*

6. Recommendation for consultation re. osteopenia?

7. Other Recommendations?

Sample - Male Age 42 NF1 – history of repaired pulmonic stenosis –NF1 related and other issues have recently surfaced.

NF/Neurology 01/22/24

Treatment goals:

1. Extend quality of life.

2. Protection of cognitive function is the single highest priority.
3. Protecting vision, hearing, other senses, and mobility/physical abilities second priority

2. Extend length of life (only when QOL intact)

2. Philosophically – better to get less tx benefit and preserve QOL with any tx
3. My medical POAs have very specific instructions regarding my care and when to d/c all tx.

Issues/Updates/Questions

10. Cardiovascular

- a. Decrease in tachycardia incidents since catheter ablation. Last incident = 06/27/23
 - i. Occasional brief (13 beats) tachycardia are occurring per monitor.
- b. Complete set of cardiology testing = no concerning findings (reports in chart).

11. Prediabetes -- monitoring

12. Status of Polycythemia Vera – Besremi recently increased to 175mcg. Max tolerable dose.

- a. Continue to feel well overall – better than 10 years ago.
- b. JAK2 VAF reduced from 38% to 9% - 12/22. Now at 10% - 12/23
- c. HCT is back at target as of 01/17/24. Leukopenia at acceptable levels.

13. Acephalgic Visual Migraine – post resection of brain tumor 06/01/2019

- a. Last incident on 11/17/23. First migraine since 10/05/22
- b. Resolved with Ubrelvy within 1 hour.
 - i. NOTE: Switched to Nurtec 75mg PRN
- c. Have not needed lorazepam for migraine escalating to palinopsia.

14. MRI results

- a. Any sign of recurrence?
- b. Monitor for brain tumor recurrence - what frequency?
- c. Monitor flair spot. – anterior horn right lateral ventricle – seems stable?

15. Skin changes (nonsignificant)

- a. No change in lumps on abdomen/ribs (likely lipomas).
- b. No change in cNFs noted.

Treatment

8. PRN prescription Nurtec for visual migraine.

9. Continue with lorazepam PRN for migraine palinopsia when due for refill?

10. Continue to monitor at 6-month intervals? When to move to 12-month intervals?

- a. Any promising new approaches to adult gliomas? *Interferon efficacy for NF1 tumors?*

11. Monitor for secondary cancers (note increased risk due to JAK2 and NF1)