Your Voice, Your Vision

A MacTel Patient's Checklist for Appointments, Advocacy & Daily Life

A free guide from Melissa R. Williams, RN, MSN, CPN, NC-BC — Nurse Patient Advocate & Life Coach

Living with Macular Telangiectasia (MacTel) means ongoing appointments, a care team that can be easy to lose track of, and real day-to-day changes that don't always come up in a short visit. This checklist walks you through your appointments from start to finish, plus the quality-of-life piece that often gets left out entirely — so you can advocate for yourself (or someone you love) with clarity and confidence.

1 | Before Your Appointment

Walk in prepared, not overwhelmed.

- [ ] **Track how it's affecting your daily life.** Driving, work tasks, reading, screens, cooking, recognizing faces — note what's gotten harder and since when.
- [ ] **Write down any vision changes since your last visit.** Which eye(s), what changed, and when you noticed it.
- [ ] **Arrange a ride to and from your appointment.** Your eyes will likely be dilated — line up a driver ahead of time rather than assuming you can drive yourself home.
- [ ] **Note your current care team.** Everyone you see for MacTel or related needs, so nothing falls through the cracks between providers.
- [ ] **Note your family history.** MacTel can run in families — worth mentioning if relatives have vision or retinal issues.
- [ ] **Bring a trusted person, and ask about recording the visit.** Dilation makes reading and writing difficult afterward — ask if you can record the conversation or get a written summary before you leave.
- [ ] **Write your top 3 questions in advance.** Appointments move fast — a written list keeps you on track.

2 | During Your Appointment

MacTel is progressive, so each visit is a chance to track what's changed and keep your daily life part of the conversation.

- [ ] **Ask what's changed since your last visit.** Have your provider compare today's imaging to your last set, not just describe it on its own.

- [ ] **Bring up your daily-life list, even if they don't ask.** Driving, work, and reading struggles often go undiscussed unless you raise them first.
- [ ] **Ask about your options in plain language.** “Can you explain that in a way I can take home and remember?”
- [ ] **Ask whether a newer treatment applies to you.** An FDA-approved implant is now available for some patients — ask if you're a candidate and what it can and can't do.
- [ ] **Ask what would signal it's time to come back sooner.** MacTel is progressive — know the changes that shouldn't wait for your next scheduled visit.
- [ ] **Ask about next steps in writing.** Tests ordered, referrals made, and a rough timeline for follow-up.

A few phrases worth keeping in your back pocket:

“I want to make sure I understand — can we go over that once more?”

“How does this compare to my last visit?”

“I'm not comfortable moving forward until I understand my options.”

3 | After Your Appointment

Living well with MacTel is an ongoing process, not a one-visit conversation.

- [ ] **Confirm your status and plan in your own words.** Ask the care team to check you've got it right before you leave.
- [ ] **Get everything in writing.** Diagnosis, stage, imaging results, and the follow-up schedule — not just verbal.
- [ ] **Confirm your follow-up plan.** Date, provider, and what would prompt an earlier visit.
- [ ] **Know your red flags.** Write down the specific vision changes that mean “call sooner, don't wait.”

4 | Quality of Life & Local Resources

The part most appointments never get to — and the part that shapes your daily life the most.

- [ ] **Ask for a referral to low-vision rehab.** This is different from your retina follow-up — it's about adapting daily life, not just monitoring the disease.
- [ ] **Look into your state's services for the blind & visually impaired.** Many offer free adaptive tools, training, and case management regardless of income or insurance.
- [ ] **Ask about local or online MacTel support groups.** Programs like the MacTel Project connect patients to research and to each other — you don't have to navigate this alone.
- [ ] **Plan for longer-term transportation independence.** Paratransit enrollment, rideshare programs, and driving evaluation centers are easier to set up ahead of a change than during one.

Ask about a home safety or daily-living evaluation. Lighting, contrast, and layout adjustments can make a real difference day to day.

Don't skip the emotional side. Ask about counseling or peer support for vision loss — it's rarely offered unless you ask.

When It's Time to Call In an Advocate

Most physicians manage the medical side of MacTel well — but the quality-of-life piece, the local resources, the emotional weight of a rare diagnosis, often falls through the cracks in a short appointment. That's exactly the gap I help fill — as a nurse, patient advocate, and life coach who sits in your corner and helps you find clarity, confidence, and a plan for what's next.

If that's where you are right now, let's talk.

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