



WELL SAID HEALTH

Episode 1 Show Notes — Everyone Needs A Health Advocate

Season 1, Episode 1 • Live Sept 1, 2026 • Guest: Anne Llewellyn MS, BCPA, RN, CMGT-BC, CRRN, FCM • Runtime 43:22

Episode summary

Anne Llewellyn helped invent the health advocacy profession — then, in November 2014, a sudden brain tumor diagnosis made the advocate's advocate need one of her own. Anne shares how two advocate friends and her husband Corky (a mechanic with a \$3 notebook) changed the course of her care, from a small community hospital to the University of Miami's Sylvester Comprehensive Cancer Center. Then Robin turns the story into a toolkit: the exact words to use before and during a health crisis.

Timestamps

- **00:04 Cold open** — When fear walks in, your ears walk out — why this episode matters.
- **01:27 Why advocacy emerged** — The missing link in healthcare: the patient's voice.
- **02:44 Las Vegas, November 2014** — New glasses, unreadable slides, and the day everything changed.
- **04:08 “You have a brain tumor”** — The eye doctor, the car accident, and the ER diagnosis.
- **06:15 Calling in the advocates** — Two friends show up — and question brain surgery at a small community hospital.
- **09:08 The transfer** — A network phone call gets Anne into a university hospital over Thanksgiving weekend.
- **12:51 Notes and recordings** — Why “you can't take notes” was wrong — and how to ask to record a visit.
- **16:45 Corky the advocate** — The binder, the progress notes, the MRI disc, and the video that got the doctor's attention.
- **21:58 Confidence and protocols** — Asking “can we do this?”, learning the why, and trusting the specialist who knows the drugs.
- **22:37 Rehab and the team** — Healthcare is a team sport — and the patient is part of the team.
- **26:04 Be a person, not a head in the bed** — Posters and pictures that make the staff see you.
- **26:50 Building your team** — Who takes the lead, and the types of advocates: clinical, insurance, and social.
- **30:16 Finding and affording an advocate** — Directories, pricing conversations, scope of practice, and professional background.
- **31:47 Caring from three states away** — The top moves for a long-distance caregiver.
- **33:07 The appointment game-changer** — Come prepared with written questions — and an agenda.
- **35:01 Closing** — Gratitude for the profession's founders and the BCPA credential.
- **36:00 The Toolkit** — Robin's recap: five phrases to write down, plus this week's homework.
- **42:02 Anne's health hacks** — Water exercise three times a week, faith, and family.

The Episode 1 Toolkit

Five phrases to put in your phone — the printable one-page version is the last page of this document:

1. **Make it official:** “If something ever happens to me, you're my person. Will you be my advocate?” Say it before the crisis.
2. **The notebook words:** “What is that? What is this for?” And when something doesn't match: “That's not what we heard from the doctor — could you go back and check?”
3. **The second-opinion question:** “Who would you have do this if it were your daughter or your wife?” If the answer doesn't sit right: “We'd like some time to consider other options.”
4. **The appointment opener:** “I have some questions I'd like to ask you. Can we make time after the exam to go over them?” Write your top three questions down before you go.
5. **Caring from a distance:** “Can I join my mom's next appointment by phone or video?” Most offices will say yes — you just have to ask.

Homework this week: (1) Have the advocate conversation — ask your person, be someone's person. (2) Buy the notebook and bring it to every appointment. (3) Write your top three questions before your next visit and use the appointment opener.

Find a professional health advocate

Independent health advocates work for you — not the hospital, not the insurance company. Look for the letters BCPA (Board Certified Patient Advocate) after their name. Many, like Anne, offer a free first consultation.

- **HealthAdvocateX** (co-founded by Robin) — healthadvocatex.org • Advocate directory: healthadvocatex.org/directory-professional
- **Greater National Advocates** (where you'll find Anne) — gnanow.org • Find help: gnanow.org/find-help.html
- **NAHAC** — National Association of Healthcare Advocacy — nahac.com • Directory: nahac.com/directory-of-advocates
- **BCPA credential** — Patient Advocate Certification Board — pacboard.org
- **AdvoConnection Directory** (Alliance of Professional Health Advocates) — advoconnection.com

About our guest

Anne Llewellyn, MS, BCPA, RN, CMGT-BC, CRRN, FCM, is a pioneer of health advocacy and a leader in case management since 1988 — a critical care nurse, award-winning nurse blogger, digital journalist, and brain cancer survivor. She wrote the foreword to Robin's book.

- Website & Nurse Advocate blog: nursesadvocates.com
- Anne on Greater National Advocates: gnanow.org
- Anne's HealthAdvocateX profile: healthadvocatex.org/anne-llewellyn

From Robin

Get the words and the confidence to navigate your care: *The Secret Language of Healthcare: How to Ask for the Care You Deserve* — Anne wrote the foreword. [Find it on Amazon.](#)

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Next episode: You go to the hospital and your doctor isn't there — meet the hospitalist, with one of the first hospitalists in the country.

The Advocate Toolkit

Five phrases to keep in your notebook — before you or someone you love needs them

1 MAKE IT OFFICIAL

"If something ever happens to me, you're my person. Will you be my advocate?"

Say it before the crisis, not during. Everyone in your family should know who their person is.

2 THE NOTEBOOK WORDS

"What is that? What is this for?"

"That's not what we heard from the doctor — could you go back and check?"

Every medication, test, and white coat goes in the notebook — dated, with names. Tell the team you're taking notes so you don't miss anything.

3 THE SECOND-OPINION QUESTION

"Who would you have do this if it were your daughter or your wife?"

"We'd like some time to consider other options."

This one question moved Anne from a community hospital to a top cancer center.

4 THE APPOINTMENT OPENER

"I have some questions I'd like to ask you. Can we make time after the exam to go over them?"

Write your top three questions before you go. Patients who bring an agenda get better care.

5 CARING FROM A DISTANCE

"Can I join my mom's next appointment by phone or video?"

Most offices will say yes. You just have to ask.

YOUR HOMEWORK THIS WEEK

1. Have the advocate conversation — ask your person, be someone's person.
2. Buy the notebook. Keep it with your health stuff; bring it to every appointment.
3. Before your next visit, write your top three questions and use the appointment opener.

FIND A PROFESSIONAL ADVOCATE

They work for you — not the hospital or the insurance company. Look for BCPA after their name. healthadvocatex.org • gnanow.org • nahac.com • pacboard.org

From The Secret Language of Healthcare: How to Ask for the Care You Deserve by Robin Shapiro • Hear the full story: