



PATIENT PLAYBOOK

When You're Told There Are No More Options

What that sentence means, and what to ask next

This is one of the hardest conversations anyone has. If you are reading this shortly after having it, take whatever time you need before going further.

When you are ready, there is something worth knowing. The sentence people usually hear as *there is nothing left* is often a different sentence: *there are no more standard options*. Those are not the same thing, and the difference is sometimes where the next months come from.

What we are not saying

We are not saying your doctors are wrong, or that something is being withheld from you.

Sometimes there genuinely is nothing further that would help, and a good oncologist telling you that plainly is doing you a service, not failing you.

What we are saying is that the conversation is worth having explicitly rather than assuming. Ask the questions. The answers may confirm what you have been told. At least then you will know.

Questions worth asking your care team

Take this page to your next appointment. Ask as many as you have energy for. Bring someone with you to write the answers down, because almost nobody remembers these conversations accurately afterward.

About what "no options" means

- When you say there are no more options, do you mean no more **standard** options, or no options of any kind?
- Are there treatments you would consider if I were willing to accept more uncertainty or more side effects?
- Is there anything you would try if this were a clinical trial setting rather than routine care?

About testing

- Has my tumor had comprehensive genomic or molecular testing? If not, would it change anything if it did?
- If it was tested, was that before or after my most recent treatment? Tumors change.
- Are there biomarkers that might open a trial to me that I do not currently qualify for?



About clinical trials

- Are there trials here I might be eligible for?
- Are there trials elsewhere you would consider referring me to?
- If I am not eligible for anything today, is there something opening soon, and how would we know?
- Is there anything about my current treatment that would make me ineligible later? Some trials exclude people who have had certain drugs.

About investigational drugs outside trials

- Is there an investigational drug that might fit my situation, even without an open trial?
- Would you be willing to submit an expanded access request and supervise treatment if we found one?
- If you would not, is there a colleague or center you would refer me to who might?

About a second opinion

- Would you support me getting a second opinion? Where would you send someone in my situation?
- Is there an academic or NCI-designated cancer center that sees more of this diagnosis than we do here?
- What would you want them to look at that we have not?

A note on second opinions: asking for one is not an insult, and most oncologists expect it at this stage. If a doctor reacts badly to the question, that itself is information.

About what happens now

- If we pursue nothing further, what does the next period realistically look like?
- What symptoms should I expect, and what can we do about them?
- Is it time to involve palliative care? Can we do that alongside treatment rather than instead of it?

On palliative care

Palliative care is often confused with hospice. They are not the same.

Palliative care is specialist support for symptoms, pain, and quality of life. It can run alongside active treatment, at any stage, including while you are pursuing trials or investigational drugs.

Asking for it is not giving up on treatment. Several studies have found that people receiving palliative care alongside cancer treatment report better quality of life. It is one of the most under-requested things in oncology.

What to do in the next two weeks

1

Get your records

Request your complete medical records, including pathology reports, imaging, and any genomic testing. You are entitled to them.

Every second opinion, trial screening, and expanded access request will need them. Having them ready removes weeks of delay later.

2

Ask about a second opinion at a center that sees your diagnosis often

Especially for rare cancers, volume matters. A center that sees your diagnosis weekly thinks about it differently than one that sees it twice a year.

NCI-designated cancer centers are a reasonable starting point, and most accept second opinion requests directly.

3

Decide who is helping you

This is more work than one person can carry while also being ill. Someone needs to make calls, track paperwork, and keep notes.

If you do not have someone, say so out loud to your care team. Social workers and patient navigators exist for exactly this and are usually free.

4

Let yourself stop, if that is what you want

Everything in this guide is about what is possible, not what is required.

Choosing not to pursue further treatment is a legitimate decision made by thoughtful people every day. It is not giving up, and nobody who loves you should treat it that way.

The point of asking these questions is so that whatever you decide, you decided it — rather than defaulted into it because nobody explained the alternatives.

Notes from my appointment

Date, and who I spoke with

What they said about standard options versus other options

Trials, testing, or referrals mentioned

What I am doing next, and by when



If you are struggling and need someone to talk to, the 988 Suicide & Crisis Lifeline is available 24 hours a day by calling or texting 988.

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