A PROTOCOL & PEOPLE™ PRODUCTION

Taking Notes

Somewhere to put the questions before you get there, and what was actually said once you are home.

Free. Yours. Write on it however you like.

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How to use this

Most of what is said in an appointment does not survive the drive home. That is not a failure of attention, it is what happens to everybody under that much pressure.

Between 40 and 80 percent of medical information is forgotten immediately, and close to half of what people do remember is remembered wrong. Writing it down is the part that is within your control.

THE THREE PAGES THAT MATTER MOST

- [ ] **Page 4.** Your three questions. Write them before you go. Three is the number that fits in the time you will get.
- [ ] **Page 7.** What was said. Fill it in while you are still in the parking lot, not that evening.
- [ ] **Page 11.** Who to call. Fill the numbers in now, while nothing is wrong. That is the whole point of it.

Bring someone if you can. A second person hears different things, and they can write while you listen.

There is no right way to fill this in and no page you have to use. Take what helps and ignore the rest. Page 12 has no prompts worth speaking of; it is for the things you have not said out loud, and nobody is going to read it.

The basics, written down once

You will be asked these in every waiting room and by every new person you meet. Writing them once saves saying them forty times.

Name _____

Date of birth _____

Record number _____

MY DIAGNOSIS, IN MY TEAM'S WORDS

_____

_____

STAGE, IF GIVEN

_____

GRADE, IF GIVEN

_____

THE TREATMENT I AM ON, AND ITS NAME

_____

_____

ALLERGIES AND OTHER CONDITIONS

_____

_____

If you do not know your stage or the name of your treatment, that is a reasonable thing to ask for, and asking does not mean you were not listening.

My three questions

Write them before you go. If you get through more, good. If the appointment goes somewhere unexpected and you only get one, make it the first.

1 · THE ONE I WOULD HATE TO LEAVE WITHOUT

2

3

IF THERE IS TIME, I WOULD ALSO ASK

What I want my team to know

Clinicians ask what has changed. It is much easier to answer if you wrote it down at the time than to remember it on the spot.

WHAT HAS CHANGED SINCE I WAS LAST HERE

WHAT I AM MOST WORRIED ABOUT

WHAT IS GETTING IN THE WAY, AT HOME, AT WORK, OR GETTING HERE

Say the worry out loud even if it sounds unreasonable to you. The things people decide not to mention are very often the things that change the plan.

What I take, and what for

Everything, not only the cancer treatment: blood pressure tablets, painkillers, inhalers, supplements, vitamins, herbal remedies, anything you buy yourself. Some of them interact.

NAME	DOSE	HOW OFTEN	WHAT FOR

What was actually said

Date _____ Seen by _____

NOTES

WORDS I DID NOT UNDERSTAND, TO ASK ABOUT

WHAT HAPPENS NEXT, AND WHEN

How this week actually went

A line a day is enough. Patterns are much easier to see written down, and your team can only act on what you tell them.

DAY	WORST THING	0–10	ANYTHING ELSE
Mon			
Tue			
Wed			
Thu			
Fri			
Sat			
Sun			

Side effects are not a price you have to pay quietly. Most can be treated, and telling someone early is easier than telling them late.

Thinking about a clinical trial?

Already written out, so you do not have to think of them in the room. Check what you want answered and hand the page over if that is easier.

- [ ] Where does this trial sit among my options, and what else could I choose?
- [ ] What is being tested, and what is already known about it?
- [ ] What does the other group get?
- [ ] Who decides which group I am in?
- [ ] What extra visits, scans or tests would I have?
- [ ] What will it cost me, including travel and time off work?
- [ ] Who is watching for harm while the trial runs?
- [ ] What happens if I say no, or if I stop halfway through?
- [ ] Will I be told the results?
- [ ] If the treatment works, do I keep getting it afterward?

If your team brings up a trial, it does not mean anyone has run out of ideas. You are allowed to take days over the decision.

Who is who

Cancer care involves a lot of people and it is genuinely hard to keep track. Nobody expects you to know who is who, so write them down as you meet them.

NAME	WHAT THEY DO	HOW TO REACH THEM

WHO IS COMING WITH ME, AND WHAT I WOULD LIKE THEM TO DO

Who to call, and when

Fill these in now, while nothing is wrong. At two in the morning nobody is in a state to go looking for a number.

Center, daytime _____

24 hour line _____

My nurse _____

Emergency dept _____

Person to call for me _____

ASK YOUR TEAM TO FILL THIS IN WITH YOU

Every team sets its own thresholds, so these should be theirs. Ask: *what temperature, and what symptoms, mean I call you straight away?*

Call if my temp is _____

Also call if _____

_____

If your treatment affects your immune system, a fever can be an emergency even when you otherwise feel well.

The things I have not said out loud

Grief is not only about death. People lose the year they planned, the body they trusted, and the version of themselves who did not think about any of this. Most people around you will expect you to be frightened, and fewer will expect you to be grieving, so you may have to say it.

If any of this will not settle, ask your team who you can talk to. Most cancer centers have someone, and asking is not a sign that anything has gone wrong.

Made by Protocol & People™

We answer the questions that come up after a cancer diagnosis, and explain how clinical trials work, in plain language.

protocolandpeople.org

Educational only. Not medical advice, and not a substitute for the conversation with your own team. It is meant to make that conversation possible.

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Page tabs

Cut one out, fold it along the dashed line over the edge of the page it names, and tape or glue it down. The blank half wraps behind the page, so the color still shows from the back. Print onto label stock if you have it, ordinary paper if you do not.

MY QUESTIONS · 4

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MEDICINES · 6

THIS WEEK · 8

TRIAL QUESTIONS · 9

WRITE YOUR OWN

WRITE YOUR OWN

Page 11 is the one to tab first. It is the page you will want to find fastest and in the worst circumstances.

STICKERS, IF YOU WANT THEM

For the front of a folder, a phone case, a water bottle, or the top of page 4.

Ask your team

I can say no

Write it down

Bring this in

Take your time