A FREE TOOL FROM BEYOND CARE

The First Call

What to ask when your parent gets a dementia diagnosis. A two-page appointment sheet for the daughter trying to remember everything. Bring it into the room. It knows what to ask when you can't think.

KYLIE GOLDMAN, MSW · MORE THAN 12 YEARS OF CLINICAL PRACTICE WITH FAMILIES

Before you go

Bring your list

Whatever you have written down, however messy. Dates and what happened. If you have nothing written, take ten minutes now and write what you remember, oldest first.

Bring the medication list

A complete one: prescriptions, over-the-counter medicines and supplements, including anything she takes "only sometimes."

Bring one other person

If you can. To listen and take notes, so you can stay in the conversation.

The eight questions

1. **What kind of dementia is this, and how sure are you?**
   The word "dementia" is a starting point, not the whole answer. There are several kinds and they do not behave the same way. Ask which one, and how sure they are.

2. **Is there anything here that can be treated or improved?**
   Some things that look like dementia are not, and some things that make it worse can be adjusted. That is a question for them, not for the internet.

3. **What should we expect over the next six to twelve months?**
   Not the whole future. The next stretch. You are trying to plan a year, not a decade.

4. **What would tell us things are changing faster than expected?**
   This is the one nobody asks. You want to know what you are watching for, so you are not guessing at 2am.

5. **Who else should be involved now, and can you refer us?**
   Ask by name. Occupational therapy. Social work. A memory clinic. A pharmacist review. Before you leave, ask who is making each referral and when you should follow up.

6. **What do you advise about driving?**
   Ask the clinician to discuss driving directly, and write down the recommendation. Driving is one of the decisions families struggle with most, and it goes very differently when the answer comes from the doctor instead of from you.

7. **What should we get in place while she can still take part in the decisions?**
   Planning now gives her more opportunity to take part in the decisions. You are not being morbid. You are including her while she can be included.

8. **Who do we call when something happens, and what counts as something?**
   The most useful sentence you can leave with. Get a name, a number, and a threshold.

One more page. *For after the appointment.*

AFTER THE APPOINTMENT

Before you leave the building.

Three things go on paper while it's still fresh. Then this page tells you what you are allowed to put down.

What they actually said

In their words, not your summary of it.

What happens next, and who is arranging it

A referral is not a plan until someone owns it.

The follow-up

Ask when it should happen, who will arrange it, and how you will be contacted. Write the answer down, or you will be the one chasing it in four months.

What you do not have to decide today

Where she lives.
Whether you cut your hours.
What happens in five years.
Whether you can do this.

> **None of that is today's decision. Today's decision was showing up and asking better questions than you were given. That is done now.**

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One next step

Put the follow-up in your calendar. Then open a note on your phone and write today's date and one line about what you noticed. That note is the start of the record, and the record is what makes the next appointment easier. **You are not behind.**

If you left with a diagnosis and still don't know what to do next, start here.

The driving talk, the money, the guilt that comes with deciding. I work through those out loud every day at **@beyondcarewithkylie**. Scan the code, or search the handle. Keep this sheet for the next appointment too. The questions still work.