PRACTICE

WHAT YOUR PATIENT IS THINKING

Appointment day—the tip of an iceberg

Anya de longh gives a snapshot of what a rare appointment with a consultant feels like for the patient, and suggests how to make things better

Anya de longh *BMJ patient editor*

To you, my appointment might just be another slot in a hectic day. My perspective is different. As a person with long term conditions, my one hospital appointment a year with a consultant is an important event, with a build-up, an aftermath, and a barrage of emotions.

D Day –7: A sheet of paper on my kitchen table is full of questions to ask. I need to cut them down to what can be covered in an appointment—that is, very few of them. The appointment is already dominating conversations in our house. I wonder how often doctors support patients to prepare for appointments like this, perhaps by sharing an agenda.

D Day –6: I'm worried because I've agreed to do something the day after my appointment, but I know I will be wiped out; emotionally, mentally, and physically.

D Day –5: How am I going to relay all my problems to the consultant in a few minutes?

How can I cope if I don't get answers and have to carry on like this for another year or more until I see him or her again?

D Day –4: What if I see a registrar instead and spend 90% of the appointment going through my history and a few seconds at the end with the registrar repeating what the consultant has already told me? Can doctors find a way to save us from having to repeat our story so often?

D Day –3: My heart is racing. I've spotted a missed call on my phone. Was it from my specialist nurse or a secretary? Neither tend to leave messages and rarely call back. Returning the call involves pressing lots of option 1 and 2 buttons. The caller only wanted me to confirm the appointment. It would be helpful if I could give consent for clinicians to leave messages on my phone, and I was provided with a direct number to use.

D Day –2: When you only see a consultant for a few minutes each year and the consequence of that appointment affects you every day, it needs serious planning. The hardest thing is prioritising the questions. What could I survive the next year not knowing?

D Day 1: I'm terrified of not getting my tone right. It's a fine line between getting angry because I am so upset about my situation and appearing overly grateful. I have to be honest, but

I'm so used to protecting friends and family from the worst of my illness, that it's easier said than done.

D Day: The appointment comes and goes. My parents and I walk in silence to a nearby cafe. I hardly slept last night, and I'm tearful, overwhelmed, and exhausted, and rerunning the appointment in my head means I will struggle to sleep tonight. The consultant listened to me about my symptoms, but didn't acknowledge my emotions. Even "How are you feeling about this?" or "I know these appointments can be stressful" would have helped me to feel understood, relax, and probably engage better in the consultation.

D Day +1: During breakfast, I write a list of things I didn't fully understand and questions that the appointment has generated. I don't know what to do. I wish my consultant would tell me it is OK to ask him follow-up questions by phone or email.

D Day +2: Tearful all day. Daunted by the prospect of another year with the same symptoms and no prospect of change.

D Day +3: Cross with myself. Could I have done more to express how much I am struggling? What could have happened if I had?

D Day +4: My parents admit they feel drained by the experience. It would have been helpful if the consultant acknowledged the impact on them. We are a team.

D Day +5: Feeling low. I try to do all the right things to manage my conditions, but think that I get little recognition for my efforts. If the doctor mentioned them it would boost my confidence and motivate me.

D Day +6: Kicking myself for not asking the consultant more questions when he mentioned a new drug. An information sheet would have been useful.

D Day +7: Still thinking about the "what ifs."

What you need to know

- Acknowledging patient's emotions and the stress of appointments can build rapport and trust
- Supporting patients to prepare for appointments can mean they are less likely to leave with unanswered questions and worries
- Consider organisational changes to make it easier for patients to contact services about appointments and follow-up to reduce stress for patients

Education into practice

- What understanding does this article offer you about patients' preparations and reactions to their appointments?
- How could you alter your manner or questioning to encourage patients who have further questions and concerns to discuss them during an annual appointment?
- How might you show a patient that you understand how difficult an appointment can be for her or him?
- What might you consider doing differently as a result of reading this article?
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