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WHAT YOUR PATIENT IS THINKING

Don't torment me with hope

Alexandra Filby describes the last few weeks of her father's life and the importance of pre-emptive conversations about end-of-life care.

Alexandra Filby

The clinician who told us that my father's cancer had returned was professional, sympathetic, and paused appropriately. Only seven weeks earlier, we had been gratefully celebrating the success of my father's treatment. But, too soon, a dull pain in his pelvis had brought us back to the hospital. I had prepared myself to hear that nothing could be done.

Let's be optimistic

The health professional went on to discuss the next steps, and I noted a subtle change in their tone. The solemnity was gone, and in its place was optimism. There were no extravagant claims, no mention of cures, but their assured familiarity with our situation began to diminish the finality of my father's diagnosis. It felt like permission to pursue survival rather than death, and that was irresistible.

My father, who was not an optimist by nature, was more suspicious: "How long have I got?" We received a well practised answer, which provided no details: "I would be lying if I told you." The health professional then returned to their optimism and continued to discuss all they were going to do.

It suited me to be carried along with this clinical patter. Asking for clarity about the ultimate course of the disease, the associated pain, disability, and end-of-life care would have been much harder. It would have felt like a rebuttal of the generous offer of hope. And that was the only hope we had.

No one said he was dying

We counted down the days to the next appointment, impatient for some active treatment. My father deteriorated by the day. His symptoms became unmanageable and we coped inadequately. We were so uninformed about my father's condition we never questioned why we had no input from palliative services.

The long awaited appointments were dominated by yet more discussions of possible treatments—risks, benefits, side effects, time courses—none of which would ever be commenced. Scans and bloods were booked but never taken. I sensed a lack of urgency, but no one ever said he was dying.

It was a healthcare professional not so well practised in skilful management of the "how long?" question who finally told us. They offered: "I hope and pray you live as long as possible." But we did not want their hope. Hope had become a ludicrous torment. We pressed them again and they faltered: "I would be surprised if you were still alive in two months."

Thank you, my father said. We all did. We stopped chasing treatments, cures, and hope, and instead clung to dignity, compassion, comfort, and love.

Discussing end of life

My father died nine weeks after his diagnosis was confirmed. He deteriorated rapidly. His pain was severe and his loss of independence abrupt. If the reality of death had been discussed at diagnosis, and access to palliative care services provided, we might have been able to seek out what we needed when it was lacking: pain management, specialist equipment, physiotherapy, hospice care, and Macmillan nurses. Instead we were chasing his pain and his evolving needs, always one step behind.

Discussing end-of-life care early with all palliative patients is not about predicting when they are going to die, but raising awareness and expectations for this inevitable outcome, no matter the timescale. If your patient leaves unaware that death is a reality, and what that might look like, then the conversation has been a failure.

What you need to know

- Honesty in discussing the variant courses of a terminal disease prepares patients and their families
- The needs of a patient receiving palliative care evolve continuously, so check regularly if they have the support they require
- Consider discussing end-of-life care alongside the patient's other treatment options

Education in practice

- When would you refer a patient to palliative care?
- How can you ensure a patient, and their family, feel informed about disease progression?
- What other support can you offer patients who are nearing the end of their life?

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