



PRACTICE

WHAT YOUR PATIENT IS THINKING

Finding hope in dying

Molly Bartlett discusses how to have those difficult conversations around not continuing treatment, and how she made the decision to enjoy the time she has left

Molly Bartlett

I received a diagnosis of renal cell carcinoma 20 years ago and had a nephrectomy. By 2013 three more tumours had appeared. I took a hard look at the treatments on offer—an operation or dialysis. I felt pressure to “do battle” and not wave the white flag too soon. But neither of the treatments was a cure and waging war with my body could result in the loss of good time. I decided to jump off the medical treadmill and not pursue any further treatment. Friends and family can put many people in a similar position under pressure to be treated and hold out for a cure, even if treatments offer only a slim hope of more time. I wanted to focus on the quality of time and am lucky to have an understanding and supportive partner who respects that decision.

Difficult conversations

After making the decision to decline treatment, I wanted openness and honesty from health professionals about what lay ahead. I also wanted a space where options could be discussed, with “no treatment” being part of the discussion. Some health professionals assumed I would want treatment and sometimes I felt there was no room to think otherwise. In the end I wrote a letter to those involved in my care as I wasn’t confident that I could maintain my decision, and explain this, face to face. The letter greatly helped me in sharing my wishes and for the health professionals to work with me in refining the details of forward planning. Being able to make this decision for myself, I felt in control again.

“Nothing” can mean hope

Hearing that no further investigations are needed or treatments available can feel as though nothing is left—a feeling of abandonment or being cast away with no hope. But for me “nothing” still meant living the remainder of my days in a meaningful way—it meant focusing on living well today. I wanted to feel like myself during this crucial time, which further treatment could have prevented. It has made me reflect on my life and how I want to live this part differently.

My time is precious, and I still have much to enjoy—being in the garden, listening to the birds, and spending time with my partner, friends, family, and cat. I have also started stargazing. I have found hope in preparing myself, and my loved ones, to fulfil my wishes. This also feels like a time when I can still

contribute to relationships with loved ones and to society. I hope that sharing my experience and decisions with medical students and others has contributed to changing attitudes around patient choice and the decision to stop treatment.

Hope can be found in many ways. Hope that those around me will have the support they need. Hope to have control of decision making for myself. Hope for comfort at the end of life and being supported to do it in my own way. My priority now is to remain positive and enjoy the time left.

What you need to know

- Writing a letter can help patients gather and express their wishes for difficult conversations
- The option to stop treatment should be discussed with patients as much as any other treatment
- Never assume patients will want to continue with treatment. Patients should have the control over this decision if they are able

Education in practice

How could you include no further treatment as a treatment option for patients?

When and how could you encourage patients to write or record their wishes?

This patient wanted to make the decision, to not have treatment for her cancer, alone. How could you support the family members of a patient who has made this decision?

Additional resources

What Now? Questions to ask after a terminal diagnosis <https://compassionindying.org.uk/library/what-now-questions-terminal-diagnosis/>

My Decisions <https://mydecisions.org.uk/>

Free specialist info and support from Compassion in Dying 0800 999 2434, info@compassionindying.org.uk, www.compassionindying.org.uk

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