Tidsskriftet
DEN NORSKE LEGEFORENING

Hope – even when there's hardly any left

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ANONYMOUS
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Patients with terminal diagnoses need hope. The doctor's attitude may help enable a patient to find a meaning in life when time is running out.

The doctor's gaze flickers between the patient – my wife – and the paper in his hand. He has been charged with the thankless task of communicating the result of the biopsy to the patient, who has recently undergone a tumorectomy. He has never talked with her before.

The doctor starts by describing the diagnosis, a severe form of cancer. He then continues with a brief description of the limited range of treatment options, before concluding by saying how sorry he is and how pained he is by having to deliver such a message. He then looks down at his desk before he shakes our hands. We leave the room, both of us devastated and devoid of hope.

Not the doctor's experience, but the patient's

The main issue here is not the doctor's inept remark about his own discomfort, but his failure to concentrate on the patient's situation – apparently showing no appreciation of the implications of such a message for the person or persons concerned.

What makes us doctors behave like gods who believe that we can tell for certain when someone will die, and think we know that life until the time of death will be unliveable? The essence of the message conveyed to us was that this would be such an ordeal that immediate death would be preferable. At least, this was the impression that the conversation left us with. Not a single word about how life, despite the diagnosis, was still worth living. The patient was left with the impression that no more than a few months of life were left to her, even if this was not made explicit.

My wife lived for two years after receiving this first message, which is significantly longer than the median survival for this type of tumour. During this period she had to mobilise a lot of mental strength to live life to the full, while also preparing for death. I know that it would have made it easier for her if the doctor who communicated the diagnosis could have given her some form of hope. For what did this doctor know about the illness of this unique patient or her ability to mobilise hope, fill her life with activities and find meaning in exercise, diet and mental mobilisation?

As well as possible

Doctors who are unable to instil hope in the face of terminal illness should not communicate these diagnoses. By hope I do not mean false expectations related to miraculous cures, but hope of living for as long and as well as possible. Doctors must be able to refer to the fact that some patients live longer than the average and that many live fairly good lives in spite of their incurable illness. Many things can be healthy and meaningful, even in a body with very diseased organs.

In the two years that this patient continued to live after the diagnosis had been made, she came into contact with more than fifteen doctors, all of whom took care to say something that gave hope or comfort. They supported her active attitude to what she was able to do: to exercise, travel, spend time with her family to the extent that her strength permitted. Not at variance with realities, but within a medical reality, for this unique patient at this time in the course of her illness. This supported her in doing the right things to maintain her function and meaning, one hour and one day at a time.

Nevertheless, my experience is that the story of that first encounter is not unique. I too follow up patients with incurable metastasising cancer. They tell me similar stories. They may rely on drugs that have a positive effect on their health, prolong their lives and cause tumours to recede. The patients are happy about this, but they also wonder why some of the doctors responsible for them appear to have little faith in these effects. They do not rejoice with the patient, they rather seem to believe that it is too good to be true.

Respect for uncertainty

Doctors will never be able to ascertain how long patients with terminal cancer will live. We can predict, estimate, assume, believe and hazard a guess, and we may feel proud if our estimates come close. We should have greater respect for uncertainty and let it benefit the patient. Instilling hope is not peddling unrealistic optimism, but supporting patients in their endeavours to continue to live a meaningful life. By not instilling hope we exclude this.

Section 1 in the Code of Ethics for Doctors says: 'A doctor shall protect human health. A doctor shall cure, alleviate and console. A doctor shall help the ill to regain their health and the healthy to preserve theirs.' Our family's experience fell short of this ideal.

We doctors are the ones who possess the knowledge about our patients' diseases. They are at the mercy of our assessments and our choice of words. They listen intently to what we are saying and try to understand what it means. Terminal diagnoses must not become absolute death sentences – such judgments are not ours to make.

Published: 25 March 2019. Tidsskr Nor Legeforen. DOI: 10.4045/tidsskr.18.0826