

## The Chronically Sick Cancer Patient how Should we Take Care of this Patient Group in the Best Way?

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### Opinion

Let me tell you about Josefin.

Josefin was 30 years old when she first came to our clinic in August 2003.

Josefin died 10 years later.

For 10 years, Josefin lived with widespread cancer, bowel cancer with lung metastases.

One month before she died, she competed in a show jumping competition.

She didn't win but she took part.

During the course of these 10 years, her children grew to be 19 and 20 years old. These years were of inestimable value to the family.

Josefin is an illustration of a new patient group, one we see more and more often. The chronically sick cancer patient who may live for many years, going through phases of treatment where symptom-free periods and breaks in treatment are interspersed with treatment and a variety of side-effects and consequences for the patient's quality of life.

When Josefin first sought help from her local health center, her symptoms were not taken seriously. At such a young age? No, you can't have cancer. But Josefin knew, so she returned home and read up on the subject, learning about the very worst symptoms associated with bowel cancer and when one should be X-rayed. THEN, on her fourth visit to the health center, she was finally X-rayed. However, by then the cancer had spread to her lungs.

Josefin was prescribed a wide variety of medication during those 10 years.

She was able to live a healthy, active life for much of this period and was able to follow the development of her children through school and graduation, to share their everyday joys and sorrows, ups and downs.

When she began her treatment she was a university student in Linköping. She and her partner had a farm, Josefin was a down-to-earth woman who midwived the ewes during lambing, took care of the home, worked full-time during those 10 years as well as tending to the house and farm.

Can we afford to treat these patients? What is a human life worth? How do we calculate the profit in two children spending 10 more years with their mother?

What measurement do we use?

Who will measure?

Who will do the calculations?

As the treating physician I had the privilege of following Josefin and her family on her life journey with a metastasised cancer for many years. We shared a great deal.

I was impressed by her courage, her strength, her mental resources, her ability to find joy in everyday happiness, her presence in the here-and-now. In life, in family. I know that every day that Josefin could get out of bed, make breakfast for her children, work on the farm was, for her, a good day.

There are many Josefins around us. Every year 6,000 people in Sweden are diagnosed with bowel cancer. Some of these relapse and then it is generally a chronic, incurable sickness, a matter of winning time and slowing the course of the disease. Treatment is interspersed with treatment-free periods during which the goal is to live as long as possible with the optimal quality of life.

For this mortal life is the only thing we know, our only certainty, and I can assure you that we hold nothing as dear as that we are about to lose. Every day counts, every day is important. Flowers have never been so beautiful, the sun never as warm, the sky never so blue because we know that everything is finite.

That your time on Earth is but a moment becomes all too tangible when one is struck down with an incurable sickness.

Not all patients with metastasised cancer can live for 9.5 years with the help of inhibiting drugs. However, modern medicine has continually increased average life expectancy, from 3 months to 36 months, from 36 months to 3 years and for some, much longer. Every day counts.

Some are diagnosed with cancer in old age. One of my patients was 84 when she contracted bowel cancer. I was hesitant to prescribe treatment; an aging body is less able to repair the side-effects of chemotherapy. But 84 year-old Inger was stubborn. "If there's even the slightest chance of buying a little more time with chemotherapy, I want to give it a try. Because life is wonderful, and it doesn't come around again you understand," she said to me, "and I don't feel that I'm done with it yet."

So, after an additional X-ray and a further visit to the surgery that demonstrated that the will to proceed with treatment was still there, we began with inhibiting medication. Slowly, the tumour shrivelled, discomfort decreased and at Inger's last check-up with me in 2015, she was feeling great. Two years after we began her cancer treatment with inhibiting medication and two weeks after her latest visit to the surgery, I received a letter which began like this:

Maria, when I visited you on Wednesday I was so pleased and surprised by the positive prognosis you gave me that I forgot a couple of questions I had intended to ask you.

The questions followed, and the letter finished thus:

P.S. Everyone around me received your positive news with joy. We had a party!

Inger is enjoying a pause from treatment over the summer. Her family runs a hotel in which Inger is very active.

We have a new patient group in this long and narrow country.

The chronically sick cancer patient. How should we take care of this patient group in the best way?