Sophie Fosså: The survival expert

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Choosing a career as a urologist in Norway was always going to be a tough option for a German woman in the 1960s, and she often felt isolated and unwelcome. But Sophie Fosså's outstanding work as a researcher gained her recognition, and eventually gave her the confidence to look beyond the purely medical needs of her patients.

Sophie Fosså is one of the most decorated oncologists in Norway, recognised internationally for her work on testicular cancer and with cancer survivors, a popular visiting Professor at the European School of Oncology, and a proud wife and mother. For someone at the top of her tree, she did not have a promising start.

She was born at the wrong time to parents whose politics were confounded and discredited. Two successive generations of her family had seen their aspirations shattered, and learning became the only treasure the growing Sophie could trust.

As a young doctor she fell into oncology by default, in a country where she was regarded with suspicion. Moreover, her focus was on science, rather than patients. As she grew more confident and happier, her attitude changed. Her research became less about tumours and more about people. Her consultations became more discursive.

She thinks deeply about her patients and about the next generation of oncologists. She has even learned to unwind a little, albeit she still works hours that make her colleagues flinch. She would like to be a better grandmother, but not yet. Her legacy will be in understanding the effects of cancer and treatment on those who survive.

Born into Nazi Germany

Sophie Gericke was born in Germany in 1941. Her mother's family had escaped revolutionary Russia where her grandfather was secretary to the Czar. Many of her relatives had been shot.

Driven by fear of Stalin's Russia, her school teacher mother became a patriotic German and a member of Hitler's National Socialists. Her father was a soldier and a convinced Nazi. By the time of Sophie's birth, her mother was having second thoughts, and in 1942 she left the Party, an act of some courage. Although both parents survived the war, their marriage did not and in 1945 they divorced. Sophie's early memories are of dreaming that the Russians were coming to kill her.

Her multilingual mother got a job translating for the British army, which allowed Sophie, her brother and two sisters to eat in the military

kitchen. Amidst the ruin of post-war Germany they were able to survive.

"We were very poor. My grandmother and mother taught us that you can lose everything in this world except what you have learned – nobody can take your knowledge from you. So our home was based on intellectual things." Her mother translated English and Russian stories for the children to read.

Sophie's ambition was to be a professor. Aged 17, she went to Münster University and then to Bonn. She fell in love with a Norwegian medical student Jon Fosså, the child of a poor farmer. She returned to Münster to take her final exams and at the age of 23 qualified as a doctor. Sophie and Jon married one week before they left for Norway.

A German in Norway

"Being German in Norway in 1964 was a problem, and the war again became important. When I came to Norway no one could accept anything positive about Germany, even people who knew that I was nothing like a National Socialist."

Her first job was in psychiatry, with troubled adolescents. She took the job because it came with a flat, and had regular hours, which her husband, by now an orthopaedic surgeon, did not. "We wanted six children and we realised that if he was on duty every third night and I did the same, it would be quite impossible. When I came down from University – I knew about diseases. Now I learned that other things were important."

In 1968 she changed direction. Feeling it was impossible to follow her first option of internal medicine, she chose oncology as second best, and moved to the Norske Radium Hospital (NRH) in Oslo. "Lots of people warned me not

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to do oncology. They said it is so depressing. But this was a way I could have children and manage. It was a practical decision." After post-graduate training she began to specialise in urological cancer – the only specialty nobody had reserved. Bladder cancer was treated by urologists and treatment was not up to date.

"The NRH had not much contact with international colleagues, at least not for urological cancer. Chemotherapy was not used for bladder cancer. I had to find my own way and I found it through the European Organisation for Research and Treatment of Cancer (EORTC). I learned about new drugs and new ways to treat this cancer. It took a long time before my hospital accepted that I could introduce them.

"The urologists even wrote a letter of protest to my chief that I was a woman, and this was a male cancer, and I was a foreigner and not an urologist. I understood that the only way to convince them was to publish and look for support in other countries."

She did her doctorial thesis on the study of DNA in bladder cancer using cytophotometry. She worked alone, without supervision, at night after finishing her day's shift. Despite having a young family, she went to the hospital at 5 am for two hours before going swimming with her children and then going back to work. Professionally she felt isolated and unwanted.

"At one time I really thought about suicide, they went so much against me. Norway and the Scandinavian countries had a different way of life. They prioritised their leisure time. They wanted to go skiing or sailing. Very few people really understand that I still think it is fun to do research and to publish."

She was increasingly beguiled by her work. "I saw the research as compensation. I will confess that in the first ten years I was probably not the best doctor for my patients. I saw the medical problem, not the human problem." The father of one young man, wrote: "She is probably a good researcher, but she will never become a good doctor."

In the late 1970s and 1980s the awards for research began to flow, including four from the Norwegian Urological Association. She became a consultant in 1982 and achieved her childhood ambition in 1993, when she was appointed Professor. It is a title she discourages her junior colleagues from using. "I am quite an ordinary person. I don't take myself very seriously."

Fosså took an increasing interest in testicular cancer, where treatment was improving through a combination of surgery, radiotherapy and chemotherapy, especially with the introduction of cisplatin. Confident in her ability to cure these young men, Fosså became interested in their other concerns.

"The patient is scared, but in the back of their mind they wonder, 'If I survive, what kind of man will I be? Will I be able to father children?' I say to these young boys, 'I know that you think about it, so let's talk about it.' The patient will not talk about fertility and sexuality unless I raise it.

"I think young men feel secure and safe when they come to me. Most patients look at me as a kind of mother at this time."

She kept pictures of her four growing sons on display in her consulting room to reassure the young men. "They knew they would get treatment as good as in the Royal Marsden in London or in America. I take a lot of time to talk to them. They have their teddies in their bed and are like children again. Our staff and nurses understand their problems and take care of them."

She introduced a sperm bank 20 years ago. Of the 400 patients who deposited frozen sperm, only 30 have used it, as most fathered children in the usual way.

Survivor work

In 2001, Fosså opened a long-term cancer survivorship unit at the NRH. "I started with

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testicular cancer patients because I had treated them for 30 years and I wanted to know the long-term effects. I also explore the mental side. I think it is very important to see what problems cancer survivors have to cope with due to the disease and their treatment.

"We have done a long-term study of 1,400 testicular cancer survivors in Norway. The quality of life for testicular cancer survivors is as good as the rest of the Norwegian male population. Sexuality is also the same. There is no difference."

She did, however, find other problems. In 2002 she published a paper in the *Annals of Oncology* showing that 20–30% of men who had been successfully treated for testicular cancer in the 1980s had decreased kidney function. In 2004, Fosså spent several months at the National Cancer Institute in the US reviewing a large number of testicular cancer cases. "We know that by giving treatment to these young men we induce new cancers after 20 years. We want to know what kind of cancers we induce after what kind of treatment. I would today be very reluctant to give radiotherapy to testicular cancer patients, which has been a routine treatment.

"I also tell the patient that they may have problems with obesity, blood pressure and cholesterol. They can do a lot through lifestyle factors and physical activity, if they know about the higher risk."

Her work on prostate cancer also demanded a human approach. "I saw patients on whom the urologists had given up. I had to understand that they only had a few months left and help them to get the best out of it. I am very clear and do not hide the prognosis. I think they have the right to know if they will die, to do the practical things they have to do. As I became older it was easier to talk about these things with my patients."

Fosså opposed moves for routine prostate screening. "The urologists wanted the PSA test for all men over the age of 50. I said that there was no scientific evidence that this would help survival. The urologists did not like that very much. Today, they understand that it was a good decision." The Norwegian Urological Cancer Group refused to recommend that Norway take part in the European Randomized Study of Screening for Prostate Cancer trial.

Fosså was gratified to read in October 2004 that Thomas Stamey, who developed the PSA test, now believes that it is overused.

She is hopeful that Taxotere (docetaxel) may be the first in a line of new drugs to prolong life in prostate cancer patients with metastases. But for those at an earlier stage of the disease there are unresolved dilemmas.

"Surgeons have become much better. But they do not operate so many cases as they did. They are very selective. The problem of urinary incontinence has decreased very much. Impotence is still a large problem. Radiotherapy also gives a high chance of impotence."

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So what advice does she give? "You have to sit down with a man and tell him all the side-effects that can be expected. It is very difficult for men to live with the idea that they have cancer but do not get treatment. Quite often he asks 'What would you do, if it was your husband?' I say, 'My husband is my husband and you are you. I would say that this or that option is best for you, but you have to decide.' Most patients want the doctor to take the responsibility, and of course we cannot. The most important thing is to find a doctor you trust and who follows the latest developments."

Fosså also sees patients with cancer of the kidney, and was one of the first in Norway to use interferon to stimulate the immune system. However, there is no effective curative treatment and no cytotoxic drugs that kill cancer cells in the kidney.

"When I started my medical education only

"Quite often a patient asks 'What would you do, if it was your husband?'"

a cure was important, but this is not true. You can do such a lot of things to relieve pain, give palliative treatment and help the relatives. Last week I saw a 95-year-old woman with a large metastasis at the neck. Her only wish is to die in peace without giving trouble to her daughter and family."

"We tell our patients very honestly whether we go for curative treatment or palliative treatment. It is essential for a good doctor patient relationship that both know what is possible and what is not."

Research and practice

Fosså does not see much distinction between research and clinical practice. "Every treatment I give, I do it as systematically as possible in order to be able to use it for research. And I always ask myself, how can I use what I learned in research on the next patient?"

Her long-term survivors' unit is expanding. Fosså sees 10 women a month who have breast cancer. She will also, over the next two years, include patients who had Hodgkin's lymphoma. "I want this long-term outcomes unit to flourish and become a national centre of competence."

Her other remaining ambition is to teach and to help young doctors. She supervises a number of PhD students and lectures. "My children think I should spend more time being a grandmother, and they probably are right. But I have my life and I am invited to conferences. My daughter in law called me to see if I could babysit. I said I can't come, I am in the USA."

In 2001 she organised a meeting in Moscow on testicular cancer, which proved highly emotional for her. "I was very happy to be in Russia. I feel a special link. I closed the conference with a picture of my mother."

Despite starting work daily at 4 am, she claims she is learning to relax. "I only work five days a week, not Saturday or Sunday! A few years ago, I learned downhill skiing, which was an adventure. The first time I went on the ski-lift, it caught my anorak and went up with me hanging from it. I fell to the ground. I told myself that if I did not try again, I would never do it. So I learned downhill skiing and I now love it. It showed me that even at my age I can do things that I never thought I could do."

Two of her four sons are doctors, and one, Alexander, is an oncologist at the Norske Radium Hospital, working on Hodgkin's disease. Her children speak German and Norwegian. One son became a German citizen, married a German girl and lives in Norway. Another married a Finnish girl and lives in Germany. A third married an English girl and lives in London. "We are a very international family."

When, in 1997, she received H.M. King Olav's Research Award, Sophie Fosså knew she was truly accepted. "It was very nice to get an award at the castle. I feel Norwegian, but a Norwegian European. I do not like nationalism, but you have to have somewhere you feel at home. For me that is Norway. When I was first here, there was always some restriction in my heart. I knew that Germans were the reason for many young Norwegian deaths. By engaging with testicular cancer, and especially fertility problems, I have assisted many young Norwegians to be alive. It gives me some comfort."

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