

A carer's perspective on a long and difficult cancer journey.

There's only so much you can do for someone who doesn't want to be helped.

This is the conclusion a number of family members are forced to come to, including one local woman whose husband battled cancer for more than 20 years.

It can be so hard to stand by and do nothing, when your husband or partner won't help themselves.

Else and her husband Robert* moved to the Camden Haven region of New South Wales in 1985.

When not working long hours in their small business, they enjoyed living in the natural beauty of the hinterland area to the west of the Pacific Highway.

In the early 1990s, Robert sent off a bowel test kit, not thinking much about it.

The result came back positive.

Further tests showed he had bowel cancer.

"It wasn't what he expected," Else said.

Within a few weeks, Robert had major surgery, described by Else as "horrific".

"Afterwards he had a colostomy bag, and was being drip-fed; he lost over 20 kilograms [in weight] in a very short time."

"He was so weak when he first came home."

Robert's wellbeing improved steadily once he recovered from the surgery and was rehydrated, and about three months later he had a second, successful operation to remove the bag and restore bowel function.

Asked how Robert felt about the diagnosis, and how readily he accepted her help, Else is unsure how to answer.

"He made it clear my help wasn't welcome," she said quietly.

"He had his own ideas; it was as if what I said or thought didn't matter."

In the early 1990s, Robert sent off a bowel test kit, not thinking much about it. The result came back positive.

* Not their real names.

For certain personality types, it's par for the course to avoid discussion, and to struggle to find an acceptable way to seek help or accept it when it's offered.

"Robert was not a man to show emotion; that's just how he was."

The main point of contention was Robert's smoking. A heavy smoker since his teens, he had resisted any suggestion [from Else or others] to give up.

"He often said that if he found a good reason to stop smoking, he would stop."

When tobacco prices started to climb, his solution was to start growing and drying his own tobacco at home, cutting it finely and rolling it to make his own cigarettes.

Although Robert did stop smoking for a short while after his bowel cancer treatment, he went back to it again.

"He was not prepared to discuss his smoking," Else said.

Approximately two years later, Robert was diagnosed with prostate cancer.

This time the surgeon made it a condition that he give up smoking prior to surgery, so he did.

This time the surgeon made it a condition that he give up smoking prior to surgery, so he did.

"He came home after the surgery and seemed OK – the whole thing didn't seem to affect him much at all."

Life returned to normal after that. Robert discovered computers and eBay, and started buying and selling electronics, computer parts and other bits and pieces.

"I think he needed something new, some kind of regular activity to replace the smoking."

About two years after the prostate surgery, Else received a disturbing phone call from Robert's GP during a consultation. The doctor asked her to come and collect him immediately, and to take him straight to a heart specialist in Port Macquarie.

"When we saw the specialist, he rang the hospital and we went straight there."

"One minute Robert was at the doctor [in Laurieton] and the next he was being admitted to hospital."

The next morning Else was told that Robert was being transported to Sydney for emergency surgery.

"His arteries were nearly blocked, so they put three stents in."

"Throughout this whole heart episode, he didn't seem to show any symptoms, he didn't seem to be unwell or suffering at all."

"Afterwards, he just came back home, still exactly the same."

Life returned to its natural rhythms again, and in 2003 the couple decided to sell their business.

Else smiles as she describes how they bought a new car, and that she managed to stop Robert smoking in it.

A few years later, at age 64, a regular health check-up revealed shadows on Robert's lungs.

It was lung cancer.

Robert was soon on his way to Newcastle for surgery, which involved the removal of a large portion of one lung.

"It was a big operation; there were so many tubes coming out."

"I'm alright," Robert said straight away, and once again, he recovered well.

"The physiotherapist he saw once he was home had no real advice for Robert, as he was doing everything he should have been doing."

A year later more spots were discovered on Robert's lungs and his liver.

"This time he was told there was no use doing any more surgery."

As Robert quickly became weaker, Else, who was now aged in her 70s, wondered if she would manage to look after him at home.

"A community nurse came one day to deliver oxygen and a few other things, but she told us he needed to go into palliative care."

Else and Robert made their way to Wauchope Hospital, where staff did their best to settle Robert in.

"The palliative care people were lovely".

Five days later Robert passed away.

Asked if she got to say goodbye or if she and Robert had engaged in an end-of-life conversation in those final days, Else shakes her head.

"No."

"A few friends came, but I don't think he ever resigned himself to the fact that he was going to die."

Always the pragmatist, Robert simply didn't want special attention or "care".

"I don't feel my role ever changed from being a wife to being his carer. I did the usual cooking and cleaning but he didn't want anything more."

Else has recently dealt with her own health issues, and in the time since Robert died, she's had time to think about their life together.

"At times I've felt really angry. He was only 66 when he died; what a waste of life."

Else also feels his early death could have been prevented [by giving up smoking earlier].

"There was no use arguing about it."

"He was not one to admit being wrong."

"At times I've felt really angry. He was only 66 when he died; what a waste of life."

Else still isn't comfortable about being referred to as a "carer"; she was never allowed to do much "caring" as such.

"He wouldn't let anybody help, even after all those traumatic surgeries."

Else decided to share her story so others in a similar situation might learn from her experience.

"In the end I had to accept that help wasn't welcome."

"It left me feeling helpless; it was alienating."

"In the end I had to accept that help wasn't welcome."

Today Else has come to terms with the fact that *he* was the only person who could do something about his health, and his smoking.

But he didn't want to.

"Robert didn't want to be cared for; he did everything by himself, including dying."

Thank you for sharing Else

"Our Stories" Project – empowering people to share their stories.

To see read more stories, go to www.hastingscancertrust.org.au/our-stories

Contact: OurStoriesProject1@gmail.com



This story forms part of the "Our Stories" Project, which is funded by a 2016 grant from The Hastings Cancer Trust.

The Hastings Cancer Trust is a local not-for-profit organisation that supports local cancer services via their annual grants program.

For more information go to www.hastingscancertrust.org.au.