Stefan Gijssels beat the odds in colorectal cancer. Diagnosed with a cancer of the colon in 2015, a laparoscopic surgery intended to remove what was thought to be a locally contained tumour revealed something much nastier. The cancer had pierced through the colon wall, it had spread to part of the small intestine, and there were metastatic tumours in the lining of his abdominal cavity.

The chances of surviving a diagnosis like that, a stage IV colorectal cancer, were around 1 in 10. Yet more than five years on, he not only remains cancer free, but says there is literally nothing that he did before he had cancer that he is unable to do today. Gijssels knows he is extremely lucky to be the one who survived – and survived well.

Had the cancer been of a more aggressive phenotype, or if it had progressed just a little further by the time it was diagnosed, things might have turned out differently. Had he been more frail, or had more comorbidities, he might not have been able to tolerate the radical surgery followed by six months of highly toxic chemotherapy, and his story might have ended differently.

But Gijssels also believes there is more to the story than just luck. There were things that tilted the odds in his favour. One of these is that he was treated at the Digestive Oncology unit of Leuven University Hospital (in Belgium), under the leadership of Eric Van Cutsem, which, despite handling more than its fair share of challenging cases, delivers some of the best five-year survival outcomes in Europe. This matters, given that, across Europe, quality of care can differ widely between treatment centres in the same country, or even the same city.

Also improving his chances, says Gijssels, was the contribution he himself tried to make, as an active patient, to getting diagnosed (just) in time, and doing what he could to maximise the impact of his treatment, promote his recovery and reclaim his life. Gijssels now spends much of his time working with advocacy groups, policy makers and hospital managers to ensure that knowledge and information derived from the collective experience of patients like him is made available to newly diagnosed patients early on, to give them a chance to be active in tilting the odds in their own favour.

So what can patients themselves do, and what can treatment teams do to maximise the chance of survival with a good recovery? *Cancer World* put the question to Stefan Gijssels and his oncologist Eric Van Cutsem.

Beating the odds: diagnostics and treatment

There’s no magic formula, says Van Cutsem. “You cannot improve your outcome statistics by just changing one thing, you need to address everything. It takes time and a lot of effort.”

Thanks to progress in imaging, diagnostic biomarkers, treatment techniques and technologies, and in knowledge of how best to apply them, some patients who would once have been recommended palliative treatment are now potential candidates for treatment aimed at a cure. The biggest disparities in survival statistics are likely to related to patients at this curability frontier.

> “You cannot improve your outcome statistics by just changing one thing, you need to address everything. It takes time and a lot of effort”

“In many patients with metastatic disease [cure] is clearly not possible,” says Van Cutsem. “But it is possible with some.” One group he mentions is certain patients who present with metastases in the liver that are clearly not resectable. “If you downsize them you may cure some of them. Even in exceptional cases of stomach cancer, which is a tough disease, you can do that.”

Patients presenting with locally non-operable rectal cancer is another group he mentions, where he says significant differences between outcomes delivered by different hospitals can be seen even for stage 2 and 3 rectal cancers. “With more intensive treatments, with chemo and/or radiotherapy before operation, you can more often go for cure in some of these patients.” The quality of surgery also plays a very important role, he adds, together with other aspects, such as the quality of intensive care, for patients who need it.

Getting the diagnostic imaging right, to be certain about exactly where the disease is, and how far it has invaded and spread, is absolutely essential to making the call on treatment options, says Van Cutsem. This includes use of standard technologies, such as endoscopy in rectal cancer, to determine how far the tumour is from the patient’s sphincter to the tumour. But for identifying and analysing metastatic spread, for instance, high-quality MRI is essential, he says.

“It’s not just a question of doing an MRI, but a high-quality MRI and expert radiologists… In Leuven we have access to the best MRIs, with which you can look very adequately for peritoneal metastases – much better than with CT scans.” PET scanning and functional MRI, which provide information about cells’ metabolic or biochemical function, are also needed, after treatment for metastatic disease for instance, to see whether a patient is responding or not.

Part of this comes down to having access to cutting edge equipment – and Van Cutsem stresses the wider importance of access to innovation, including through clinical trials, which are “particularly important for patients with stage 4 cancers”. But equally important is the involvement of radiologists who are expert in capturing the right sequences and analysing and interpreting them correctly. The radiologists he works with at Leuven all specialise in digestive cancers – they spend their working lives immersed in visualising and analysing tissues of that part of the anatomy.

Growing knowledge about how the biology of tumours and their microenvironment influence prognosis and response to treatments also requires integrating new layers of expertise around the multidisciplinary team. “You need people in the lab – a team of marker geneticists, marker biologists, marker pathologists who understand the different platforms and different fusions, mutations and variations in different genes. And can do the interpretation and who can explain its relevance.”

This can be important, for instance, in deciding on treatment options in certain cases of pancreatic cancer. “Should we go for more marker testing or not? In many patients it is not needed. But if you can give a call to the geneticist’s number, you have the knowledge in this situation.”

> “Team work in oncology is not one person, and the team is as weak as the weakest part of the chain”

When Van Cutsem speaks of the importance of working as a multidisciplinary team, it’s clear that he himself relies heavily on the expertise of those around him. “Team work in oncology is not one person, and the team is as weak as the weakest part of the chain. Small hospitals may have good radiologists or good surgeons, but you need the whole team if you are to give a chance for survival.”

What counts, he emphasises, is how well and how fluidly members of the team are able to interact to ensure clinical decisions along the entire treatment pathway are informed by the full range of diagnostic and treatment expertise.

And it is that clinical decision making process that Van Cutsem highlights as a final point. Many treatment centres, he feels, rely too heavily on clinical guidelines, which, while extremely important as a general framework, should not be used as a ‘cook book’. They don’t look hard enough at the specifics of each cancer – imaging, pathology, molecular biology – and of each patient – their health status and priorities – to identify those at the ‘curative frontier’ who are most likely to defy the odds.

Beating the odds: the active patient

Stefan Gijssels has nothing but praise for the treatment and care he received once the cancer was diagnosed, and he is deeply grateful to the whole team – including the dedicated nursing staff – who saw him through some dark days and left him seemingly cancer free.

But as a patient advocate he also feels it is important to highlight the contribution people/patients themselves can make to tilt the odds in their favour. Outcomes will be better when patients actively participate in their treatment pathway, and are given the help and advice they need to do it.

Early diagnosis

An awareness of signs and symptoms that could indicate a cancer, and of possible genetic predisposition, is probably the single biggest contribution anyone can make to tipping the odds of surviving cancer in their favour. But getting doctors to act quickly when patients raise reasonable concerns is not always easy. It’s understandable – complaints of the digestive system are things GPs deal with every day, and it can be tricky to identify the small minority that are associated with a cancer. Gijssels advises people who have serious concerns not to take no for an answer.

In his case, the first symptom was acute pain on one side of his abdomen. He doesn’t blame his GP for suggesting it could be an inflamed appendix, and trying antibiotic treatment. When, after a second lot of antibiotics, the pain was worse than ever, at his GP’s suggestion, Gijssels visited the emergency department at Leuven hospital. He has no good words for the consultant who he says interrupted a more junior doctor in the middle of going through a list of questions, to ask him: “Do you play sport?” On hearing that Gijssels had been playing tennis the day before, he concluded that the problem was a muscle in his abdomen.

“I said: I’ve been playing tennis for years, I know what pain in my muscles feels like. And it couldn’t have happened yesterday because I’ve been complaining about it for months.” But Gijssels was sent home. “They didn’t take me seriously. They didn’t do anything. No scan, no X-ray.”

> “You do what you have to do to tilt the odds in your favour”

Gijssels went back to his GP and told him that both his father and grandfather had died of colorectal cancer. It was almost true: they had both died of cancer. It did the trick, he was referred to an immediate colonoscopy, and that is how his cancer was diagnosed. You do what you have to do to tilt the odds in your favour.

The right treatment centre

For patients trying to survive a cancer with a poor prognosis, finding a treatment centre that consistently delivers good patient outcomes is the single most important thing that could help them beat the odds. Unfortunately, says Gijssels, hospitals, the medical profession, health systems, don't like publishing that information. In August 2018 he found information on the zorgkwaliteit.be (Care Quality) website that showed the five-year survival rates achieved for rectal cancer on named hospital basis, and revealed a difference between the worst and the best of 25 percentage points (62.7% vs 87.7%). Shortly afterwards, he says, the site completely changed, and such transparent data are no longer available.

Gijssels can see no acceptable reason for denying that information to people whose lives could depend on it. In common with patient advocates everywhere, he is arguing for treatment centres to publish their results, as an exercise in transparency but also quality improvement, and he is hopeful that the argument is beginning to gain some ground.

The right diet

Nutrition is another area Gijssels believes patients can help their recovery chances. He sees himself as someone who always made an effort to eat healthily. “My cholesterol was too high, my sugar content in my blood was at the limit so I really looked at what I ate.” But no-one told him that a ‘healthy diet’ for his pre-diagnosis self might not be what his body needed when it was recovering from radical surgery, missing a chunk of colon, receiving chemotherapy and vomiting quite a bit. As a result, he lost 15 kilos over six months.

Six in every 10 patients with digestive cancers suffer from cachexia, says Gijssels – like him, most of them will not have been given dietary advice, and like him, they probably won't know to ask. It matters, he says, not just because your body needs energy to start recovering its strength and fitness, but it can reduce the impact of the treatment. On the one hand, it can reduce tolerance to toxic effects of the chemotherapy, and thereby impact on adherence. On the other, studies show that the catabolic drivers that accompany cachexia also speed the elimination of some anti-cancer therapies, which has been shown to affect survival in some cancers.

The right exercise

Physical activity is another area where good advice and encouragement could help patients tilt the odds in their favour, says Gijssels. Its benefits to people recovering from cancer and cancer treatment have been well documented, but pain and exhaustion can make it hard to get started.

“Don't overdo things… be very cautious… don't lift heavy weights,” was the – very valuable – advice he was given on leaving hospital. As he points out, patients are more than happy to comply, “because it hurts”. But you do need to work to get back in shape, he says, “and that was never mentioned – there was no advice on how best to do that.” As luck would have it, Gijssels is married to an experienced physiotherapist, who helped him get on his feet and walk a few steps, in the first days home, and then encouraged his progress.

The severity of fatigue you can feel while on cancer treatment is something Gijssels says his pre-diagnosis self could not have imagined – just the effort of taking a shower could leave him collapsed on the sofa in a sweat. But some days are better than others. After a few weeks, Gijssels was able to take a short walk on most days. As his fitness began to recover, these would typically last an hour or more, and they became a highpoint in his day.

Advice on walking or other forms of exercise is essential in helping patients assist their own recovery, says Gijssels. “Walking is the best,” he believes. “It is easy to do. Natural. Not exhausting. But it gives you back your lung capacity, your energy.”

Love and friendship

Relationships are another deeply important area of life that can be put under strain – and improve or fall apart – as a result of going through cancer. Here again, talking things through, or getting advice, can help patients steer things in the right direction. It’s easy to get isolated, says Gijssels; friends become awkward, they don’t know what to say, they often just keep their distance. His advice is to reach out to them: “They will appreciate it. You will get energy from it. Don’t isolate yourself because you don’t hear from them anymore.”

> It’s easy to get isolated… friends become awkward, they don’t know what to say, they often just keep their distance

He’s learnt to laugh at some of the insensitive things people can say. An example that would infuriate his wife was: “Oh colorectal cancer – my mother died of colorectal cancer.” “What they mean is ‘I can empathise with you’,” says Gijssels, “You have to accept that and be tolerant. People are not trained to deal with people who have cancer. They say the stupidest things.”

Gijssels found his daily walks were perfect settings for conversations that were able to touch on things and feelings that matter – with close friends, with his wife, with his children.

He’s not saying it is a blueprint for everybody, but that relationships can need attention just as much as nutrition and fitness, and helping patients access advice from professionals and from the collective experience of patients who have been through it before, can be invaluable.

The same can be said about the other aspects of life that cancer can disrupt, including your employment and financial stability, your sex life and physical intimacy, and countless others that will be so familiar to people who have been through the experience – and often entirely below the radar for those who have not.

The best possible outcome

Van Cutsem and Gijssels both agree that there is no recipe for surviving cancer, and surviving it with your life intact. There are things you can do, however, to get the best chance of the best possible outcome. At the medical level, it’s about “and, and, and” – the right infrastructure, the most expert team members who work effectively together, the access to innovation, the personalisation… At the patient level, it’s about recognising how much you can do to help your own diagnosis and recovery, and knowing where to go for help and advice.

At the health system level – and this is what Gijssels has been working on over the past couple of years – it is about ensuring that the two sides work together. A new patient pathway guide in colorectal cancer and pancreatic cancer, designed as part of the Innovative Partnership for Action Against Cancer (iPAAC), states that after diagnosis patients should be referred to a disease-specific patient organisation, as these have the expertise and experience to orientate the patient in relation to all aspects of the disease and treatment, and equip them to play an active role in their own treatment and care, to help them tilt the odds in their own favour.

Illustration by: Maddalena Carrai