

# Deciding Whether to Have Treatment and Understanding Side Effects

In the throes of your anxiety about the future or your enthusiasm to just get started with treatment so you can beat the disease, you might regard this chapter curiously. After all, what's there to decide about having treatment for a condition as serious as cancer? As more than one patient has scoffed, 'I will die without treatment, so what's the decision here?' I hate to imagine that my patients think I am frittering away their time with indulgent questions that they can ill afford to ask. But this is an emerging question in many areas of medicine, not all cancer-related—what is the net benefit of a treatment that is usually accompanied by side effects? For some the benefit is clear. They are being treated with the intention of cure, which means that the inconvenience of temporary side effects may be worth the long-term chance of being free of disease. But for many people, especially those with advanced or metastatic (and

hence typically incurable) forms of illness, or conversely, very early cancer, if we agree that one of our goals is to maximise quality of life by avoiding significant toxicity, this is an important question to ponder. Like many patients, you might be feeling too frightened or overwhelmed to give this matter much thought, but I think it is worth your time.

I want to start by telling you about a memorable patient, Peter. Everyone wants to own him as a patient—the surgeon, the radiation doctor and the oncologist. But, in a polite way, Peter dislikes medical professionals and, given half a chance, is quick to espouse the view that the secret of his wellbeing is his successful avoidance of doctors.

At eighty-two years of age, Peter was diagnosed with early prostate cancer via a blood test that his doctor obtained as part of his annual check-up. Scans and a biopsy followed and a multidisciplinary team concluded that with his type of early prostate cancer, there was no so-called ‘best’ treatment. Rather, there were options, and it would come down to an informed decision taken by the patient. Armed with the phrase he had heard most often in the past few weeks—‘patient preference’—he did the round of doctors to see if they could help him decide.

The urologist kept Peter waiting for two hours as he was caught up in theatre. Finally, the surgeon arrived and ushered—or as Peter described it, *herded*—him in. He was a man in his forties who worked at a flying pace. Everything from the surgeon’s illegible writing to his advice was rushed and he made no attempt to curb it. The prostate cancer was early and hence operable; Peter could have the operation next week. The procedure was reasonably straightforward, he performed a few every day, and the outcome was usually good. ‘But there is a risk that you could end up with

impotence or incontinence and —’ At that point, Peter lost interest. When his wife, Elizabeth, asked him later what the surgeon said, all he could reply was, ‘I don’t think the operation is necessary, love.’ In his mind he thought that even if it was, that surgeon wasn’t the right man for him. He wanted someone with more time.

Peter’s doctor arranged for a second opinion from an older surgeon. He didn’t think that surgery was essential but spoke about suppressing the male hormone testosterone that encouraged prostate cancer growth. But along with the names of drugs, he rattled off another list of side effects that seemed no less daunting than the surgery’s. Peter heard ‘impotence, hot flushes, heart and bone disease’ and thought that if it were up to him, he would just collect his spade and shears and get right back to gardening. But Elizabeth would worry, so he felt he had to try harder.

Next on the list was the radiotherapy doctor. She was a pleasant Irish lady and they spent a bit of time talking about his youth in Ireland. She told him she could offer radiotherapy but it too had a variety of side effects, some long-lived. Peter’s thoughts went immediately to his friend Barney, who suffered persistent diarrhoea and the urge to urinate following radiotherapy for prostate cancer. What could be worse than running to the toilet every hour while he was tending his garden? He heard that the radiotherapy would happen every day for a few weeks. Who would run his business if he was constantly in and out of hospital? Elizabeth could manage for a few hours or days but not weeks. She couldn’t keep track of where the various plants were, and hated doing large orders. It didn’t take long for Peter to cross out radiotherapy as an option, but he couldn’t bring himself to tell the doctor just yet so he asked for some time to think it over. In actual fact, he was going to use that time to plant a long-promised rose garden for an old friend.

As he enjoyed getting his hands dirty in the soil, he noted to himself that the two surgeons and the radiation doctor were equally confident about their recommendations. Could it be possible that both treatments were similarly effective? And if so, why didn't anyone say so clearly? Why did one expert pit his opinion against another? The final doctor on his list was the oncologist, which was me. With delays and cancellations, it had taken him two months since diagnosis to get through his list of doctors. I could tell that he was impatient to cover the last base. 'I know that surgery is not for me, neither is radiotherapy. I have talked to my GP, Dr Joe, about hormones to block testosterone, and I can't say they sound too good either. Hot flushes, impotence, heart problems are just the ones I remember.' He fixed me with an earnest gaze. 'Tell me, doc, is it really necessary to have any treatment?' I looked at him curiously. Usually the question from patients is about how much treatment, not whether to have any.

'I have some graphs and figures I can show you that help predict the risk of the cancer spreading—would it help if you saw them?' I offered.

He simply answered, 'No, I want to trust someone to be straight with me.'

All doctors make decisions about their patients—whether to try one drug or another, whether to recommend surgery or not, whether to even bring up the possibility of certain therapies that may disappoint or are unaffordable. But somehow, the recommendation whether to have or forgo cancer treatment seems particularly weighty and in a different class altogether. I think it's because the subject of mortality never strays too far from the mind when one mentions cancer. Starting or stopping someone's aspirin or blood pressure tablet may well have serious long-term consequences, but

if you get cancer therapy wrong, the results can be acutely distressing and potentially fatal. So it is always with a heightened sense of respect and responsibility that I take on a patient's request for me to judge what is best for them.

As I listened to Peter, however, I was consoled that he had long made his decision—he was just looking for an oncologist to back him up. It was clear that Peter's life revolved around his ability to work. He was indefatigable in the garden and was very clear that he wanted to be in a healthy state for as long as possible.

'Peter,' I advised, 'if you were much younger, there could be an argument to act now, because of the potentially longer lifetime over which the cancer could grow and spread. But at eighty-two with early prostate cancer, you can afford to watch and wait.'

'When I first found out, of course I wanted something done about it,' he said. 'But the more people I talked to, the more I realised that nobody was offering me a free cure. There are serious problems associated with whatever you do—I'm damned if I do and damned if I don't. I'm a simple man, doctor. I just don't think the risk is worth taking, not at my age.'

'What does Elizabeth say?'

'She says to get back to the job and stop wasting everyone's time if I've made up my mind!'

'Peter, let me ask you something. Does uncertainty bother you? I mean the uncertainty of relying on your instincts, when experts around you are recommending their treatment.'

'No. All my life I have trusted my gut feeling.'

'I wish more people could put as much trust into their instinct as you do.'

'I've listened carefully to all the doctors. Now, no one is saying

I *must* have treatment. What they are saying is that treatment is available. I reckon they're two different things.'

I was struck by the astuteness of a man who would rush to describe himself as simple and unsophisticated. Thanks to decades of painstaking work, there is plenty of good evidence in oncology about things that work and don't work. But scientific data is nuanced, there to be interpreted as liberally or conservatively as you like. Should an operation be done simply because it is technically feasible? Is a six-week increase in survival due to chemotherapy significant? It depends. To a thirty-year-old mother of three, every day counts. To the octogenarian ailing widow, perhaps not. Would you be willing to exchange greater toxicity, including, say, vomiting, fatigue or infection risk, for a potential gain in life? Again, it depends on the value you place on quality versus quantity. If you are twenty-four years old, that gain could mean a lot. If you are sixty-four, you may just think about it a little more. But at ninety-four you might dismiss the proposal completely. So decisions about chemotherapy are not always about right or wrong, black or white, as much as living by a personal philosophy, elements of which change with age.

The next week I sat down with Peter and his wife to reassure her that he had not made a rash decision but an informed choice. I made arrangements to see Peter in a few months' time. I told him that if he wanted, I could do an occasional PSA test (PSA stands for Prostate Specific Antigen, a blood test used to monitor prostate cancer) and we could always revisit his decision. He seemed happy with this degree of control and on his way out told the secretary that he was delighted at the reprieve. He had not slept the previous night thinking that I would change my mind.

That was six years ago. Peter is now eighty-eight, completely well, and still working hard in his nursery. He has had to hire an extra hand—his eldest grandson, who takes after his grandfather. Two years after his initial diagnosis, Peter decided that he didn't want to have his PSA checked at all. 'I feel fine and I'm not interested in knowing what a number is doing,' he declared. It was hard to argue with his logic.

It seems that like many older men, Peter will die *with* and not *of* prostate cancer. He still comes to see me, joking that he does so as a public service reminder that all cancers do not equate to doom. When I see him I can't help thinking that his life could have been significantly adversely affected by the proposed treatment. Peter is a good example of taking ownership of one's health decisions. No one could have predicted the precise effect of therapy on Peter, but he himself was always sure about one thing—he wanted to be the chief decision-maker. This is not an easy role to assume but for those who do it successfully, it can be a rewarding one.

Patients like Peter who have early disease are lucky to avoid toxic treatment, but there are many others who are found to have metastatic disease (i.e., cancer that has spread beyond the initial site) and for whom chemotherapy would be a usual recommendation. Perhaps you are in this situation, where you are expecting to have chemotherapy. But you may be wondering whether it is right for you. How do you know that you will tolerate it well and, moreover, derive benefit? And what will the benefit look like? You likely wonder whether you will eventually be healthier and live longer.

The diagnosis and staging of cancer is relatively straightforward compared to the decision about treatment options. Thirty or forty years ago, treatment options were as woefully limited as our knowledge of how cancer behaves. Chemotherapy was available for

only a few diseases, and it was ruthlessly toxic. One of my retired bosses recalled sedating patients to enable them to tolerate treatment. If initial chemotherapy failed and the patient survived, there was the occasional option of a second-line drug, but it wouldn't be uncommon to accept that there was nothing else. Incidentally, palliative care as we know it today was yet to take shape, so even the comfort care was basic, relying on sympathetic words and gestures more than carefully studied therapies to alleviate suffering.

But in the last decade or so, medical knowledge has exploded, leading to ongoing advances in the design of new therapies. As a result, there is a profusion of treatments, and if you take into account various clinical trials being conducted around the world, and the ubiquity of internet-based information for the patient and oncologist, the most common cancers have more treatment options than the average oncologist can utilise. If the only question asked is 'Is there *any* chance that this treatment will help?' you will find the answer likely to be yes. Unfortunately this answer is not really helpful.

Before we discuss whether treatment is right for you, let's go over some of the common terminology. Standard or first-line therapy (whether involving chemotherapy, radiotherapy, hormonal therapy, targeted therapy or a combination of these) is one that has usually been rigorously tested on large numbers of patients and has been shown to make a significant difference in some specific parameter, such as the time to cancer recurrence, prolongation of life or a reduction in troublesome symptoms. In other words, there is evidence that it helps patients and it can be useful to know roughly how it will help you.

Second-line, third-line, fourth-line therapy, and so on, refer to a change in chemotherapy treatment after standard therapy is



deemed to have failed. The failure may be due to progression of the cancer or intolerable side effects, or a combination of causes. (Experimental therapies are those being studied on current cancer patients. These therapies are usually offered via a clinical trial or specialised access schemes run by drug companies. I will discuss them later in a separate chapter.)

Generally speaking, every time disease resists one line of treatment, the chances of responding to the next line are smaller because cancer cells are very good at developing new ways of resistance to drugs.

A medical oncologist's armoury contains three main weapons against cancer. They are chemotherapy, targeted therapy and hormonal therapy. Chemotherapy is the traditional form of treatment. The number of chemotherapy drugs currently outweighs targeted and hormonal therapies. It is also true that the vast majority of current cancer treatments utilise chemotherapy as the main treatment to which non-chemotherapy drugs can be added, although this might change in the future as more targeted therapies emerge.

Targeted therapies, virtually unheard of in clinical practice a few years ago, are becoming increasingly prominent. They are different from chemotherapy in important ways. Rather than the more blunt approach of chemotherapy, these therapies target specific internal pathways in dividing cancer cells. Traditional chemotherapy does more collateral damage to normal cells, which is why one experiences nausea, vomiting, hair loss and infections from it. Targeted therapies don't have the same severe side effects as chemotherapy, and are usually better tolerated. This doesn't mean that they are entirely without side effects. Many patients complain of a rash, nausea, diarrhoea or lack of appetite, and indeed, some targeted therapies can lead to life-threatening problems. Many

targeted therapies are given in combination with chemotherapy, which exaggerates side effects.

Hormonal treatment is used for cancers that grow under the influence of hormones, such as breast and prostate cancer. Less frequently, they may also be used in other conditions. Contrary to popular belief, they too have side effects, but these are rarely life-threatening and patients are able to fashion a lifestyle that accommodates these effects.

Since chemotherapy is the backbone of most modern cancer treatments and its toxicities are the most dreaded, I want to use the next section to deal with decision-making about whether or not to have chemotherapy.

There is a common saying that applies as much to medicine as it does to other aspects of life. If you go to a baker you will get bread and if you go to a butcher you will get meat. If you go to a complementary medical practitioner you will get vitamins and if you go to a chiropractor you will get manipulation treatment. Loosely speaking, in cancer treatment (oncology), a surgeon may recommend an operation, a radiation oncologist may recommend radiotherapy, and a medical oncologist chemotherapy. Competing recommendations usually occur when there is no straightforward solution. This is what happened recently when a patient of mine developed a recurrence of her cancer. The surgeon felt that the lump was small enough to remove. But the radiation doctor recommended first shrinking the tumour with a few weeks of radiation. Then someone suggested she should have chemotherapy too and sent her to me. The young woman had been through a very difficult time during her initial diagnosis and was adamant that she would not have more chemotherapy or another operation. When she told me frankly that the thought of further chemotherapy or

surgery would plunge her into depression, as she'd experienced the first time, I knew that we had to avoid these two options. In the end, she received only radiotherapy, which worked well and provided a durable response, avoiding the need for an operation.

You may wonder how one diagnosis can attract such a variety of treatments. Surely one is superior to another and doctors should be able to decide which is best in a situation. But this is not necessarily true. Furthermore, every professional knows their area best and feels most confident recommending their form of treatment. The emergence of multi-disciplinary teams in hospitals means that many experts weigh in on treatment to ensure that the patient receives optimal care. But it's well known that the availability of more options increases the risk of over-treatment.

If you are sent to a medical oncologist, your referring doctor thinks that you either require chemotherapy or should at least have a discussion about it. Oncologists don't necessarily intend to talk you into having treatment but prescribing chemotherapy is routine for them. The average oncologist sees hundreds of patients a year and a condition that seems unique to you is commonplace to them. This means that sometimes oncologists can unintentionally sidestep crucial information that you might expect us to broach. Harm minimisation is a good example—it has different meanings for doctor and patient. When discussing chemotherapy side effects, a busy doctor might tend to prioritise them into a hierarchy of what a patient most needs to know, which means perhaps emphasising some side effects and skimming over others considered less important.

'You told me about infections and hair loss, but you never said the nausea would be so bad that I couldn't get out of bed,' a patient once reported tearfully. 'I have not been able to lift my head for the

whole week. It's ten times worse than being pregnant.' I felt regretful that I had only mentioned nausea in passing while spending plenty of time on the remote risk of heart failure.

'The ringing in my ears is driving me insane,' said another. 'I can tolerate everything else but the ringing is like a shadow, following me day and night. I wish someone had told me it could be this bad because I would never have had chemotherapy.' This seventy-year-old patient unfortunately went deaf soon after abandoning his chemotherapy. His enjoyment of music disappeared and he became depressed. It's hard to know whether he would have had chemotherapy treatment if someone had emphasised the small but real chance of deafness, but the problem had a terrible impact on his life.

With the genuine improvement in cancer cure rates, many patients will be left to grapple with the sequelae of chemotherapy.

It is very important, then, that any discussion of chemotherapy entails a detailed mention of side effects and the degree to which you should expect them. Although it is impossible to predict exactly how chemotherapy will affect you, an oncologist can make educated decisions based on your age, general health, stated preferences of what effects would concern you most, and the proposed treatment itself. This is the only way in which you can decide which side effects are worth putting up with. For a diabetic on the verge of dialysis, any prospect of worsening kidney failure may be unacceptable, while for an actress hair loss may be the deal-breaker. If you spend most of your time reading documents, diminished sensation in your fingertips may not be as objectionable as it would be to a concert pianist whose livelihood would be ruined if her fingers did not register the finest of touches. A woman with terrible memories of vomiting from her last chemotherapy twenty years

ago could not bring herself to have any treatment that might lead to nausea, while an elderly man refused to have chemotherapy that might bring on diarrhoea and compound his existing problems with a colostomy bag.

This is a good place to mention that you should always try to take somebody with you to an appointment, especially those where key decisions are made. No matter how well and capable you feel, it is quite likely that a trusted escort will provide you support and add value to your recollection of the medical conversations you have.

Although the list of side effects from chemotherapy is daunting, modern medicine has made tremendous gains in handling many of them. Older oncologists speak of a time when they felt helpless against severe nausea and vomiting and needed to sedate patients—with the advent of powerful anti-nausea drugs those days are fortunately over. Over the years we have also learnt how to better use antibiotics, painkillers, blood growth factors, transfusions and other measures to support patients through chemotherapy. When I mentioned this to a 25-year-old nurse receiving chemotherapy for breast cancer, she looked at me in disbelief. Not having been out of pyjamas for a week after her first cycle, she could scarcely imagine that her peers twenty years ago might have suffered worse. Her plight highlighted the fact that despite major advances, chemotherapy-related toxicity is a major drawback to cancer treatment and one that can have enduring physical and psychological effects. So it is vital to be informed about what you are signing up for.

Many patients, of course, are courageously willing to brave intense toxicities for the sake of getting better. They may be self-motivated or be encouraged to do so by others. But the key ques-

tion is when should you soldier through side effects and when should you say enough is enough? 'I'm willing to go through this whole damn process, tough as it is, if you can tell me there's light at the end of the tunnel,' James, an electrician with malignant mesothelioma, recently told me. Mrs Jones, a 76-year-old widow, put it like this: 'Having chemo means a year out of my grandchildren's life—if I know that I can make up for it in the next five or ten years, I will do it, but if the answer is no, then I really need to think carefully about whether to put up with it all.'

James and Mrs Jones are not unique in expressing the concern that undergoing the rigours of chemotherapy must make life substantially better than the alternative of forgoing it. This is a common sentiment—spoken and unspoken—in every patient's mind: 'Is it worth it?' Most people will want to know whether chemotherapy will help them live longer. Answers to that question can be interpreted in different ways: 'There's a reasonably good chance', for example, leaves room for different levels of confidence. Evaluating the risks involved in chemotherapy and its potential benefits—the risk benefit ratio—is helped by the available statistics. And while, again, no two patients, or for that matter two oncologists, will interpret the numbers in exactly the same way, it is important for a patient considering chemotherapy to try to get their head around them. Stay with me as I quickly explain the paramount concepts of *relative* and *absolute* risk reduction.

Few people—including among oncologists—enjoy talking through statistics, but allow me to illustrate their benefit with a very simple example. Take a group of 100 patients with the same type and stage of your cancer. Without chemotherapy, ninety-eight will live and two will die in the next five years. With chemotherapy, ninety-nine will live and one will die. The *relative risk*

*reduction* is 50 per cent, since the number of people who have been helped by having chemotherapy is one out of two. But the *absolute risk reduction* is 1 per cent, since only one extra person survived as a result of chemotherapy and ninety-eight people were destined to survive anyway. So one person out of 100 was helped by chemotherapy, but all 100 were exposed to the harms, some of which were immediately visible, others not. It is possible that one or two people out of the cohort of 100 might suffer fatal toxicity.

Here is a second example. Out of 100 patients with another cancer, fifty will survive and fifty die within five years. With chemotherapy, seventy-five will survive and twenty-five will die. The *relative risk reduction* is again 50 per cent, the same as the previous example, because where fifty patients would have succumbed to cancer, with the chemotherapy only twenty-five will. The *absolute benefit* is 25 per cent. This means that out of every 100 people to have chemotherapy twenty-five will benefit, a much better figure than one out of 100. However, here, too, all 100 people will be exposed to potential harm.

A conversation with the oncologist in both scenarios may unfold like this:

‘Doctor, what are the chances of chemotherapy helping in my situation?’

‘Pretty good, actually. By having chemotherapy, you halve your chances of dying from cancer.’

To most people, this would sound like an appealing, even highly optimistic prospect. Studies have shown that patients are willing to accept much, much smaller gains in survival than 50 per cent.

But if the first question was followed up with further queries, the answers may give pause for thought.

‘What does that actually mean for my condition?’

In the first scenario I described above, the answer is: ‘Well, the figures show that roughly one out of every 100 people like you will live longer due to chemotherapy.’

But the answer in the second scenario is different: ‘Studies show that out of every 100 people like you, twenty-five will live longer due to chemotherapy.’

So, although both chemotherapy treatments in these scenarios claim to halve your chance of dying, the true or *absolute* benefit gained is significantly different. For some patients, a one-in-100 chance of a benefit is unfavourable and they would turn down chemotherapy outright in favour of enjoying quality of life without the side effects of treatment, and take a chance on survival. Some may consider a twenty-five in 100 chance of benefit unacceptable too, but others would conclude that having chemotherapy would put the odds in their favor. The key is that patients were able to make an informed decision.

Another way of explaining benefit is known as *number needed to treat*; that is, statistically, how many patients need to have this chemotherapy before one of them is likely to receive a benefit? If chemotherapy is beneficial, you want the *number needed to treat* to be small. If chemotherapy has limited potential to help, lots of people will need to be treated before one patient sees a benefit, so the number needed to treat is high.

In the first example, the number needed to treat is 100—this means that 100 patients need to have chemotherapy for one person to benefit—and hence the gain from chemotherapy is small. In the second example, the number needed to treat is four—only four patients need to be treated for one to gain—and hence the benefit is much larger.

Advances in cancer medicine mean that there are several good



decision aids available to the oncologist to explain difficult concepts in simple terms with the help of words, numbers and graphs to suit different understandings. Part of understanding the numbers is appreciating when chemotherapy doesn't necessarily prolong life but is used to reduce the burden of cancer symptoms. It is true of many metastatic cancers that even the most aggressive chemotherapy may not buy any meaningful time; however, it may improve quality of life by alleviating symptoms, including pain, shortness of breath, coughing, headaches, weight loss and tiredness. This alone may make chemotherapy a worthy endeavour, provided the patient understands the difference between prolonging life and controlling symptoms. Thinking about these things may also help you choose between different types of chemotherapy, which might offer different absolute benefit along with their varied levels of toxicity.

Lara was a 49-year-old patient of mine with metastatic cancer of the pancreas. When I met her I couldn't help noticing that she was spending a week of every month in hospital due to chemotherapy-related toxicity. Sometimes it was for a blood transfusion, other times for hydration. Some weeks her pain was awful, other weeks her bowels didn't work. I asked her why she was continuing to have chemotherapy and she snapped at me, 'For the same reason as everyone else—I want to live longer.' She was devastated to eventually realise that far from adding time to her life, chemotherapy might actually end it prematurely. At first she denied ever having been told this, but on closer reflection she said, 'I've been avoiding asking these tough questions, hoping the oncologist would find a way of letting me know if it was really bad.' When I advised that she should stop chemotherapy altogether, she

was relieved that someone had made the decision for her. Far too many patients brave chemotherapy due to misconceived notions. They assume it will prolong their life or, even in the face of mounting evidence to the contrary, believe that they will eventually feel better. In some cases, it is indeed true that if you can withstand the rigors of chemotherapy you will stand to benefit, but often this is not the case. Patients then believe that if things aren't looking up, their oncologist will surely let them know. But from an oncologist's viewpoint, for a patient like Lara, who looks comfortable with her own decisions, it's the right thing to keep giving chemotherapy until the patient says no more. After all, no one wants to paint a picture of doom and gloom if it isn't absolutely necessary. Despite good intentions, conversations about goals of care are unfortunately uncommon.

For some patients *any* plausible chance of benefit is worth the risk. Others value quality of life over everything else; still others want to know that they have done everything humanly possible to defeat the cancer. The frustrating thing for both patients and oncologists is that there really is no right or wrong answer. So when a patient asks me what I would do, I can't help feeling like a surly teenager when I answer, 'It depends.' To which they sometimes respond impatiently, 'Depends on what?'

To me, it depends on what you value. You might value the spirit and courage that has helped you in the past. You might have a gut instinct that you will beat the disease. You might value knowing within yourself that you fought a good fight. Or you might value an untainted quality of life for as long as possible, and the freedom from recurrent hospitalisation, travel to the chemotherapy unit and blood tests. You might value taking the holiday of

a lifetime or spending time with your children or grandchildren. You might not see the value in living longer if that life comes with complications, or you may feel that you have led a full life and don't fear death. Naturally, life is rarely simple, rarely an either-or situation. I believe facing decisions about cancer treatment is a time to act according to one's fundamental values.

Navigating one's values becomes easier when the medical information is complete. Research shows that patients presented with only *relative risk reduction* information are more likely to endorse chemotherapy—it sounds very promising expressed in this way—but they're also more likely to be dissatisfied with their decision, because they're left uncertain about what it means. When presented with further information, such as *absolute benefit* or *number needed to treat*, such patients are more likely to change their decision. If people clearly understand that chemotherapy will not prolong their life, they make different decisions to those who mistakenly believe it will. Of course, it is equally important to understand if chemotherapy will prolong life because the information might buoy you in difficult times.

'I don't understand why you guys don't give that information in the first place,' a 62-year-old woman once grumbled, after having the risk and benefit evidence explained to her. She made a good point. Different oncologists explain what they are offering in different ways. Medical professionals don't intentionally withhold information, but far too many patients complain that they don't receive anywhere near as much information as they would like. I know that sometimes I'm not sure about the answers, and other times, despite the best of my efforts, a patient is not interested in having a conversation about numbers and statistics. Sometimes a

patient prefers to trust me to do the right thing, and other times she has made up her mind well before she comes in to see me, because there is no lack of advice, information, and misinformation about cancer.

You may be at a point where you are really not sure about what to do. It's common to feel lost but willing yourself to think through some options with a cool mind might save you future worry. Take some time to think of the things that matter most to you. Share these with your oncologist when deciding on treatment. Don't assume that they are personal things in your life that your doctor won't be interested in hearing—a good oncologist will be glad you are sharing your thinking with them, and will find it helpful in guiding you to the best treatment option. Perhaps together you can write out a list of things chemotherapy will and won't achieve. This is why it is so important to find an oncologist whom you feel you can talk to. When you make a decision, you should feel it is an informed one.

### **Key Points**

- Not every cancer requires immediate treatment and some cancers may never require toxic treatment. Doing nothing is a reasonable option sometimes.
- You cannot make a decision about the value of chemotherapy without having a frank and honest discussion about your priorities. This is especially relevant when your cancer is incurable.
- Central to your cancer management is understanding absolute and relative risk. Ask your oncologist to explain

these to you in plain language using decision aids so that you can make informed decisions about treatment at this crucial time.

- Take a trusted carer or friend to any appointments that discuss major decision points. You may not remember everything that is said. Write down important information, request plain language explanations, and don't feel rushed into making a decision.