Are you feeling lucky?

Discussing risk and treatment options with patients

→ Anna Wagstaff

Doctors use trial-based evidence and years of experience to assess risks of treatment and relapse. But patients make choices based on their own experiences and priorities. How can doctors best explore treatment options with patients? *CancerWorld* asked the experts and offers Ten Tips for Effective Communication About Risk.

ancer is beset by uncertainty. Despite dramatic increases in the amount of information from clinical trials and translational research, doctors are still unable to accurately predict who will suffer recurrence or relapse or who will respond to a particular therapy. Patients often have to decide whether to opt for adjuvant chemotherapy, radiation therapy or hormone therapy to protect themselves from something that may never happen. Treatments can expose the patient to serious risks, and may make them feel worse than the disease. People at high familial risk may decide to take radical preventive measures such as having ovaries or breasts removed, without any certainty that they would ever develop cancer. Patients with metastatic disease have to understand the trade-off between treatment and

side-effects, and decide whether to sacrifice quality of life for the chance of extra months of life.

Not only must patients make choices that could save their lives or mean damaging treatment for no benefit, but no-one can ever be sure before or after the decision whether it is, or was, the best decision for them. So it is very important that these decisions on treatment options should be made jointly by the doctor and patient in partnership.

This is easy to say, but not so easy to do, because doctors reach decisions on treatment options through a process which is alien to the way most patients approach the same decisions. Most patients are illequipped to grapple with statistics and science; while many doctors have trouble seeing beyond the disease and its epidemiology. It is easy to overlook what the diagnosis and treatment options might mean for the patient's work life, family life, social life and sex life.

Doctors base their knowledge on evidence-based medicine, which is often derived from trials involving thousands of individual patients, who have been stripped of personal characteristics and reduced to a selection of potential prognostic and predictive factors, from which appropriate guidelines and protocols are derived.

Deciding on the best treatment for an individual patient involves matching them up with the relevant prognostic and predictive factors, and throwing in data on comorbidity. These calculations become increasingly complex as research uncovers new biological and molecular markers. Nowadays, doctors often make use of nomograms to make risk-benefit calculations, to support their own clinical judgement.



A partnership. The doctor knows more about the disease and treatment options, the patient knows more about how these may affect his life

Evidence-based medicine is not under question. However, nomograms do not provide data about any individual patient, all they do is offer values for the apocryphal 'average' patient with a defined set of prognostic and predictive factors. Drawing up guidelines involves value judgements about relative costs and benefits. which can lead in different directions. There is, for example, a greater use of adjuvant chemotherapy for early breast cancer patients in the US than in Europe, while UK paediatricians have tended to opt for less intensive use of radiotherapy in young rhabdomyosarcoma patients compared with their US counterparts.

Prostate cancer most clearly illustrates the catastrophic results that can occur when treatment options are not informed by the priorities and values of the patient. The introduction of PSA screening led to a generation of men having their lives blighted by incontinence and impotence because a generation of urologists failed to understand or communicate the true risk associated with more slow-growing or indolent prostate cancers, or to explore with patients the effect of treatment on quality of life. As a result, it is estimated that at least one-third of patients with good prognostic signs treated with radical prostatectomy in the previous two to three decades never would have needed it. Today, a doctor is much more likely to recommend intensive monitoring, than plunging in with the knife.

Patients often have huge faith in their doctors, and sometimes want to pass on the responsibility of taking the decision. "What would you do in my shoes, doctor?" is a question that is often asked, but no doctor is in a position definitively to answer it.

Presenting information to patients in a way they can understand and act on is a high-level skill. Yet many oncologists finish their training inadequately equipped to communicate effectively with their patients. He or she has to understand how the patient perceives their diagnosis, their hopes and fears, their background and responsibilities, their preferences and their level of knowledge. To help the patient to make a decision, a doctor requires listening skills, time with the patient, opportunities for repetition, endless patience and the ability to call on other means of support.

But circumstances are stacked against this. The medical setting in which the consultation takes place tends to undermine the patient's sense of identity, individuality and autonomy, and time is at a premium. As Louis Denis, Director of the Antwerp Oncology Centre, says: "The doctor is in a hurry, the patient is panicking."

CancerWorld has talked to patients, oncologists, cancer nurses and a genetic counsellor and distilled their knowledge into Ten Tips for Effective Communication About Risk.

Tip 1 It takes two

Effective communication requires *lequal status* for what the doctor and patient bring to the consulting room. Too often authority wears a white coat, while the patient feels like a number or a bundle of case notes.

Both sides can do something to change this. The patient can bring a family member or trusted friend to the consultation as a way of retaining their personal identity, and for practical back-up (see Tip 6). The doctor can involve other health professionals, such as specialist cancer nurses or psycho-oncologists (Tip 7), who are able to spend more time getting to know the patient in advance and talking things through later on.

Having a row of medical students observing the consultation can feel very intrusive. Medical students have to learn, but the patient should be given the option to refuse their presence *before* inviting them into the room, numbers should be limited to one or two, they should be properly introduced.

Terms of address should reinforce a sense of equality. Patient and doctor should either both use first names or both adopt a more formal 'Mr' and 'Dr'. If possible, avoid carrying out a physical examination at the consultation session, particularly if this involves undressing or wearing a hospital gown. It is hard to feel equal without clothes.

Make it clear that there is no rush to reach a decision, and that the patient will have time to absorb the information and, if need be, come back and discuss it further. Be aware that patients often pick up a sense that the doctor's time is short while they are sitting in the waiting room. Patients who feel under time pressure will be inhibited from asking questions or expressing their concerns.

Many patients are torn between wanting to know, and fear of hearing something they cannot cope with. If a doctor launches into a routine explanation, the patient is unlikely to enter a dialogue. Doctors can ask the patient what they understand is the purpose of the consultation, giving them an early opportunity to talk about what they hope, fear and feel about what they are going through.

"It is a dialogue. Not, 'here are the facts, now make a decision,' but being able to establish a rapport. Let them talk a bit about how they feel, and where they are at, and that will help you tailor the information to them."

Clara Gaff genetic counselor

"It's so important to encourage the initiative of the patient, so they are not automatically led into something they have not had the chance to absorb, never mind consent to... Listen, listen and listen again to the patient. What is the patient saying between the lines?" **Rita Pilbrow Carlsson** breast cancer patient

Tip 2 Keep language simple

Make an effort to use language that is easy for non-medical people to understand, and explain words that carry a different meaning in everyday language. For instance, "response" means that a tumour shrinks or grows less quickly - but patients may assume it means "cure". "Aggressive" means the cancer is fastgrowing or will spread quickly, but it carries other connotations in daily language. Avoid euphemisms like "lump" or "tumour" or "neoplasia", at least until the patient understands that these words relate to cancer. Patients are not stupid and most will suspect they might have cancer. Until they are clear about whether or not they do, it will not be possible to move on to focus on examining options.

"My consultant [specialist], 1 think was frightened of my response and said something like: 'On a scale of cars, you have a 2CV as opposed to a Ferrari,' and didn't mention the word cancer. My GP (family doctor) drew me a diagram, explained it to me and gave it a name."

Eve Setch haemangioendothelioma patient

"Generally speaking the patient asks the nurse for more explanation or clarification, because the nurse usually speaks in simpler terms."

Kath MacLachian and Lynn Dowde specialist breast nurses

Kath MacLachlan and Lynn Dowde work for Breast Cancer Care, UK: www.breastcancercare.org.uk

Side-effects: keep it personal

I t is important to consider how each potential side-effect might impact on each individual patient.

The doctor needs to understand the patient's lifestyle, priorities and preferences and be willing to have a meaningful dialogue exploring what each option could mean. Care should be taken to *avoid making assumptions* about, for example, who will be most concerned about possible impotence. The side-effects of treatment may damage someone's self-image, selfesteem and self-confidence, just when they need those things most.

A doctor understands infertility, early menopause, incontinence, impotence, neutropoenia, fatigue and neuropathy, but not what each of these means to the patient.

Mastectomy, hair loss, hot flushes, incontinence or impotence can each have a devastating effect on one patient, while others may find them easier to cope with. Fatigue may be less important to a patient who can take time out to look after themselves, than to a patient who feels obliged to keep working, or to continue 'normal' family life. Some people will be desperate to avoid the risk of becoming infertile, while for others this could be a minor issue. Neuropathy may mean trouble with buttons for some people but loss of a job for others.

"Some oncologists do tend to assume that a patient with a disability, perhaps in a wheelchair, won't want to attend daily radiotherapy. But some people want treatment to minimise the risk, no matter how old they are. And we know from experience that any woman, regardless of her age, can be devastated at the thought of losing a breast."

Kath MacLachlan and Lynn Dowde specialist breast nurses

Tip 4 Statistics: explaining the figures

Deciding on the best treatment often involves complex trade-offs between alternative risks or combinations of risks. For instance, adjuvant therapy becomes more attractive the higher the risk of recurrence, the more serious that recurrence would be, the greater the effect of therapy in reducing a risk, and the less serious the risk of side-effects and their consequences.

Although not all patients want to explore statistics, doctors need to be able to help them navigate their way through choices by explaining numbers in the simplest possible way. A great deal of research has been done on how to do this most effectively.

THE PERCENTAGE GAME

A survey asked respondents how many people out of 100 would develop a disease if the chance of getting it was 10%. One person in five could not work it out. People are most proficient at comparing two risks and indicating which one is larger. They are less proficient at adding risks, interpreting a trade-off in risks (e.g. a drug cuts one risk in half but doubles another) or understanding a sequence of risks (the probability of a side-effect occurring, and the probability that if it occurs it will be serious).

Risk factors and probabilities can be presented in a variety of ways: 20% is 1 in 5, or 20 in 100, or a ratio of 1:4. *Try to stick to one system*.

Patients find it easier to interpret trade-offs when risks are presented in the form of 'N in base' comparisons (20 in 1000 compared with 70 in 1000).

However, they understand percentages best when interpreting a sequence of risks (for instance a 70% risk of relapse and a 20% risk that any relapse will be fatal). Any percentage smaller than 1 is poorly understood.

Studies also show that some people understand 1 in 10 as a higher >>>

risk than 1 in 5, simply because they associate the higher number (10) with higher probability. This can be avoided by using *the same denomina-tor*: i.e. compare '2 in 10', '5 in 10' '1 in 10', in preference to '1 in 5', '1 in 2' and '1 in 10'.

Some people find graphical presentations easier to understand than figures. Decision trees (see opposite) can be helpful for evaluating options that involve a number of successive risks (e.g. risk that you will survive the transplant, risk that having survived you may go onto relapse, etc.). Bar charts and line graphs can help explain benefits in survival over time. However, they can also be misleading. For instance, graphs that show only the top half of the survival curve (i.e. from 50% to 100% of the patient sample) can make the increase in survival offered by a particular therapy look twice as great as it really is.

Relative risk is frequently a source of confusion for doctors and patients, and can magnify perceived levels of risk or risk reduction. Clearly if the risk of an adverse side-effect rises from 1 in 1000 to 2 in 1000, the risk has doubled, but the odds remain extremely favourable. To give a real life example, for women with Her2+ breast cancer, adjuvant early Herceptin can decrease the relative risk of recurrence in the first few years by around 50% - i.e. it halves the risk of recurrence. But that risk without Herceptin is only about 20% in the first few years, so the absolute risk reduction is only 10 percentage points. The patient is much more likely to focus on the 50% ("my risk is halved") than on the 10% that is relevant to her decision.

Avoid the abstract. People may understand statistics better if they are put in human terms. "In a group of 100 women with your type of diagnosis, the chances are that 20 will have a recurrence within 5 years, and 80 will not. We don't know whether you will be one of the 20 or one of the 80. If all the women took adjuvant hormonal therapy, it is likely that only 10 will have a recurrence and 90 will not."

Using *comparisons* such as "as likely as being struck by lightning" or "you are more likely to be run over by a bus" may be less informative than they sound (patients will have their own ideas about how likely these may be, and anyway both depend heavily on circumstances), and may be misleading. The odds of a big win on a national lottery are said to be smaller than the risk of being murdered, but every week millions of people confidently predict that their numbers will come up on the lottery, without worrying about murder.

Many of the above findings are contradictory (or true within some contexts and not others), and they mainly relate to written presentations. A doctor-patient consultation gives an opportunity to discuss the risk, in a situation where the doctor can assess how well the patient understands these concepts, and can tailor their approach. The examples of Roger Wilson, a leiomyosarcoma survivor, and Jan G, a CML patient, shown below, show how differently patients approach the question of risk, and how important it is to be able to tailor the information and the discussion to the particular patient.

APPLIED STATISTICS 1

Roger Wilson: "You either will or you won't survive"

Roger Wilson is a leiomyosarcoma survivor with a background in the media. When diagnosed with cancer his response was to look for as much information as possible. However, he did not find statistical data very helpful in decid-

ing what to do. Roger is 1 of 4 complete remissions out of 322 patients who participated in a trial six years ago comparing doxorubicin with two experimental schedules of ifosfamide for metastatic leiomyosarcoma. The odds against him were 80–1, but as far as he is concerned, the success of the treatment in his case was the statistic that really mattered. "In your mind, whether the odds are 30:70 or 70:30, for you it is still 1:1. It is a binary issue. You either will or you won't."

APPLIED STATISTICS 2

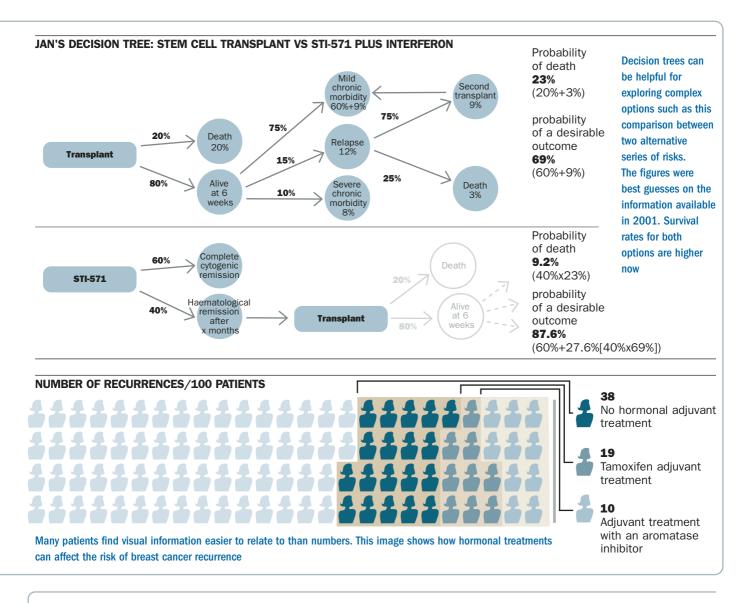
Jan G: "I calculated the odds and used a decision tree"

Jan G is a chronic myeloid leukaemia (CML) patient with a background in information technology. When he was diagnosed in 2001, at the age of 28, his response was to turn to the statistics for guidance: "I got the figures from medical



reports, Internet discussion forums and various doctors – I took the median of those." Jan had two options: immediate bone marrow transplant, or joining a phase II trial of STI-571 – now Glivec (imatinib) – and interferon. He drew up a decision tree (see opposite) to show the likelihood of dying associated with the two options, and decided to opt for the Glivec. So far, the decision has served him well, but he recognises that many patients find this highly objective approach "too rational", and that many would not have the statistical skills to do this for themselves.

GrandRound



Tip 5 Statistics: keep it personal

S tatistics can seem a welcome oasis of hard information, but even patients who understand the figures often find them unhelpful when interpreting their own situation. Tailoring information to the individual can make a big difference. The doctor may view risk factors as per-

"Patients cannot and do not want to see themselves in statistical terms, and probably find it very unpleasant and unconstructive to have to discuss their treatment options with a doctor who talks like that." **Rita Pilbrow Carlsson** breast cancer patient

centages, but the patient may find it easier to consider 'real-life' risk factors rather than figures, such as what was found at surgery, various >>>

"What does help is to assist the patient to understand that the treatment they are recommended is tailored specifically to them as an actual person." **Kath MacLachlan and Lynn Dowde** specialist breast nurses

pathological reports and scans, and relevant medical history.

Some doctors find Adjuvant! online (www.adjuvantonline.com) useful. This is an Internet programme for breast cancer assessment, which draws on information from various databases and the literature. Available to health professionals (and designed to be used by the health professional and patient together), it calculates the risk of negative outcomes, the reduction of risks afforded by therapy, and the risks of side-effects, once a doctor (or nurse) feeds in data from the patient's pathology reports and medical history. Estimates are printed out in graphical and text formats, for discussion with patients.

It can be helpful to *use words as well as numbers* to indicate risk levels. Although phrases such as "highly unlikely", "not very likely" or "fairly likely" are unspecific and open to interpretation, studies have found that they actually do a better job of representing true feelings than numeric scales using odds or percentages, due to the way most people process information.

It is also important to recognise that patients interpret statistical risk according to their own preconceptions, "Asking survey respondents to place a numeric probability on the occurrence of a health outcome and then comparing their answers with objective data is one of the least meaningful and least reliable measures of risk understanding." **Neil Weinstein** (*JNCI* 25:15–20)

experiences, emotions and so on.

Events that are more serious are often perceived as being more likely to happen. Thus a chance of 1 in 8 seems objective, but feels more likely to a patient when applied to more serious outcomes, such as metastases, than to less serious outcomes such as neuropathy.

People also think that something that has already happened to someone they know is more likely to happen to them. Thus, two women with identical breast cancers may have very different views about probable outcome, if one had a mother who died from the disease, while the other has two friends who both survived it.

Doctors should therefore be aware that the statistical message they are giving may be different from the one the patient receives. This is why it is helpful early in the discussion to *talk about what experiences and prior information the patient already has*. Asking, "What do you know about the cancer/proposed treatment?" is one way of doing this. This can help the patient to reveal the experience that is influencing their judgment. The doctor may then have an opportunity to explain: "From what you say it sounds as if your mother was diagnosed when the cancer was already quite advanced. Luckily your cancer has been picked up quite early, which means there is a much better chance the treatment will be successful."

The immediacy of the risk can also affect perception. Faced with a cancer diagnosis, a patient may panic and only be able to think about the risk of the disease and getting rid of it as soon as possible. They may find it impossible to focus on the longerterm implications of treatment options. Encouraging a patient to take time to talk through the risk of sideeffects may help them to balance one risk against another. For example they might consider how a risk such as infertility or impotence would impact on their mental health, their relationships and their plans for the future. Patients may later become very bitter about such outcomes if they feel they had no opportunity to discuss them when they were deciding on treatment.

FROM MORE THAN ONE ANGLE

G enetic counselors tend to use absolute figures (e.g. your risk of developing colorectal cancer during your lifetime) and relative figures (e.g. you are three times more likely to develop colorectal cancer than an average person of your age). They may also offer 5- and 10-year probability figures (your risk of developing colorectal cancer within the next 5/10 years). Giving data that present a different angle on the same issue may confuse some patients, but will help others to formulate a more complete picture in their mind.

Take enough time – use it well

ack of time is the single constraint Limentioned most often by doctors as hampering communication with their patients. But time has to be taken. The issues are complex, and the patient can be overwhelmed by the situation and the amount of information. Faced with a cancer diagnosis, patients can panic and reach for a snap decision. In most cases, the patient loses nothing by giving themselves a week or two to decide how to proceed. They stand to gain a great deal by taking stock of their situation, and talking through options with their doctor, friends and family. Trying to rush a con*sultation can be a false saving.*

Make best use of time with the patient. A lot of time in consultations is wasted going over information the patient already knows, while things they need to talk about are barely touched on. Asking patients what they already know saves time. Reading the patient's notes avoids asking the same questions two or three times (a common complaint from patients). Focus on the information most relevant to the decision that has to be made.

Around 70% of information provided when the patient is first given a cancer diagnosis is not retained. Retention can be improved if the patient *brings a member of the family or close friend* as a second pair of ears, and if they take notes. See also the advice under Tip 8 (Signposting the patient) about how to reinforce information.

"I tell the young urologists that you need to give more time in the first consultation and you will gain it back in all the subsequent consultations." **Louis Denis** urologist

"Take time for explanations after the diagnosis. Re-explain if the patient doesn't understand. Give them the impression there are no silly questions. Offer them the chance to come back after they have made up their mind, and ask questions again. If this time is invested in the beginning, it will make things much easier in the course of the treatment."

Jan G CML patient

LISTENING SAVES TIME

"One of the feelings some doctors have is that consultations will take much longer if they have to do all this touchy feely stuff, but an Australian study looking at oncologists' reactions to cancer patients' verbal cues (Butow et al. *Psycho-oncology* 11:47–58) has shown that this isn't the case. What can happen when people aren't really getting what they want or when they don't feel they've been heard or understood is they start asking the same question over and over again, sometimes in slightly different ways, and the doctor can get quite frustrated thinking: 'I've already given them the information, why are they asking again?' It tends to be an indication that some underlying emotion is not being recognised." **Clara Gaff** Genetic Counselor

A team approach

I t is hard for one doctor to fulfil all a patient's needs for information and for discussion. Patient and doctor can both benefit from the involvement of specialist cancer nurses, psycho-oncol-

ogists and other members of a team. There is great scope in much of Europe for *making better use of nurses and other health professionals*. Nurses who are part of a cancer team normally have more contact with the patient, and know more about the family situation and their emotional state, and may be better placed to talk things through with a patient at his or her own >>> pace. Patients often feel more relaxed with nurses, and it is common for patients to open up and ask more questions after the doctor has left the room. However, it must be the doctor who plays the critical role in discussing and helping the patient decide on treatment options.

"Doctors often feel they have to provide every bit of support and information to a patient. They don't have to do it all themselves. They need to be aware of who is around and who can help."

Kath MacLachlan and Lynn Dowde specialist breast nurses

Signposting the patient

T here are many avenues to helping patients to take in information, understand their condition and judge available options. Some doctors encourage their patients to *tape the consultation*, so they can listen to it again where and when they want. Written information should be provided from the start, and the patient should be asked to read it before they attend their next consultation. Patient groups are very willing to check written information to ensure that it is appropriate, relevant and easy to understand. Doctors can supply their patients with a short list of the clearest and more accurate *resources on the Internet* that are designed for patients. This will help them to access good-quality information and make it less likely that they will visit sites with poor-quality or misleading advice.

There are many *independent sources of support and information* to help a patient build a picture of their disease and treatment options. Many countries have support agencies with free help lines staffed by health profes-

"It is extremely important that doctors do not work against the patient's request for a second opinion. It should be encouraged and not met with the arrogance I received from one consultant [specialist] in a UK hospital. His exact words were: You can either believe me or choose another consultant." **Rita Pilbrow Carlsson** breast cancer patient



Doctors should offer their patients a list of good-quality relevant Internet sites. This comprehensive list of French-language sites was compiled on the initiative of Rouen University Hospital

sionals who can be an additional source of information and advice. Some hospitals have a cancer information centre or a psycho-oncology service that takes referrals.

All these options provide sources of support and information, which patients can access in their own time.

Cancer units should *compile a list* of all these resources and should make them available to patients. Though this might seem an obvious point, doctors are not always natural networkers, and often omit to mention patient groups or cancer information centres, even those attached to the same hospital!

Doctors can also *encourage a* patient to seek a second opinion. It can be reassuring for a patient to hear another specialist talking in similar terms, even if the second opinion varies slightly from the first. Suggesting a second opinion and offering a list of names gives an important signal that the patient is being encouraged to make an informed decision, rather than following recommendations out of blind faith.

Patient groups

Many patients say that the insights and information they found most useful came from other patients. It can be easier to discuss painful and frightening issues with someone in the same situation, who talks from personal experience. Patients in patient groups are often also experts – and have good reason to be.

Most European countries have patient groups for many cancers, local or national or attached to a particular hospital. Patient websites and chat groups can also provide information and put patients in touch with people facing similar situations, although language may be a limiting factor for non-English speakers.

Working with patients to *set up a patient group* where they do not already exist is an important way that specialists can help patients learn what they need to know.

"If you really do believe in partnership with patients and joint decision making, I cannot see how you can work effectively without a patient group. [Helping set up a group for stoma patients] was the best thing I ever did in my life. It takes a lot of patience and time to get them organised. But once they are organised, if you are lucky they work on their own and are certainly not dependent on your opinion, they form their own opinion, because then they have contacts."

"I think quite often one of the biggest influences on a patient's decision is another patient who has been through that decision before. You get some sort of 'decision inheritance' that works in an untraceable way." **Roger Wilson** leiomyosarcoma patient

Tip 10 The right decision?

Doctors have a responsibility to ensure, to the best of their ability, that a patient's decision is based on an accurate picture of the medical facts. *Talking through with the patient how they reached their decision* may reveal misunderstandings or logical flaws that need to be explored further. However, afterwards, it is never possible to say whether a decision was right or wrong. There is no telling whether a recurrence might have happened with or without adjuvant chemotherapy. "Some patients have said 'no thank you' to a recommendation of anti-hormonal medications such as tamoxifen or aromatase inhibitors. Others have refused chemotherapy. These patients should be informed fully about the statistics and treatment guidelines, with material they can take home to read, but most of all their decision should be respected. Some patients have felt threatened into having the recommended treatment, although their inner voice says something quite different."

Rita Pilbrow Carlsson breast cancer patient

There is no knowing which patients gained tremendous benefits from treatment, and who suffered sideeffects needlessly. Patients with similar diagnoses make different decisions based on a myriad of factors, including different priorities and preferences, and differing feelings about their chance of being one of the lucky (or unlucky) ones.

The patient lives or dies with the consequences of a decision, and it is not for a doctor to say whether it was right or wrong.