II

Your body, your choice
If you remember only the five questions discussed in this chapter when you finish this book, its purpose will have been fulfilled. Keep them in mind and refer back to them as you read the rest of the chapter. They form the basic toolkit that will help you put into practice many of the things that we suggest.

1. What will happen if I wait and watch?
2. What are my test or treatment options?
3. What are the benefits and harms of these options?
4. How do the benefits and harms weigh up for me?
5. Do I have enough information to make a choice?

Figure 5.1 Five questions to ask when making a smart health choice.
1. What will happen if I wait and watch?

This explores:
- What can I expect to happen ‘naturally’ in my situation?

2. What are my test or treatment options?

This explores:
- What tests are available for people in my situation?
- What treatments are available for people in my situation?

3. What are the benefits and harms of these options?

This explores:
- How accurate are the tests in people like me? Could having the tests be harmful?
- How effective are the treatments in people like me? What aspects of my health could be improved by the treatment? Could the treatment be harmful?
- How likely are the benefits of treatment for me? How common are the harms?
- When could I expect to see these benefits and harms?
- How long lasting are the benefits and harms if they occur?

4. How do the benefits and harms weigh up for me?

This explores:
- What benefits are most important to me?
- Am I prepared to take the risks in order to achieve the benefits?

5. Do I have enough information to make a choice?

This examines:
- Does the available information answer my questions?
- Have I found out about all the test and treatment options that I want to consider? If not, where can I go to find out more?
Depending on the severity of your illness, and whether your practitioner has satisfied you that he or she practises evidence-based healthcare, you may not need to explore the quality of the evidence behind the answers to the first three questions. But if you do feel the need to validate the evidence to these questions, you will find the necessary techniques to do so in Part 4 of this book – Evaluating the evidence.

When we talk about ‘tests’ in this book we don’t just mean blood tests and X-rays. In many ways, even having a health practitioner examine you is a type of ‘test’. Similarly, when we talk about ‘treatments’ we refer to more than medication. ‘Treatment’ can include lifestyle choices such as exercising more or drinking less alcohol. It could also include physical treatments such as massage or heat packs or acupuncture.

We now take these questions one at a time to explore how they can help you make smarter health choices.

1. **What will happen if I wait and watch?**

   A few years ago Lewis Thomas, an influential and thoughtful essayist on scientific matters, wrote that the dilemma of modern medicine, and the underlying central flaw in medical education, is the irresistible drive to do something.

   *Glennys Bell*

   There is a natural temptation for consumers and health professionals alike to assume that, if something is broken, they should try to fix it. But many conditions are self-limiting – you will recover from them, and perhaps treatment will not speed up this process, or will only quicken it marginally with the chance of causing an adverse effect.

   That said, good sense should always prevail. If the condition is likely to have serious consequences if no action is taken, it is probably not advisable to take the approach of ‘watchful waiting’. Whether you decide to seek treatment may also depend on how much the condition is affecting you and your personal circumstances.
Bruce, for example, wakes up feeling rotten, with a sore throat and thick head. He recognises the symptoms of a cold, and considers his options:

1. He could battle on for a few days, going to work as usual, to see if it gets better without treatment. This option is called watchful waiting.
2. He could take a tablet to relieve his symptoms, knowing that this will not actually cure the cold but may make him feel well enough to continue his usual activities.
3. He could take a few days off work.
4. He could ask his practitioner for advice on other options.

As Bruce has an important conference looming, he decides on the fourth option to make sure that he does not have anything more serious than a cold and to get some additional advice on symptom relief.
Taking this option may not make any more difference to Bruce’s recovery than taking the first option, but his decision is affected by his circumstances. As watchful waiting is usually the first option, it should be the baseline against which all other options should be measured.

How you perceive the seriousness of a problem will determine how much time and energy you want to spend on the remaining questions: none for a trivial problem but much more for a major illness. Remember that the decision to wait and watch should be an informed choice, not an avoidance technique just because you cannot decide on another option.

2. What are my test or treatment options?

There are often many possible options for diagnosis and treatment, so it is a good idea to consider the most reasonable few options first.

What tests are available for people in my situation?

It is not always useful to have a diagnostic test – for example, if your condition is one of three possibilities, all of which have the same treatment, you may consider that it is not worth the time and effort to have tests. And the mere fact that a test exists does not mean that it is necessarily useful. For example, many people with acute low back pain are referred for X-rays, although the results of such tests do not provide a reliable guide to what treatment should entail or even to the cause of the problem.

Any test involves risks and most tests are not 100 per cent accurate. If there is a risky test for your illness but a relatively safe treatment, you might prefer trying the treatment first to see if the problem disappears. However, if there is real uncertainty about what your problem might be, and what is the best way to treat it, a diagnostic test might be valuable.

What treatments are available for people in my situation?

You need to know whether the treatments are aimed at curing the condition or simply relieving the symptoms. You may wish to
consider a range of options from different types of practitioners, for example, your pharmacist, GP, specialist or homeopath.

3. What are the benefits and harms of these options?

Remember that you can only judge a test or treatment’s benefits and harms by considering what would have happened without them. Finding out about the benefits and harms of the options involves asking:

- How accurate are the tests in people like me? Could having the tests be harmful?
- How effective are the treatments in people like me? What aspects of my health could be improved by the treatment? Could the treatment be harmful?
- How likely are the benefits of treatment for me? How common are the harms?
- When could I expect to see these benefits and harms?
- How long lasting are the benefits and harms if they occur?

It is important to keep these issues in mind for all options, whether considering a diagnostic test or a particular treatment.

How accurate are the tests in people like me? Could having the tests be harmful?

Diagnostic tests almost always involve some inaccuracy. As a result of this, a positive test result does not necessarily mean that you definitely have the disease, nor does a negative result mean that you definitely do not have the disease; there will always be some false-positive and some false-negative test results.

Say you decide to have a test for an infection. If the result is positive, you may have, for example, only a 60 per cent chance of having the infection – or a 90 per cent chance – depending on the test’s accuracy. (In other words 40 per cent – or 10 per cent – will be false-positive results.) If the test is negative, however, you still have a chance of having the infection – perhaps somewhere between
a 5 and a 15 per cent chance. This is why it is important to find out, in terms of probabilities, exactly what the test results might mean in your case. If your practitioner simply says the result means that you are at ‘low risk’ or ‘high risk’, you may understand these terms very differently from your practitioner, whereas it is much
clearer if you are told you have a ‘10 per cent’ or a ‘95 per cent’ risk.

If your practitioner suggests that you have a test, you should consider asking these questions:

- What disease are you testing for?
- What do you think my chances are of having the disease?
- If the test result is positive, what is the chance that I do have the disease? Or, if the test result is negative, what is the chance that I have the disease anyway?
- How will the test result influence treatment of my condition? (If the result will have no effect on your treatment, you may want to think twice about having the test.)
- What are the potential harms of the test?

(For further information on the accuracy (sensitivity and specificity) of tests see Chapter 16. For further approaches to deciding when a test is worthwhile, see Chapter 17 on decision thresholds.)

**How effective are the treatments in people like me?**
**What aspects of my health could be improved by the treatment? Could having the treatment be harmful?**

You need to know how the benefits and harms of any treatment might affect your quality of life and your survival, rather than what it is likely to do to your red blood cell count or your blood pressure – often called *surrogate* measures. Surrogate measures describe the results of different biological tests. They are not necessarily an accurate reflection of what is most important for you, the quality and length of your life – these are *person-centred* outcomes. It’s important for you to know what aspects of your health could be improved by the treatment, not just what numbers might appear on a laboratory printout of test results.

Surrogate measures are used as markers for disease but do not describe the more important *person-centred* outcomes that affect how long and how comfortably you might live. For example, knowing that a treatment will lower your blood pressure, or that some diet will alter the bacteria in your bowel may be interesting, but tells you
little about whether your pain will be reduced or your symptoms relieved. It also tells you nothing about whether you will live longer (on the benefit side) or whether you might feel lethargic, lose your hair or have diarrhoea (on the harm side).

Research has not, however, always examined the effects of treatments on person-centred outcomes; instead it often examines their impact on surrogate measures, such as blood counts. Sometimes, in the absence of evidence about whether your life will be happier or longer, you may have to make decisions based on the assumption that a beneficial effect on surrogate measures will translate into a beneficial effect on your health. For example, many people with HIV began taking drug cocktails because they had been shown to reduce the amount of virus in the body, but before it was known whether this would improve the length or quality of their lives. Understandably, as HIV is such a serious disease, many people were willing to take such medications because of evidence showing that they improved surrogate measures.

But such assumptions can be mistaken, as we describe in more detail later, with the drug that was widely used to treat arrhythmias – an abnormal heart rhythm that can occur after a heart attack. As people with arrhythmias are more likely to die after a heart attack than those without arrhythmia, it was assumed that giving a medication to suppress the arrhythmia would prevent deaths. When a randomised controlled trial was eventually completed, it showed that the antiarrhythmia drug suppressed arrhythmias but increased the number of people dying. Similarly, the drug mibefradil was taken off the market around the world after it became apparent that the drug, although effective at lowering blood pressure, could also cause serious problems when interacting with other drugs.

**How likely are the benefits of treatment for me?**

**How common are the harms?**

You can never be certain about the outcome of any treatment; it is impossible to predict exactly what will happen to you when you have a disease or embark on treatment. What can be predicted, however, is the probability that a particular outcome will occur.
This issue is more complex than it might first seem. Consider, for example, the prediction that taking a certain drug will reduce your risk of dying from a heart attack by 20 per cent over the next 5 years. What if the drug is also known to increase the death rate from all other causes by 20 per cent over the same period? You may assume that this 20 per cent decrease in coronary deaths and 20 per cent increase in other types of death will balance out. In fact this may not be the case if fewer people die over this period from coronary heart disease than from all other causes combined.

Making an informed decision about whether to take this drug will depend on what is known about your risk of dying from a heart attack versus your risk of dying from other causes over the next 5 years. The probability that an individual will experience particular benefits or harms from the treatment is related to that person’s level of risk. A healthy adolescent, for example, will have little risk of dying from a heart attack over the next 5 years so does not stand to benefit from taking a drug to reduce death from heart disease. For him or her, the 20 per cent increase in the risk of dying from other causes clearly outweighs the benefit of the intervention. In other words, a 20 per cent reduction in a relatively uncommon cause of death is not balanced out by a 20 per cent increase in a more probable cause of death.

At the other extreme is someone at very high risk of dying from a heart attack – such as someone who has already had a heart attack or who has unstable angina. For someone in this situation, the benefits of the treatment are likely to outweigh the harms.

Another example might be to consider by how much your risk of getting or dying from bowel cancer might be reduced by having a faecal occult blood test (FOBT) every 2 years. Several large randomised controlled trials have shown that doing this will reduce your chance of dying from bowel cancer by around 23 per cent. We also know that your risk of bowel cancer increases with age, and that it is more common in men and increases if you have a family history of bowel cancer. So if you are a 60-year-old man whose mother died of bowel cancer in her 70s, your risk of dying from bowel cancer over the next 10 years is about 13 in 1000 and this is reduced to 10 in 1000 with 2-yearly FOBT. If your risk is lower to start with, then the 23 per cent reduction won’t be quite as much.
The number of lives saved by screening will be much less if you are younger and don’t have a family history.

So it is important that you know not only the probability of benefits and harms from a particular intervention, but also how they relate to your situation.

When could I expect to see these benefits and harms?

Knowing when benefits and harms are likely to occur – whether they are likely to occur immediately or years down the track – can have a great bearing on their significance. For example, you may have to weigh up the immediate harms of chemotherapy for cancer – such as nausea, hair loss and discomfort – versus the chance that it will prevent future recurrence of disease and death.

How long lasting are the benefits and harms if they occur?

Knowing how long a benefit or harm is likely to last is important for evaluating its impact on your well-being. If a harm is temporary, you may consider it worth suffering in order to gain a long-term benefit. Alternatively, you may think twice if the trade-off for a short-lived benefit is a permanent harm.

An example of a temporary harm is a rash as a side effect of a treatment. When treatment stops, the rash clears. An example of a permanent harm is the loss of vision as a complication of surgery. This harm may not be reversible.

4. How do the benefits and harms weigh up for me?

‘Would you tell me, please which way I ought to go from here?’ said Alice. ‘That depends a good deal on where you want to go to,’ said the Cat.

*Lewis Carroll*

Many millions of people are willing to risk injury or even early death from jay walking. Yet many of these jay walkers would not
consider taking other risks with their lives that other people may consider to be minor.

How someone weighs up the harms and benefits of a treatment depends on many factors, including personality, history and circumstances. If you are desperate, you may be prepared to try a treatment that has a low chance of doing good, but a high chance of doing harm.

For example, a 50 year old woman may choose to take hormone replacement therapy (HRT) immediately to relieve menopausal hot flushes and night sweats. For her, the relief from symptoms that are seriously disrupting her life may outweigh the increased risk of 4 extra breast cancer cases per 1000 women if she takes HRT for the next 5 years.3 Another woman may note that about half of women have relief from their hot flushes on placebo after 12 months anyway and be prepared to wait out the symptoms rather than chance the increased risk of breast cancer. We look at the research on HRT in more detail later in this book (see page 121).

What is important is that you have enough information to make an informed decision based on a sound knowledge of the potential for benefits and harms (quantitative information that your practitioner should be able to provide) and how important they are to you (subjective information that only you can provide). You also need to know how that compares with the potential outcomes of the other options that you might be considering.

5. Do I have enough information to make a choice?

If you are unable to make a clear decision, this may mean that you need to know more about the outcomes of your options or to consider other alternatives.

Does the available information answer my questions?

You could ask your practitioner if there are any evidence-based guidelines that cover your situation. (Evidence-based guidelines are based on a systematic examination of the best available evidence
rather than on the opinions of experts, which, as we have seen, are not as reliable.) If an evidence-based guideline is not available, you could ask about the results of systematic reviews or randomised controlled trials. We discuss evidence-based guidelines briefly towards the end of this chapter and, along with the other study types, in much more detail in Chapter 10.

Many people also find it useful to speak to other people who have been in a similar situation, to get more information on their subjective experiences of the harms and benefits of a particular intervention. Remember, however, that different people experience things differently, so use their experiences only as a guide. In addition, such reports will not tell you how likely you are to experience a similar outcome. Your practitioner should be in the best situation to find out how likely you are to be helped or hurt by an intervention. If you are dissatisfied with the information provided by your practitioner, tell him or her that you still feel that you have insufficient information and want some help with getting more.

Have I found out about all the test and treatment options that I want to consider? If not, where can I go to find out more?

You may need to think about other options if, for example, you have tried a treatment but had to stop it because you experienced a harm that was described as unlikely but none the less occurred, or if the benefit did not satisfy your needs. Or perhaps none of the options to date seems to have sufficient benefit for the harms.

If you need more information about your options, ask your practitioner, other practitioners or self-help groups. Many people find information from libraries, the internet and various electronic databases, but be aware that much information on the internet is unreliable. Later in the book we describe how to decide which information is reliable and list some good internet sites. Remember to compare new options with the best previous ones and to evaluate them with the same five important questions.

You may find it useful to seek a second opinion. There is no need to feel awkward about asking for this; most responsible practi-
practitioners will respect your right to see someone else. But be careful when selecting the number and type of practitioners whom you see; doctor shopping in order to get the answer that you are hoping for is not in your best interest. If you have difficulty making a choice, do not hesitate to discuss it with your practitioner. Remember, it’s your body, it should be your choice.

An evidence-based guideline or systematic review could provide the answers to your questions

Some doctors still believe, ‘My practice is the universe’. But the idea that simply by observing our own practices we will know all the right things to do just doesn’t hold water.

Jarrett Clinton*

It is unrealistic for consumers to expect their practitioners to have all the correct answers at hand for every health problem. This is quite simply impossible given the complex and rapidly evolving state of knowledge. If it were possible, we could expect that there would be no disagreement among experts.

As long as health advice differs from expert to expert, some of it must be wrong. Practice guidelines have been developed in
many areas to help address this situation. They guide the practitioner and patient on what to do in specific situations to achieve the best outcomes and avoid inappropriate practices.

However, many guidelines are based on a consensus of expert opinions rather than on a search for unbiased evidence. This approach is not reliable, no matter how valid the views appear or how eminent the experts involved. The advice of confident experts, which form such consensus guidelines, has a history of later proving to be misguided. Examples include performing X-rays on pregnant women to judge pelvic size, which was accepted as routine practice only a few decades ago. Today we would not use this test in such a potentially harmful situation when there is no good evidence of benefit.

The authors of evidence-based guidelines review the evidence from research and appraise its credibility in a way that most practitioners simply do not have the time or expertise to do. Ideally, practice guidelines should be set by a multidisciplinary group including health experts in the content area, researchers to assess the credibility of the evidence, and consumers to ensure a ‘patient-friendly’ perspective.5

We discuss systematic reviews further in Chapter 12, but for now will simply tell you that these are summaries of all the best quality randomised trials that have been done on a particular treatment.

Many practice guidelines are written with consumers in mind, so that they can be easily understood and interpreted by non-professionals as well as professionals. Summaries of good quality systematic reviews are also becoming increasingly available on the internet.

Examples of a consumer version of evidence-based guidelines are the information sheets on ‘Evidence-based management of acute musculoskeletal pain’. The summary of research on treating acute low back pain tells you about treatments that have been shown to be effective, treatments for which the evidence is inconclusive or conflicting, treatments that can be harmful and treatments for which there have not been any studies.6 Another example of a consumer version of evidence-based guidelines is contained within the PRODIGY Clinical Knowledge Summaries for the NHS.7 An example of a website that summarises high quality systematic
reviews of randomised trials is Informed Health Online (www.informedhealthonline.org).

What makes a guideline evidence-based?

Evidence-based guidelines should use the accumulated high-quality evidence from research on a particular topic and recommend ways to apply this evidence to individual people who vary in their preferences and in the features of their illness. Here are some ‘ideal’ criteria to help establish whether a guideline is of high quality. They have been adapted from some internationally recognised standards from the Appraisal of Guidelines Research and Evaluation Collaboration (AGREE). A Guideline:

- should be recent, e.g. within the last 5 years. If it is not, ask if there is a more recent one. Guidelines may be updated more frequently depending on whether research has suggested changes in management.
- should be clear for whom the guidelines are intended and what they plan to address.
- should describe all the treatment options.
- should describe outcomes that are person-centred – about survival and quality of life.
- should describe both the benefits and the harms.
- should describe how the best evidence was selected and report the highest level of evidence for each recommendation. It may happen that a guideline’s supporting evidence is not ideal because no strong evidence on the topic exists, but this does not mean that such a guideline should be dismissed out of hand. It may still represent the best available information. What is important is that a guideline’s sources of evidence should be declared so that everyone knows its evidence level. The levels of evidence for evidence-based practice guidelines, from strongest to weakest, are:
  1) an evidence-based practice guideline or systematic review of all randomised controlled trials on the topic
  2) randomised controlled trials

66
SMART HEALTH CHOICE ESSENTIALS

3) other non-randomised studies on groups of people
4) case studies and opinions.

- Its development should have involved the main stakeholder groups across the relevant disciplines (for example, guidelines about managing a particular condition).
- It should be clear and accessible.
- It should be practical and relevant to its intended users.
- Its developers should have no conflicts of interest and it should be editorially independent of its funding body.

If all of these criteria are fulfilled, an evidence-based guideline should help you answer the five questions raised in this chapter.

Some people may still have some reservations about asking about the evidence behind medical advice for fear of implying a lack of trust. Many practitioners expect and welcome patients’ involvement in their healthcare decisions and this is increasingly the case. Health decisions have become far too complex to expect practitioners to have the correct answer to every problem at hand. Increasingly practitioners are using evidence-based practice guidelines to care for their patients, so be confident in asking your practitioner about them.

Not only is it your right to ask about the evidence, it is also in your best interest to do so. Evidence is not a substitute for clinical judgement, but should be used in conjunction with it. Clinical judgement alone, without the benefit of evidence from high-quality research, is not always reliable – especially for important decisions.

The rest of this chapter explores a minor and a major health decision, to illustrate how the five questions might help you ensure (as far as possible) that you will be making the best health choice.

**Applying the five questions: two scenarios**

**Scenario I: What should Fred do about his arthritis?**

Fred, 60, is a retired engineer who is in fairly good shape apart from a nagging pain in his knee caused by osteoarthritis. Although there is no cure, there are many interventions that could help his condi-
tion: weight loss, exercise and physiotherapy, and pain-killers. As Fred is thin and fairly active, the most reasonable option in this situation seems to be the pain-killers.

**Question 1: What happens if Fred decides to wait and watch?**

Osteoarthritis may progress with age in some people. As with all health problems, watchful waiting avoids the harm of any treatment but also reduces the possibility of any benefit. Fred feels that the pain in his knee interferes with his daily activities, not to mention his great joy in bowling and playing with his grandchildren. He believes that the problem is worth treating unless the treatment side effects reduce his quality of life still more than the pain itself.

**Question 2: What are Fred’s test and treatment options?**

Fred learns that non-steroidal anti-inflammatory drugs (NSAIDs) have long-term advantages if the joints are inflamed as in rheumatoid arthritis. But Fred’s doctor has told him he was 95 per cent certain the diagnosis was osteoarthritis (‘wear-and-tear’ arthritis) without any inflammatory component. This was based on a physical examination and the history of an old cartilage injury for which Fred had surgery in his 20s. Therefore, the objective of treatment is to relieve symptoms and the most reasonable treatment option seems to be a course of pain-killers. The option of a further diagnostic test, such as an X-ray, seems unnecessary with such a high probability of it being osteoarthritis.

**Question 3: What are the benefits and harms of Fred’s options?**

Like most of us, Fred has some previous experience of taking pain-killers for headaches and sprains. He knows that many are available over the counter and have minimal side effects. His pharmacist tells him that pain relief could be achieved with paracetamol and that NSAIDs, such as aspirin, ibuprofen, diclofenac or naproxen, are also often used for pain relief.

He then considers the benefits and harms of pain-killers – whether they will be long term or short term, how long lasting they might be and how likely they are to occur given his particular risk level?
Fred asks his doctor about the potential harms of NSAIDs and how they compare with those of paracetamol, which he learns can cause liver disease whereas NSAIDs can cause stomach bleeds and upsets. Fred is surprised that, although his doctor knows these side effects exist, he cannot provide any information on how likely they are to occur. The only justification that his doctor is able to offer for using NSAIDs is that many of his patients seem to be doing well on them. He tells Fred that, although several do complain of stomach pain, the pain in their joints seems well controlled by NSAIDs.

Question 4: How do the benefits and harms weigh up for Fred?

Making the correct choice is important to Fred. He knows that osteoarthritis is a chronic condition and that he is at the start of long-term treatment to control his symptoms. He is concerned about the possibility of stomach bleeds because he has had a stomach ulcer in the past. It is not yet clear to Fred how the benefits and harms weigh up for him.

Question 5: Does Fred have enough information to make a choice?

Fred is not satisfied with his doctor’s suggestion of NSAIDs. When his doctor realises how determined Fred is to be better informed about the benefits and harms of the alternatives, he agrees to get some more information. A week later, Fred finds out from the doctor that there is a systematic review of 15 randomised controlled trials of paracetamol taken regularly compared with placebo and NSAIDs.

The trials show that pain decreased by 6 points more in people taking NSAIDs compared with paracetamol on a scale from 0 to 100. Paracetamol decreased pain by 4 points compared with placebo. There was a slightly higher chance of stomach side effects (nausea, heartburn, stomach pain) in people taking traditional NSAIDs (naproxen, ibuprofen) – 19 out of 100 compared with paracetamol 13 out of 100.9

Fred’s doctor also pointed out that there is the option of paracetamol combined with other drugs such as codeine. However, these may be addictive, so Fred does not wish to use them.
On examining the results for his own situation, Fred is told that the risk of gastrointestinal bleeding is increased in people who have had stomach ulcers previously. As he had an ulcer 2 years previously, he feels that the risk is unacceptable for him, so he decides to try paracetamol to see if it controls his symptoms. If it does not, he may still need to consider NSAIDs despite their side effects because they are more effective pain-killers in people with moderate or severe pain from osteoarthritis. His doctor also finds from the Cochrane Database of Systematic Reviews that exercise can be helpful in reducing pain and glucosamine can have some benefits in the short term but by 2–3 months this is minimal. Both of these treatment options seem to have minimal or no risks associated with them so Fred will consider adding these to the paracetamol.

Talking to his friends about his decision to use the cheaper, safer drug, Fred is surprised at the number of his friends who are regularly taking NSAIDs without ever having evaluated their risks compared with the cheaper, safer treatment.

**Scenario II: What should Pat do about her mammogram result?**

Pat, 55, lives in a rural town and teaches physical education at a secondary school. She has been told that she has an abnormality on a screening mammogram that she had during a visit to her sister in another town. The initial positive mammogram was followed up by a recall for further mammograms, the results of which suggested cancer.

Let’s see how Pat answers the five questions, with the help of the consumer guideline *A Guide for Women with Early Breast Cancer* by the National Breast Cancer Centre (NBCC) and the doctor’s version *Clinical Practice Guidelines: Management of Early Breast Cancer* (National Health and Medical Research Council or NHMRC). These are the Australian guidelines that she chooses to use because the UK guidelines are not due to be published until 2009 by the National Institute for Health and Clinical Excellence (NICE). (The Scottish health department issued guidelines for clinicians only, in March 2007.)
The other excellent resource that Pat finds on the internet is an evidence-based decision aid from the Canadian Cancer Society called *Making Decisions about the Removal of My Breast Cancer* at www.cancer.ca/ccs/internet/miniapp/0,3182,3543_16897665_19702640_langId-en,00.html

**Question 1: What will happen if Pat adopts a wait and watch approach to her abnormal mammograms?**

Chapter 6 of the doctor’s guideline compares surgery with doing nothing:

Indirect evidence suggests that surgical intervention may extend survival from the time of clinical detection. In an historical comparison, women treated by radical mastectomy appeared to survive longer than women whose breast cancer was untreated.

The option of watchful waiting seems unreasonable for a life-threatening condition and Pat dismisses this option.

**Question 2: What are Pat’s test and treatment options?**

Pat realises that a diagnostic test is appropriate for such a serious disease and she agrees to have a needle biopsy, which can be done without an anaesthetic and its attendant risks. The biopsy result confirms that she has cancer. A clinical examination does not find any lymph node involvement. Pat prefers to be treated near home so she consults a nearby surgeon who recommends a mastectomy (removal of the breast).

This suggestion comes as a shock to Pat who has heard that small cancers can be treated successfully by removal of only a portion of the breast in a lumpectomy, which is less disfiguring than a mastectomy.

She refers to the guideline for women, which says in Chapter 6 that surgery for early breast cancer involves either breast-conserving surgery or mastectomy and that, in both cases, lymph nodes in the armpit will be removed. However, breast-conserving surgery includes both surgical removal of the lump and postoperative radiotherapy to the remaining breast tissue.

Pat discusses her reading with her practitioner, who confirms
that breast-conserving surgery plus radiotherapy is an acceptable option for Pat’s situation.

**Question 3: What are the benefits and harms of Pat’s options?**

The doctor’s guidelines compare the two main surgical options in Chapter 4, saying that around 70 per cent of breast cancers are suitable for breast-conserving surgery. Pat has been advised that she fits within this category, so needs to consider both options. There is no difference in survival between women who have a mastectomy and those who have breast-conserving surgery followed by radiotherapy. Each form of treatment has its advantages. They say:

About 1–2 per cent of women who have breast conserving surgery followed by radiotherapy find the cancer comes back in the same breast. In women with smaller tumours, the chances of the cancer coming back in the same breast are lower. Further surgery can usually be performed if the cancer does return. Some women who have mastectomy are happy to avoid the need for radiotherapy, and they may worry less about the cancer coming back, although they may feel more concerned about their lost breast.

Pat finds the interactive decision aid particularly helpful because it contains photographs of women after both types of surgery and provides probabilities for the risks of radiotherapy.

**Question 4: How do the benefits and harms weigh up for Pat?**

In Chapter 5 of the consumer guideline, it says:

You are entitled to choose the treatment that best suits you. Before you make a decision, it’s recommended that you discuss your treatment options with your doctor and any other people you may choose (such as family members or other health professionals).

Pat feels that it is important for her to keep her breast, for her self-image as well as for her work and social environment. But, for Pat, the personal cost of having radiotherapy includes more than the side-
effects of the treatment alone. It will involve her travelling to a centre far from home for the course of treatment. As there is good evidence showing no difference in physical outcome between mastectomy and breast-conserving surgery plus radiotherapy for early breast cancer, Pat decides the personal cost of being treated away from the support of her family and friends in her home town is a small price to pay for keeping her breast.

Question 5: Does Pat have enough information to make a choice?

The guidelines provide contact details for women who want more information, or who may want to check the references from which the information in the guideline is drawn.

Pat is satisfied that she has had enough information to make her choice of conservative surgery plus radiotherapy.

Figure 5.1 Five questions to ask when making a smart health choice.
Summary

Remember the five questions that will help you make an informed choice:

Question 1: What will happen if I wait and watch?
• What can I expect to happen ‘naturally’ in my situation?

Question 2: What are my test or treatment options?
• What tests are available for people in my situation?
• What treatments are available for people in my situation?

Question 3: What are the benefits and harms of these options?
• How accurate are the tests in people like me? Could having the tests be harmful?
• How effective are the treatments in people like me? What aspects of my health could be improved by the treatment? Could the treatment be harmful?
• How likely are the benefits of treatment for me? How common are the harms?
• When could I expect to see these benefits and harms?
• How long lasting are the benefits and harms if they occur?

Question 4: How do the benefits and harms weigh up for me?
• What benefits are most important to me?
• Am I prepared to take the risks in order to achieve the benefits?

Question 5: Do I have enough information to make a choice?
• Does the available information answer my questions?

continued
SMART HEALTH CHOICE ESSENTIALS

- Have I found out about all the test and treatment options that I want to consider? If not, where can I go to find out more?

References

2. Carroll L. *Alice’s Adventures in Wonderland*.
7. PRODIGY. *Prodigy Guidance on Acute Low Back Pain*.
Choosing a practitioner or a hospital

A few weeks after starting treatment for depression, Claire noticed a marked reduction in her libido. She was puzzled because the medication had helped improve her mood and enjoyment of life generally. She mentioned it at her next appointment and was surprised to hear that the antidepressant might be to blame. The psychiatrist explained that this particular drug affected libido in some people whereas other drugs appeared to be less likely to cause this side effect. On the basis of this information, Claire decided to try one of the other antidepressants. She wished her doctor had spent more time initially explaining the pros and cons of the various antidepressants, and resolved to ask more questions next time that she was in such a situation.

In this chapter we outline some of the aspects that you might consider in choosing from whom and where you will seek healthcare treatment and advice. We recognise that different health systems will not always provide you with the type of practitioner or hospital that you would most want. This may be a result of differ-
ences in access for private fee-paying, as opposed to government-subsidised, places.

However, most health services are becoming more patient-focused and aim to give you a greater degree of choice. Although the National Health Service (NHS) requires British residents to register with a local GP, patients have the right to change doctors without giving a reason and many GPs operate within a group practice setting. Similarly, the NHS now has a policy that, when a GP refers a patient to a specialist or hospital for treatment, he or she can choose from several hospitals in the local area. In Australia, patients are free to seek medical advice including a second opinion without restriction, although choice of practitioner in some hospital settings is restricted if you are a non-insured patient. People usually choose their own pharmacist, dentist, homeopath and other health providers, but what is the basis on which we make these important choices in seeking health advice and treatment?

Many consumers are taking more active roles in their health care. The role of many practitioners is also changing, moving from one of professional paternalism to being a partner in their patients’ decisions.

A survey of 652 Australian women in 2001 showed that 95 per cent of women wanted an active or shared role in treatment decisions about their healthcare.1 Slightly lower figures were reported in a European survey, but still a majority of 74 per cent people preferred some active involvement in healthcare treatment decisions.2

In 2004, The UK Department of Health launched a program called Better information, better choices, better health: putting information at the centre of health.3

It is a three-year program underpinned by four principles. People should:

1. have access to accurate, high quality, comprehensive information delivered in the way they want
2. have their personal information needs considered and discussed at every contact with health professionals
3. receive as much support as they want to access and understand information
4. be empowered to ask questions and be involved as far as they want in making decisions about, for example, the benefits and risks of action and how any risks can be mitigated.

The patient–practitioner partnership encourages and depends on a level of trust that demands mutual respect, clear concise communication and shared responsibility. Finding a practitioner with whom you can establish this partnership may take some time and effort, but ultimately it is in your best interests to make this choice carefully. You may have already found one, but may not have been taking full advantage of your role in the relationship. One of the aims of this book is to help you do that confidently. In other words, choosing a practitioner may include looking beyond technical expertise and also include considering decision-making expertise.

It is also important to consider your role in the broader community. When communicating one to one with your health professional about the best treatment options for your situation, it can be easy to forget that your decisions can have an impact on others. These may include your family and those who are close to you, as well as people in your workplace, school or wider community. There is often a conflict or tension between what may be your own personal preference and what may be best at a societal level—and there are no easy answers to this one.

For example, some parents choose to exercise their right not to immunise their children but this potentially puts very young babies and children with immune deficiencies at risk of disease. Similarly it is understandable that a patient with cancer might want the government to fund a new, expensive and not yet proven treatment in order to give them a chance of increased survival. However, when health budgets are limited this may divert funding from other health problems. This may lead to other people being indirectly penalised. These are difficult issues and not ones that can necessarily be resolved by individual patients but it is worth bearing them in mind. You may feel daunted by the idea of ‘examining your doctor’ in the way that we suggest in the following pages, but just ask whatever you are comfortable with. As time goes by and you ask about more issues, it will become easier.
Judging a practitioner’s decision-making expertise

Competent decision-making expertise involves good clinical judgement to make a diagnosis and the proper use of evidence combined with patient preferences to choose the best course of action. However, not all practitioners approach decision-making this way. Although it is probably true to say that most practitioners can diagnose common illnesses fairly accurately, they vary in their ability to use evidence appropriately to decide what intervention – if any – is best and in their willingness to take account of patients’ preferences.

Consider an elderly man who is considering whether to have surgery for an enlarged prostate. There is good evidence that an enlarged prostate is not life threatening, although it can be a nuisance. The potential side effects of surgery include impotence. A practitioner should be able to present information about the benefits and harms of surgery, but only you can decide which harm is the most acceptable – increased frequency and urgency of urination from an enlarged prostate or possible sexual dysfunction and incontinence from the surgery.

To help you judge whether your practitioner has good decision-making skills consider whether he or she:

- uses the best evidence available
- readily shares information with you
- takes adequate account of your preferences.

Does your practitioner use the best evidence available?

If your practitioner is using the best evidence available, he or she should be regularly updating his or her practice using the results of randomised controlled trials. Many practitioners say that they already practise evidence-based medicine, but, unless they make a conscious effort to keep abreast of the latest results from randomised controlled trials, you cannot be sure that their advice is really based on the best evidence.

There is no easy way of testing your practitioner’s approach to evidence-based care without discussing it openly. You might start
by asking their opinion on some treatment that you have found on the internet or been told about by friends. See if the practitioner evaluates it taking account of whether the effect of interventions has been tested in randomised controlled trials, and whether he or she talks about outcomes that matter, such as survival and quality of life.

If practitioners do not update their practice from randomised controlled trials, those who try to keep up to date through continuing medical education or by being involved in professional college activities are more likely to be using better evidence than those who do neither of these. Be cautious about practitioners who rely only on their early university medical education or information from the pharmaceutical industry.

**Does your practitioner share information with you?**

Another important issue is whether your practitioner’s decision-making process is based on sharing information with you – whether it be about the diagnosis, prognosis or intervention options.

A few years ago, one of us (Judy) developed a very severe pain and restricted movement in one shoulder, and was diagnosed with a tear in one of the ligaments in the rotator cuff and some tendon impingement. (This means the tendon had been ‘pinched’ or compressed slightly by the swelling.) When the pain persisted after some analgesic treatment and a steroid injection, she saw a surgeon who had an exemplary decision-making process. He explained the possible causes and implications of Judy’s condition, and then told her the options and their risks and benefits. He also gave her some written information to take home to read.

Her options, as he explained them, were:

- **Watchful waiting:** he said that, according to published studies, the pain was likely to ease within a year or so, if nothing was done.
- **Arthroscopic repair:** he said that studies show most people report considerable relief after surgical repair by arthroscopy, a relatively simple procedure to remove the impingement. But Judy remained cautious because these were case studies based on personal testimony and therefore it was not clear whether the
improvement was a result of the intervention or would have occurred anyway. It is also possible that those in whom the operation was unsuccessful were not included in these reports.

- A more complicated surgical procedure: this option, he explained, would repair the ligament and increase the rotator cuff mobility. It would require a few days in hospital and intensive, prolonged physiotherapy.

Does your practitioner take account of your preferences?

On the basis of Judy’s discussion with the surgeon and the written information that he provided, she decided that the potential harms of surgery, although small in her case, were sufficient to outweigh the potential benefits – which seemed unclear anyway. In addition, as she is not an athlete and not heavily reliant on the use of her shoulder, Judy could afford the time to wait and watch.

For some time afterwards, the pain woke Judy at night, making her question the wisdom of her choice. But within several months, she was almost completely pain free and after a few more months, she regained the mobility in her shoulder. If the problem had continued, she might have reconsidered other options.

In fact the problem did recur several years later. For some months Judy tried to ignore the pain, hoping that it might resolve, but when it continued to get worse she went to see her practitioner. As she is averse to surgery, she asked about other options and he suggested physiotherapy with someone who has special expertise in shoulder problems. Judy decided to try that option on the grounds that it might help and was unlikely to do any harm – aside from the time and financial cost that she felt were reasonable ‘harms’. The physiotherapist gave her a regimen of stretching and strengthening exercises that he monitored regularly and adapted as Judy’s mobility increased. Within a week or two she noticed a dramatic improvement, suggesting that the physiotherapy was working. Judy continues with a maintenance programme of exercise every other day, which she tries to adhere to, but, when
she lapses for a week or two, some stiffness and discomfort return. It seems to her that the physiotherapy is doing the trick, as judged by criteria outlined in Chapter 8.

In contrast to Judy’s experience, a friend, Sarah, who had a similar problem with her shoulder, had an unpleasant experience with her practitioner. He had diagnosed inflammation in the rotator cuff, but had not dealt with her concerns in the same caring way that Judy’s had done. He had dismissed her questions saying ‘Anything I haven’t already told you is not important.’

After speaking with Judy, she decided to go back to her practitioner and ask for more information. She was nervous about doing this, and was worried that he might be upset or resentful at her questioning – after all, it is not always easy for a patient to question their doctor, and doctors are not always used to being closely questioned.

But it was much easier than Sarah expected. Once she’d clearly and calmly explained her concerns and her wish for more information, her doctor provided the information and she decided that the potential benefits of surgery outweighed the small risks. Her lifestyle – having a small child and a job that involved using her arms a great deal – was not conducive to waiting it out as Judy had done. Her choice to undergo surgery was driven by personal preferences relating to her lifestyle.

**Judging a practitioner’s technical expertise**

After you and your practitioner have decided either to treat or to investigate your illness further, the procedure should be done by someone with the appropriate technical ability.

The degree of expertise of any surgeon is extremely difficult for either a GP or a patient to assess. Surgeons who enjoy a high media profile may, in fact, be more competent at issuing press releases than at performing surgery.

*Guy Maddern*
CHOOSING A PRACTITIONER OR A HOSPITAL

To assist you in judging whether your practitioner has the necessary technical expertise, you might want to know whether he or she:

• is qualified to perform the procedure
• performs the procedure often enough
• is part of a quality assurance scheme or some similar programme.

If you are seeing a practitioner in a large outpatient’s department or clinic, ask who will be performing the procedure. If it is not the practitioner whom you are consulting, ask the same questions about the person who will be doing the procedure. In some settings it may be a trainee, in which case you also need to know who will be supervising the trainee and something about the supervisor’s experience.

Is your practitioner qualified to perform the procedure?

Among the issues that you should consider are the practitioner’s special qualifications or certification to undertake this particular procedure. Even for a relatively minor operation such as an arthroscopic repair for a shoulder injury, you are likely to be better off choosing a surgeon specialising in shoulders. An unsupervised surgeon who is inexperienced in the procedure will not be a wise choice.

Report cards on doctors or health services have been discussed as an option but there is debate about how reliable they are. Some professional colleges have membership databases that will help you find a surgeon in a particular location who operates within a particular specialty area such as breast surgery (www.surgeons.org). Other directories are available, such as mydr.com.au, but none of these provides sufficient detail about the credentials of the doctor concerned. Websites based in the USA will provide you with a report card on a particular doctor for a fee. In the USA, patients tend not to use the report cards but rather follow the advice of their referring doctor. Even the former US President, Bill Clinton, went to one of the lowest-rated hospitals for heart surgery despite the publicly available rating. In addition to this, it has been shown that some hospitals tend to ‘fudge’ the reports by selecting ‘safe’ patients
for their reporting framework. Doctor and hospital report cards appear to need more work if they are to become useful tools for patients and other interested parties.

**How often does your practitioner perform the procedure?**

It is useful to know how many of the particular procedures your practitioner does in a week, month or year – depending on how common the procedure is. There is evidence that patients are more likely to have better outcomes after a procedure if their doctors perform many such procedures. Centres that specialise in a particular condition are also more likely to offer comprehensive, multidisciplinary care. But there is a paradox: although experience may increase with age, physical and mental agility decline. Professor Guy Maddern, an eminent Australian surgeon, notes that many hospitals now recommend that surgeons should not operate after the age of 70:

> While clearly some surgeons could go on longer than this and others should have stopped much earlier, choosing a surgeon over 70 to perform your operation is perhaps ill-advised.

**Is your practitioner part of a quality assurance scheme?**

The third important criterion for assessing technical competence is whether your practitioner belongs to a quality assurance or credentialing scheme to assess technical proficiency. This will be relevant only to major interventions, such as surgery. Quality assurance schemes monitor patient care by examining patient records at random to make sure that care adheres to established practice, by monitoring adverse outcomes and by evaluating satisfaction through patient surveys. Many hospitals also have a credentialing process, to ensure that practitioners are appropriately qualified and skilled to undertake certain procedures. To ensure that a practitioner is covered by such a programme, you could ask the practitioner directly, your referring practitioner or the hospital.
All doctors are required to participate in continuing education programmes with their respective professional college and this is now a mandatory condition of registration. For most other health professions this is optional.

Many people ask whether litigation is a measure of a practitioner’s technical competence, assuming that those who have been sued are best avoided. However, we do not believe that this is a reliable indicator of technical competence because studies have shown that litigation often reflects poor communication between practitioner and patient rather than technical failings.

**Finding a practice or hospital that suits your needs**

Apart from looking for an evidence-based practitioner with good clinical expertise, there may be practical issues that you want to consider. These might include the location of the practice or hospital near your home or work, the gender of the doctors at the practice, the hours of opening and after-hours arrangements, the fee structure and any special expertise among the practitioners such as an interest in skin cancers or young families or women's health.

**Choosing not to choose**

You might feel unable to participate actively in decision-making if you are overwhelmed by serious illness or have other problems. In this case, you also have the right to delegate decision-making.

But think hard about this. The more serious your health problem, the more valuable your participation is likely to be. So, if you do find yourself wanting to delegate decision-making to your practitioner, and if the problem does not require immediate attention, take some time out. Arrange to see your practitioner again after you have had a chance to reflect.

If you decide to delegate decision-making, your practitioner will be better able to make informed decisions if he or she knows something about your preferences, your general attitude and your lifestyle. It may also be a good idea to ensure that a friend or relative is aware of your health preferences in case the need arises.
CHAPTER 6

Summary

Everyone who offers you health advice should not only respect your right to be involved, but also encourage your participation. If you feel it necessary, ask for written information to take home with you.

- In most situations, you should expect your practitioner to explain to you:
  - what your problem is thought to be
  - what you can reasonably expect if your illness or condition is not treated
  - the benefits and harms of the various treatment and diagnostic test options.

- When choosing a practitioner, you should consider whether they:
  - are abreast of the latest evidence from randomised controlled trials
  - share information with you
  - respect your involvement in decision-making.

- If you are considering having a procedure, you should also assess the practitioner’s technical competence by asking about:
  - their qualifications
  - how often they do the procedure
  - whether they are part of a quality assurance programme.
References


