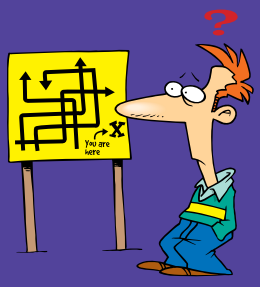
5 steps

1 My starting point



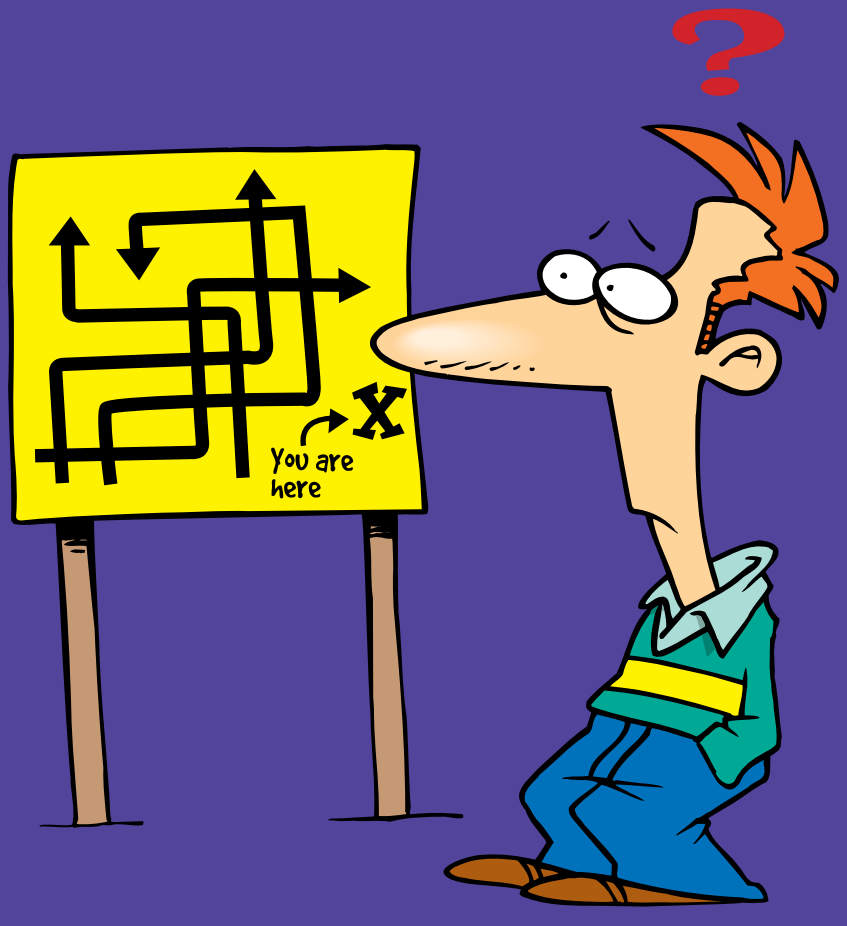
2 My end point

3 Who can help me?

4 What treatments will offer me the best value?

5 Monitoring

My starting point



To do

1 Get your diagnosis

Follow the *Diagnosis pathway*

Collect your test results

2 Understand your diagnosis

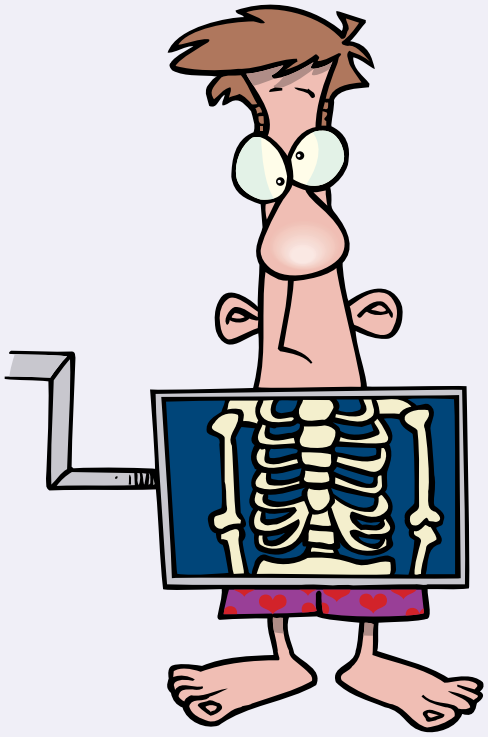
Choose your questions from *Understanding my diagnosis: a conversational approach*

Research your diagnosis

3 Define your starting point

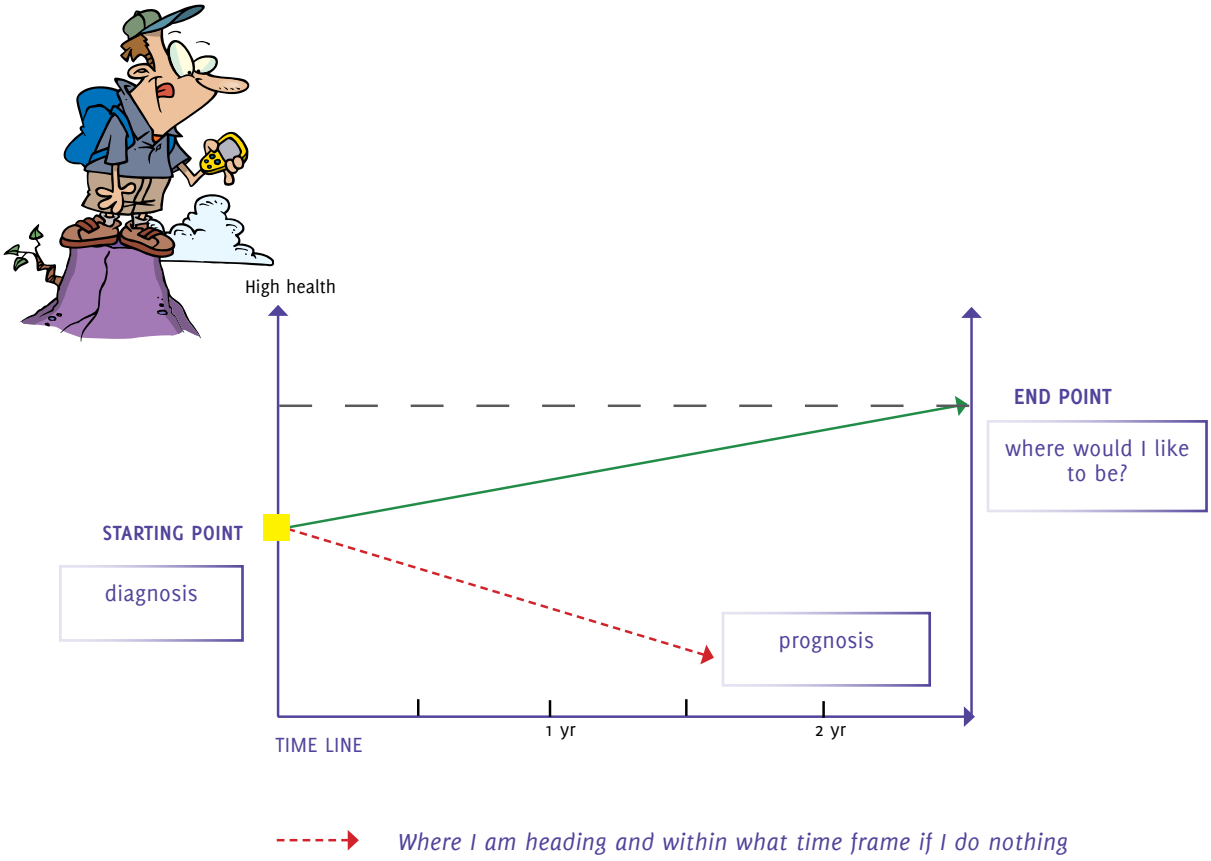
Follow the statement guide in *My Health Statement - My Starting Point*

Why do I need an accurate diagnosis?



Because no-one will know what you need to do, what to treat & how to monitor in order to make sure you get to your end point.

My Journey Road Map: my starting point



My starting point is where I am now (diagnosis), where I am currently heading (prognosis) and how fast.

1 Getting your diagnosis

Before you attend your initial appointment I would recommend that you make some notes about your health in order to give enough detail to your GP or specialist to facilitate more informed decision making on the possible diagnosis. Use the following as a guide.

The appointment

1. List your current symptoms along with any factors that make your condition better or worse, and indicate the length of time you have been suffering from these.

2. Make a note of your past history which may be relevant to the doctor:

Remember to take copies of any past medical records that you may have with you.

- previous diagnoses & dates of diagnoses;
- previous treatments for the conditions (medication, surgery etc.);
- length of time of each treatment, and dates; and
- outcome of treatment (did it work, is it ongoing?).

3. Make a note of any relevant family history

Family members, such as grand-parents, parents and siblings, that have been diagnosed with chronic conditions or conditions similar to yours.

Before the appointment familiarize yourself with the *Diagnosis Pathway* (p24) so that you know what to expect. From your description of your symptoms and other relevant information that the doctor may ask about he may have formed a fairly good idea of what is wrong with you and may simply prescribe a drug, and if the symptoms abate then this would confirm the diagnosis. Alternatively, he may run some routine examinations and send you off for a blood test or a scan, or make a referral for you to see a specialist if your condition or its diagnosis is outside his scope of expertise.

Before the end of the appointment it's a good idea to ask about the strategy using whichever of the following questions apply:

- Tests/scans: what is the test/scan for and what will it indicate?
- Treatment: what is the treatment and what will it address?

The diagnosis

Make sure that you obtain copies of your results. Write down the name of your tests along with the results that confirm the diagnosis.

Test	Result	Diagnosis
Blood test		
Endoscopy		
CT scan		
Ultrasound		

Once you have your diagnosis fill in the **Now** column on the *Full Alignment Template* (p20) with the tests you have undertaken, your diagnosis and your list of symptoms. If you do not have a medical diagnosis, or are unable to get one, then you may need to start by filling in the symptoms and any test results. If you are seeing other practitioners (allied &/or alternative) complete the non-medical section by adding the therapy type (i.e. naturopathy, TCM [Traditional Chinese Medicine], homoeopathy etc.) and their diagnosis/es.

It's a good idea to research your diagnosed condition on the internet to make sure that you have had all the appropriate tests for the diagnosis. (See p23, p30 and p223 for useful websites.)

Why do I need to understand my prognosis?

Because you need to know how fast you may be heading in the wrong direction so that you don't miss opportunities or narrow your treatment options.

The prognosis - what could happen and when

Once you are satisfied that you have the right diagnosis, you will need to understand the prognosis, or where you are heading and how fast; in other words *"what could happen to me if I don't take treatment, and how soon?"* The answer to this question will tell you how quickly you need to start treatment, whether there is a window of opportunity to make a difference to your condition before you absolutely have to have medical treatment, and what clinical events may occur and when. This information governs key decisions on time frames for treatment and monitoring (to make sure you are heading in the right direction and within a specific time frame).

Use the questions from the chart *A conversational approach: understanding my diagnosis and prognosis (p29)* in the about my prognosis column. Answers to these questions will give you enough information about what your condition could mean to you, how it could behave, what might happen - and how quickly.

When you ask these questions your doctor or specialist may factor in your individual risk factors, if they know your case. These risk factors are what make you different to others with the same diagnosis in-so-much as how the disease may affect you and how you may respond to treatment. These individual risk factors are generally linked to genetic variance (hereditary factors), your age and any other condition you have which may negatively impact the case and its treatment.

When these individual risks are not factored into the treatment, patients may be prescribed a treatment that could worsen their overall health and take them in the opposite direction. If you know your individual risk factors it means that you can check any contraindications for treatments/drugs and match these against your individual risks.

Knowing these things will give you a clue as to why certain treatments may produce adverse reactions in your case. Factoring this knowledge into your strategy means that you can tailor your treatment to meet your individual case.

Natalie was 21 years old when she sought help for endometriosis, polycystic ovarian syndrome and haemorrhagic ovarian cysts. She was offered a progesterone cream to slow the progression of her condition. Natalie applied the cream without realizing that it could worsen the nausea, vomiting and jaundice that she experienced with each cycle. She did some research on synthetic hormones in relation to her symptoms and found that they could cause gallstones in those predisposed. As her father had his gallbladder removed, and as she herself would get sick if she ate fatty food, she concluded that she had probably inherited this predisposition and that maybe synthetic hormones were not the most appropriate treatment for her condition. Natalie also discovered that hormonal imbalances often aggravated gallstone formation - so her condition was also putting her at risk for gallstones.

My end point

To do

1 Work out where you'd like to end up

Select your criteria for your end point & goals

Use *My Value Template* to establish these

2 Prioritize your goals

Complete the *Full Alignment Template*

- determine what you can & can't change
- prioritize your risks
- match each goal to a destination end point

3 Redefine your end point

Revisit the *Full Alignment Template* to determine your realistic end point

Why do I need to work out where I'd like to end up?

Because if you don't know where you're heading then how will you know if others are taking you in the right direction?

Introduction to My Value Template

My value template is a chart that covers a range of criteria that will form the backbone of your enquiries and a reference point for making sure that whatever options you choose will work for you. By doing the end point and goal exercise, you will have already determined the list for your first column *Any choice of treatment must work for me.*

If you review the template (facing page) you will see that there are four columns. The first column covers the selection criteria for defining your end point and goals, something you will be familiar with by now and is under the heading *Any choice of treatment must work for me*. The second column covers the selection criteria for lifestyle *Any choices must fit my lifestyle* which is about the feasibility of any program which includes its affordability.

The third column covers the selection criteria for your medical preferences *Any choice of treatment must fit with my own values and convictions.* This is important if you feel strongly about the type of treatment you prefer (say conventional or alternative) or if your culture or religion forbids specific treatments. It is far better to choose a health professional at the outset who is empathetic to your convictions as this will make for a more positive relationship and will smooth the road, particularly if you are having to make difficult and, at times, challenging decisions.

The fourth column covers the selection criteria for choosing practitioners and treatments *Any practitioner/product/service must demonstrate a value in helping me with my journey.* It is a set of qualifying criteria for both the practitioner (how much experience do you have) and the treatment (the type of proof you would require for the claims made). Some patients, if they have a good relationship with their practitioner and their risks are not too high will base their decision on trust, whereas others may require proof, such as clinical evidence or scientific proof, particularly when they may be heading down a path where the outcome is uncertain or if they have to make a choice between treatments.

My value template is about choice: it's about defining your own criteria for measuring the value of any option and it will help you to filter out choices that may not work for you so that you can focus on the ones or the people that could offer greater value. You will be returning to the template at various stages of your journey and it is useful to use it as your reference guide to help keep you on track.

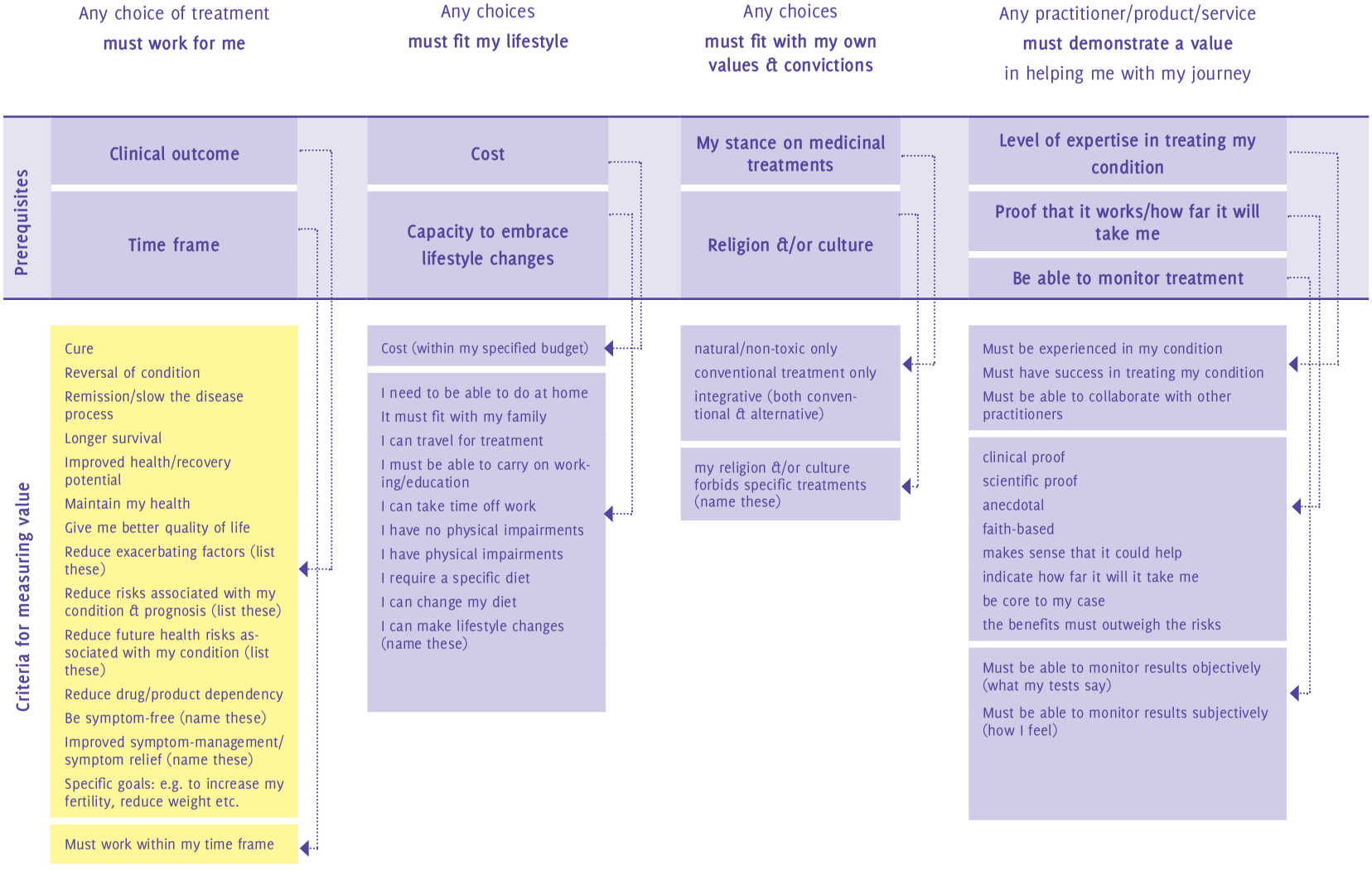
Choice, for many, is a difficult concept in healthcare. We have choice in most areas of our lives but sadly choice in health is something we seem to have forfeited in exchange for the notion that it's "free" or that "doctor knows best". One could say that these notions have been the basis of our criteria for quite a few decades, but with chronic disease on the increase more and more questions are arising as to whether what's on offer is the right way forward and whether the doctor does know best.

Even if the doctor does know best, in a climate of escalating healthcare costs and dwindling government health budgets doctors may also become victims of an inevitable health service rationing and may be unable to offer the services they know you require.

My value template is a platform that I hope will help bring choice back into your lives and will enable you to approach professionals and their recommended treatments with the objectivity that is often required when making decisions that can seriously impact one's life.

My Value Template

will help me filter out all the things that will not work for me so I can look more closely at what might work best for me



Why do I need to prioritize my risks?

Because symptoms that carry the greatest health risks, if ignored, will land you in the most trouble and could take you in the opposite direction.

2 Prioritize your risks & goals

As you can imagine not all symptoms carry the same health risks. For example, a reduction of blood pressure in a patient at risk from heart attack will take them closer to their end point than a reduction in their arthritis which may be chronic, but not as life-threatening. This is where a strategy comes in: to make sure that you are dealing with the most important risks and any initiating causes, without which you may end up heading in the opposite direction. In order to plan your strategy we need to revisit your *Full Alignment Template*.

Re-visit your Full Alignment Template

Take the information in the **WHY** column (causes, risks, exacerbating factors) and colour code the risks into risks you *can* change and risks you *can't* change. Risks you can't change will be things like age, gender, ethnicity, inherited susceptibility, past toxic exposure; and the things you can change will more likely be related to lifestyle issues. Then review your diagnosis/es and list of symptoms in the **NOW** column and try to prioritize these according to which of these symptoms pose the most risk - or those that if left untreated would take you backwards. Then put them as goals in order of importance, or categorize and colour code them into high, medium and low risk:

1: high risk (not much time on your side);

2: medium risk (some time on your side, symptoms that could eventually lead to chronic health); and

3: low risk (time on your side, or minor symptoms).

WHY	NOW			FUTURE HEALTH RISKS		
Causes/ Risks		Tests	Diagnosis	Prognosis		
risks you can't change risks you can change	Medical					
	Non-medical					
	End Point					
	Symptoms &/or diagnostics		Prioritized list of goals	End point alignment	THERAPY	TREATMENTS
			High Risk			
			Medium Risk			
			Low Risk			

Link the potential cause/s of your problems to specific goals; the more causes you can address the further you will get to your end point.

"There are three kinds of lies: lies, damned lies, and statistics."

Mark Twain 1835-1910

"

I saw a naturopath about this time last year and had the live blood analysis test done which worked in conjunction with a supplement program. I decided to do it because I am hypoglycemic, always tired etc.

I wondered if I had a hormone imbalance. However, I didn't find the program that helpful really in that *it was very tailored to the program rather than the person*. In actual fact I felt worse than I did in the beginning.

Eventually I gave up before we got to the "liver and kidney part". It was also getting expensive.

"

1 Research treatments offered

Having chosen a therapy or a range of therapies that are most aligned to your end point, you may now be in the unenviable position of being presented with a wide range of treatments or products that are recommended by the practitioner. You may feel that you need to ask about each treatment or product in order to determine what its specific value is to you, particularly if treatment is going to prove expensive and appears to offer only marginal or questionable value.

This is often where the nightmare begins, and without a framework to evaluate treatments for the individual case many people will come unstuck and may waste valuable time, energy and money on treatments that will take them nowhere (or worse still further away) and, by default, miss out on treatments that could be of more help.

If possible try to obtain an accurate diagnosis as this will indicate the cause. Treating the cause will take you the furthest. If you don't have a diagnosis you will either end up treating what you think the cause is or just the symptoms which can result in a hit and miss approach. If you don't know the cause, then you won't know what needs treating, what the treatment should be, or whether the treatments recommended are core to your case.

There are 3 key aspects to bear in mind when starting your evaluation process:

- A treatment needs to deliver *measurable* improvements within a given time frame. *What improvements can I expect and how soon?* Treatment may become a risk if it cannot deliver measurable benefits within a given time frame.
- A treatment needs to be *meaningful* in that it must align with and take you nearer to your end point. The most meaningful treatments are those which are *core* to your case; and
- You must be able to *factor in any risks* for the treatment particularly to your individual case: what you gain on the one hand you do not want to lose on the other.

Core treatments: are those that treat the cause, the greatest health risks, the risks and/or exacerbating factors - in that order. These treatments will take you the furthest toward your end point. Core treatments may also need to deliver results within a given time frame.

Adjunct treatments: treat secondary issues that are not core to the case, treat the side-effects of treatments or may be palliative. These treatments have inherent value but will NOT get you to your end point.

The framework for researching treatments

What will it do? How does the treatment work? What will the treatment achieve for me?	Is it high or low priority? What aspect of my case will it treat? (*core or adjunct*)
How long will it take? When can I expect results? How long will I be on treatment?	Benefit/Risk Are there any risks of treatment? Will the benefits outweigh the risks?

Why do I need to work out the risks of treatments?

Because you have to make sure that what others advise will take you to where you want to go.

....A University of NSW professor of clinical pharmacology, Ric Day, said there was no doubt a lot of Australians had been prescribed statins when their total risk of heart disease was not high. "It's a bit of a pity because you are taking a drug that doesn't contribute much to your protection at all," he said....

....Statins have long been touted as a miracle drug, with some doctors and researchers pushing for their use in all older people. But Professor Le Couteur said that was unwise. "Unfortunately the history of medicine is chequered with hopes that have turned out to be dashed and even caused harm," he said....

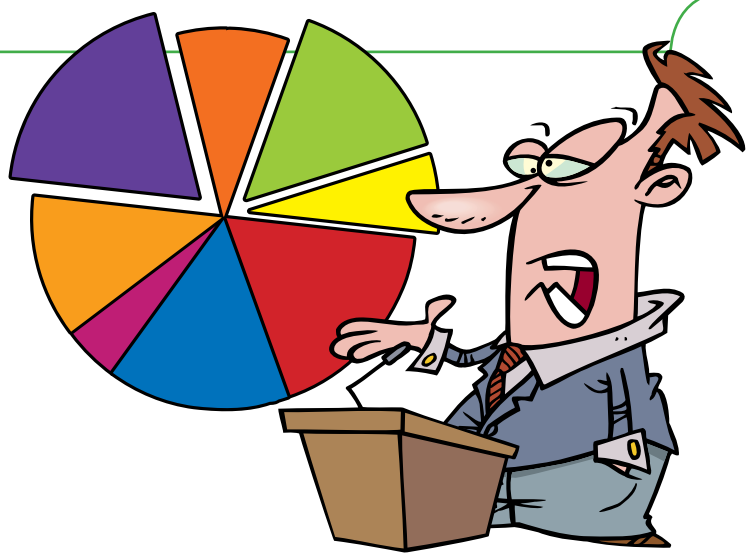
....The chief executive of the service, Lynn Weekes, said Australia's high use of statins compared to the OECD indicated it was likely low-risk people were being treated. "If they are at low risk of heart disease you shouldn't be putting them at risk for something else," she said....

....But the director of the Baker IDI Heart and Diabetes Institute, Garry Jennings, said people should not stop taking statins.

"I hope that pretty much everyone who is on a statin in Australia is on it for a very good reason, although there might be a few lower-risk people on the fringe," he said. "Statins work and there have been tens of thousands of people in trials … the overall benefit is clear.

About 500 people would need to take statins for one new case of diabetes to develop, while a major cardiac event would be prevented for every 150 people taking them....."

http://www.smh.com.au/national/health/miracle-drugs-put-thousands-at-risk-20120229-1u3ia.html#ixzz1nosnBn60



My Benefit/Risk Assessment: Understanding statistics

Statistics are simply a method of measuring your odds. There are various ways you can present statistics and depending on what you need to convey, then statistics will usually oblige. It's fairly easy to talk up the benefits of a drug using statistics to give the impression that it promises more than it does, so if your end point is not to be drug-dependent and yet you have been told that you should take medication to reduce your risks, it's a good idea to determine your odds and discover just how much the treatment offered is likely to reduce your risks.

When you are offered a drug you need to seek *qualification* as to why you are being offered it (what is the research and what does it show) and then you may need help in interpreting the clinical trial data. This may be difficult as statistics are hard to explain, and if you go for a second opinion you are likely to get another take both on your diagnosis and treatment.

So it pays to do your own checks and balances and find out what the results mean and whether they apply to you. This does not only apply to conventional medicine but also alternative and complementary medicines. If your condition does require treatment then you may need to ascertain how well your chosen option is going to work for you.

Guidelines for Evaluating Scientific Evidence

When evaluating scientific evidence you need to make sure that the product that has been tested is the one that's being offered to you, and that the people on the trial have the same condition as you. For example, if a heart drug was tested on people who were over 65 years of age, had high cholesterol and already had suffered a heart attack, but you were only 45 years old and had never had a heart attack - then the trial data would not apply to you.

Similarly, if a product has only been tested on animals, or in a test tube (in vitro) then any clinical results obtained may not apply to a human. Complementary or alternative treatments often fall into this category where "promising data" is cherry picked and forms the basis of marketing propaganda.

Working through the statistics is a hurdle in itself, but with a bit of practice you can become proficient enough to make an informed decision. The point to remember is that relative statistics are meaningless - you need the absolute statistics or the real numbers, not simply the difference between those that got sick in both arms of the trial presented as a ratio.

It's also important to take into account the absolute statistics of those in the control arm (without treatment) who did not get sick. If, for example, 80 percent of people with high cholesterol in the control arm did not go on to have a heart attack then your odds on the likelihood of suffering an acute event may be small (5:1) and you may decide against a treatment, particularly if it carries additional inherent risks.

Use the table *Evaluating Scientific Evidence* on the next page as a reference to validate the information you need to acquire before making an informed decision as to how far a product or treatment will help you get to your end point.

Don't forget to factor in any risks of treatment and see if these would apply to you. If you feel that the risks of treatment in your individual case are high and the benefits not worth it, then by having done this exercise you will not only be confident in your decision on treatment, but also when discussing options with your specialist.

Use this table as a check list and read through the following case studies to make sure you understand the mechanics of evaluating trial abstracts and interpreting statistics. There are many examples given in this chapter to help you understand how to work out the value of treatment from scientific data.

"People don't die from the old
diseases any more.
They die from new ones,
but that's Progress, isn't it? "

Harlan Ellison, 1934 -

Why do I need to monitor my progress?

Because you won't know if, or by how much, the treatment is working.

If you don't monitor then you may. . . . . .

forfeit an opportunity should you need to change treatments for more effective ones

leave things for too long and narrow your options on treatment

waste time and money on treatments that don't get you anywhere

increase your risks if treatment is ineffective

1 Qualify tests to monitor your progress

Following a treatment plan without monitoring to make sure you are on track is like going on a journey without a map. So choosing tests to monitor treatments will tell you if the treatment is working and within the estimated time frame. By monitoring you can change or add to the treatment if progress is not as expected.

So we need to monitor progress over time where we are able to measure improvement (or deterioration) against:

- a time line; and
- your end point.

The main pitfall of monitoring is that it is easy to end up monitoring the test result in isolation of where you want to go. Test results always monitor the treatment, they will tell you *if the treatment is doing what it says it will do*. However, it's up to the patient to determine how relevant the results are to where they are trying to get to. For example, if you take a drug to correct an abnormal test result, say that of reducing your cholesterol, but your end point is to be drug-free and in better health, then you could end up going backwards if you become drug-dependent and experience negative health effects. So you have to make sure that any tests and the results of treatment are relevant to your condition, your progress and your end point.

Jonathan has been diagnosed with bowel cancer. His specialist has found that he has normal/low levels of cortisol and has prescribed Cortrate 25mg. Jonathan feels better on this treatment and his blood results show that his cortisol levels have increased. Jonathan sees another practitioner as he wishes to improve his overall outcome and undertake a natural treatment for his cancer. This practitioner points out that although his cortisol test results may improve, that Cortrate is a corticosteroid and may become a risk factor for his condition. Jonathan realizes that the cortisol test result may not be relevant for monitoring his progress on his journey.

Measurable and meaningful

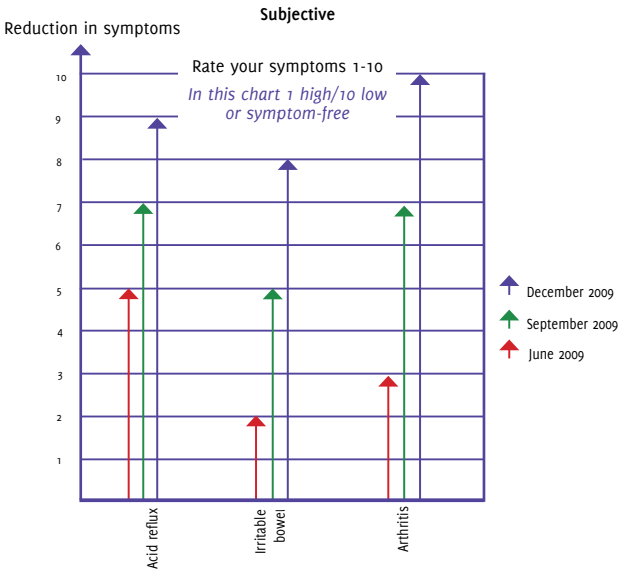
There are two distinct parts to monitoring: the results need to be *measurable* and the outcome needs to be *meaningful*. Meaningful means that the outcome should relate to your end point, not just the test result itself.

Measurable progress

Whether you are using objective tests (blood tests, scans) or a "how do I feel" (subjective) barometer you will be measuring treatment outcomes. There are different types of graphs to choose from to monitor your progress but you will need to give a starting value and an end point value. Use estimates given by your practitioner on predicted time frames for achieving your goals, and then plot way points against these time frames to monitor your progress.

Subjective measuring

When measuring "how do I feel" you may either rate your symptoms on a scale of 1-10 and then monitor improvement, or measure improvement as a percentage (for example, I am 25% or 50% better). Progress is then measured as improvement or deterioration against a base line (starting point) for each symptom.



Marketing tests

Whether for diagnosis or measuring treatment outcome, testing is evolving into a market within its own right. We now have better imaging techniques and the capacity to test for a broader range of individual markers either in tissue, blood, saliva or stool samples. These tests can facilitate diagnosis and lead to a more tailored treatment.

This emerging market of testing services is often used as a tool for the promotion and sale of products. As more products become available then so too do tests that measure the very markers that relate to or match the claims of specific products or product ranges. Many products are sold on the basis that they can increase/reduce specific blood markers associated with various health risks, or alter test profiles to reflect those of a younger person, and these changes, by default, will "improve" your health. In an industry that is product-centric this approach increases the amount of sales to a single consumer, but in a patient-centric model the basis for determining treatment is "what works".

With each test proposed, you will need to go back to the drawing board to determine:

- *what will the test tell me;*
- *what treatment will be recommended; and*
- *is this relevant to my end point?*

and with each product proposed you need to determine its value:

- *does the product address the cause or a known/proven risk factor for my condition; and*
- *what are my odds of reducing my risks if I take this product?*

For many products there are no scientific studies, so mostly these products are taken on faith (sounds good), or because the practitioner recommending the treatment has had "good" results where *good* should be defined in terms of "meaningful".

So health consumers need to determine which tests may prove the most value in indicating which treatments or products are most likely to take them the furthest.

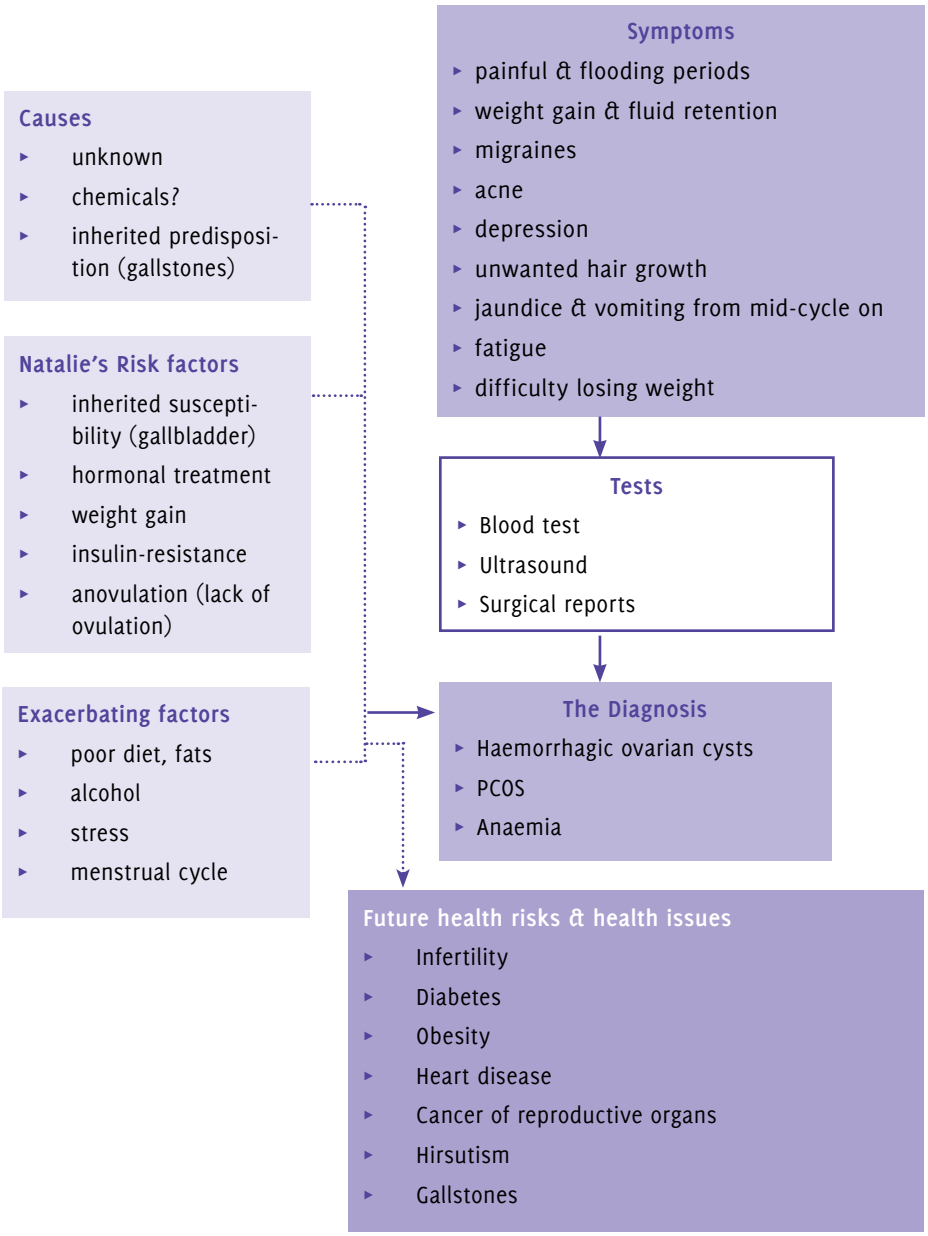
Sarah was in reasonable health but had a few food allergies herself and a family history of heart disease and arthritis. She decided to find out about genetic testing and how this could help her protect her future health. Sarah did a search on the internet and found a practitioner near to home who offered this testing service which would profile her individual DNA and the practitioner would then be able to "tailor a customized program of lifestyle choices for optimal health and well-being and bypass any roadblocks on her way to health." Sarah asked what sort of treatment would be offered in addition to common-sense advice on lifestyle and diet. She was told that this very exciting field of nutrigenomics (of applying the human genome to nutrition and personal health) enabled practitioners to offer individualized dietary recommendations and products specific to the individual's DNA profile. She was told that our genes determine our health and that although they cannot be changed they can be compensated for through a growing range of products and new functional foods (foods or dietary components that may provide a health benefit beyond basic nutrition). Her practitioner indicated that she would be able to tell her exactly what dietary changes she should make and which supplements to take that would enable her to take greater control of her health.

Sarah asked what the science was based upon and whether any clinical studies had been done to prove that these programs actually worked. She didn't get a satisfactory answer to this other than the technology and treatments were new, so Sarah could not make any determination of whether, or by how much, the treatment program would help. Sarah still decided to go ahead with the test through curiosity and thought that she would keep an eye on this growing science rather than commit to taking a multitude of products indefinitely, as although her end point was to reduce her future health risks, it didn't involve being product-dependent for life.

Natalie's Journey 2003-2009

Natalie is 21 years old and has been diagnosed with polycystic ovarian syndrome with haemorrhagic ovarian cysts. Her problems started at 20 with surgery for a ruptured haemorrhagic cyst and following this blood tests revealed PCOS. Her GP said that her condition was incurable that she would need to take some form of hormonal medication to control her condition. Over the next year she was prescribed a bio-identical progesterone cream to try and control her symptoms, but this aggravated all her symptoms especially the jaundice, nausea and vomiting. Natalie's ongoing problems were painful & flooding periods, premenstrual mood swings, bloating, fluid retention, migraines, vomiting, unwanted hair growth, acne and depression. Natalie decided to seek further help from alternative therapies to try and reduce her symptoms so that she could have a life.

Natalie's Strategy Flow Template



How serious is Natalie's condition?

- My condition may be controlled with medical treatment, but not cured
- I may prejudice my health if I don't have treatment to slow its progression
- My condition may become serious without treatment and monitoring, and I may prejudice my outcome or narrow my treatment options if I don't accept treatment now
- I need 6 monthly regular check-ups with my gynaecologist

Linda's Journey 2010-2012

Linda is 35 years old and had just given birth to her first child four months before she was diagnosed with invasive ductal breast carcinoma, stage 2, triple positive and grade 3 (aggressive). She immediately had some eggs harvested as she wished to have more children and was concerned that the treatment may leave her infertile. Her oncologist recommended surgery and chemotherapy (ACT) as a first line treatment to be followed by radiotherapy, herceptin (H) and tamoxifen + goserilin as targeted treatments. There are some additional risks with the recommended ACT chemotherapy (such as heart damage, toxicity and a small risk of leukaemia further down the track) but the advantages, in terms of overall survival (OS) and disease-free survival (DFS), are worth it, according to her oncologist.

Linda, who is concerned about her future fertility, asks if there are any studies to compare the chemotherapy treatment proposed, against just having surgery, radiotherapy and the targeted treatments and her oncologist says - no. Linda asks whether she has any patients who have opted for this, and if so, how are they doing. The oncologist says, yes she does and they are going fine, but if Linda chooses this option then she would have to pay for all the drugs as only the full protocol is available under Medicare.

Linda decides to undertake the treatment recommended as she cannot afford to pay for the targeted treatments and to do nothing would pose a greater risk than any from the treatments themselves.

Linda's Strategy Flow Template