

I've got nothing to lose by trying it

Weighing up claims about cures
and treatments for medical conditions



Thank you to everybody who contributed to this guide.

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*Some names have been changed at the discretion of contributors.

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Introduction

Every month there are dozens of news reports about medical breakthroughs and wonder drugs. The internet is cluttered with adverts and chat-room conversations testifying to ‘amazing’ benefits.

These stories offer hope of finding something that will do more than conventional medicines can. But the evidence for many of these treatment claims is unreliable. This leaves people unsure about what to try and where they can draw the line: how can we make sense of ‘cure’ stories? How can we tell the beneficial from the bogus, the likely from the doubtful?

Living with a debilitating condition is difficult, particularly if there is no cure or current treatments aren’t providing relief. When people feel that their doctors don’t have enough time or concern, alternative therapies can seem appealing.

While there is no easy way to know what to believe, there are questions you can ask. We have worked on this guide with patients, carers, doctors, nurses and medical charities and explored how they ask about evidence to help them weigh up claims and make decisions.

Sarah Mehta
Sense About Science



A cure for
everything - from
colds to HIV_

Doctor’s diary:
Miracle cure for
Parkinson’s?_

The diet that can
treat epilepsy_

On sale in the
UK: unproven
goats’ blood
treatment for MS
patients_

1. Information everywhere

The online age

There are many websites promoting unproven therapies as treatments or cures, and unfounded rumours that begin to take root in chat rooms. Some claim to tap into very new science, and others say they draw on tradition or ancient wisdom. They are rarely backed up by scientific evidence showing that they work.

These treatments are marketed with promises and definitive answers that play on people's desperation to know more. Doctors, on the other hand, are more likely to talk through the options and raise the risks as well as the benefits.



"We've come across websites that present fake research but pretend that it's clinical trial data, with graphs and charts to try to convince people. Looking closely, you can see there are only one or two anecdotal reports and it is actually a marketing ploy with a false veneer of scientific evidence."

Liz Woolf,
Cancer Research
UK

"There's a Nobel prize waiting for the person who can cure osteoarthritis, or MS, or Alzheimer's, and many other major illnesses. So, beware the huckster and the testimonial."



Caroline Richmond, Medical journalist

When treatments sound too good to be true, there are things you can look out for to begin to sift out dodgy claims:

- **What promises are really being made?** Many websites include a legal disclaimer in the small print to say the treatment has little or no benefit.
- **Are the claims anecdotal?** Some people are given discounts on treatments in exchange for giving a positive testimonial.
- **Is the treatment only available on the internet and not prescribed by a doctor?** If so, be suspicious, and remember that heavy marketing will play a role.



Eating tree bark cured my Crohn's disease, says grandmother_

Can goats' blood help beat MS? My mother is walking proof it can_

Medicine in the news: Real hope or hype?

“We have had years of so-called miracle cures, often based on whims and the isolated, freak success story.”

David has a chronic condition

Find out about reading research papers on page 16

Inflated headlines

Journalists need interesting stories that sell newspapers. But the real story may be more complicated than the punchy news headline suggests.

You can ask, does the rest of the article back up the headline? If you delve a little deeper, you might find out what the researchers set out to do and what their conclusions are. And look out for comments from any other scientists that give a different side of the story, these are often buried at the end.

Will it work as a treatment?

Some news stories report on good, early stage scientific research. It's too early to know whether testing will lead to a treatment that works. For example, some chemicals show promising results in the lab but have not yet been tested in humans – and drugs often have a different effect in people than in the lab.

Promising early trial results

Researchers will need to do extensive clinical trials to be sure that a new drug really works and is safe to use.

Look out for which stage the research is at: has it been through clinical trials? Read more about clinical trials on page 12.



A 'wonder drug' that could kill all types of cancer_

Sausage and bacon worse for the heart than red meat_

Alzheimer's miracle pill on the way_

Is coconut oil really a thyroid cure?_

How to spot good reporting

There are many journalists who report science and medical stories well. One sign of good reporting is when a journalist names the scientific journal where the research has been published.

Research published in scientific journals has passed the scrutiny of independent reviewers with experience in the field (peer review). They assess whether it is valid, significant and original work, how the study was designed and whether the results support the researchers' conclusions.



“It’s easy to be spooked by reports that say ‘risk up 20%’. But ‘20% up’ is a relative risk that can be big, or tiny. It might mean 5 cases in every 1000 people rising to 6 cases in every 1000, an absolute risk of 1 extra case per thousand. When reports of ‘big’ relative risks ignore absolute risks, beware.”

Michael Blastland,
Writer and
broadcaster

However, be cautious of reports from clinical trials presented at scientific conferences. These often hit the headlines but the research may only be preliminary findings that are not yet published. Scientific scrutiny (peer review) could show up weaknesses in the research or the conclusions at a later stage.

When an article makes a claim like “**Osteoporosis drug may double cancer risk for thousands**”, we need to know what that risk was to begin with to put the change in risk into context.

And, be particularly wary of websites that use news reports rather than published research to back up their scientific claims. This usually means the websites don’t have reliable evidence to support them.



Nicotine offers
new hope for
Alzheimer’s
treatment_

Nicotine no good
for Alzheimer’s_

Hepatitis C
wonder pill_

2. What have I got to lose?

Financial costs

The cost of unproven therapies varies, from relatively little for a new diet or an over-the-counter remedy, up to many thousands of pounds for some treatments. Alternatives seem particularly attractive where conventional medicine has little to offer, but if the treatment doesn't work, the money is wasted. Whatever the cost, we need to ask is it worth spending money on false hope that could be better spent on something else?

“We have heard about unscrupulous people making big profits from untested treatments. I feel strongly against this.”

Carole Borges has multiple sclerosis and epilepsy

“I think for me the main benefit of acupuncture was the feeling that I was doing something for my symptoms... but it was £40 a pop – a discounted rate because I'm on benefits – and seemed a lot of money.”

Pat Blalock has multiple sclerosis



“After a saliva test an ‘alternative thyroid doctor’ gave me ‘adrenal glandular’ tablets and told me to reduce my prescribed thyroid medication. I was in a lot of pain, bed-bound for weeks and it cost me a whole year out of my life, not to mention the huge costs of paid carers and useless and misleading saliva tests. My advice is not to make my terrible mistake of trusting anyone outside the medical profession.”

Christine has a thyroid condition

It may feel reassuring to spend a lot on a treatment – ‘if it's expensive, it must be good’. However, some of the most effective and commonly used drugs have been used for long enough to be ‘off-patent’, so have become very cheap.

Similarly, some people are filled with hope by travelling abroad for a new therapy, but we rarely hear about the outcomes after fundraising to send an ill person for treatment overseas. The reality is that success rates are low for controversial or untested therapies.



Scientists or swindlers?_

Can Miracle Mineral Solution help with low thyroid?_

Weighing up the health risks

It is understandably frustrating when medical therapies do not offer the benefits people need. But choosing to do nothing may be less risky (and less disappointing) than trying an unproven therapy with potentially harmful effects.

Alternative treatments could be harmful so it's important to discuss the risks with your doctor:

- Alternative treatments could interfere with conventional medicines. For example, there is a known risk from taking evening primrose oil and warfarin in the same time period.
- Stopping conventional treatment to take an unproven alternative can be risky. People with asthma who stop using their conventional medication risk life-threatening asthma attacks, and people with epilepsy who stop their medication risk having breakthrough seizures, which are damaging to the brain and in some cases can lead to serious injuries.

"I'm concerned about a company offering embryonic stem cell treatment to people with Parkinson's.

I contacted them after seeing an advertisement. All their communications have been by phone, with nothing in writing apart from promotional books on the internet. Nothing is published because 'it's too controversial' and no clinical trials have been carried out.

The treatment is illegal in the USA so they take you to Mexico for a day where you are injected with stem cells at a cost of \$30,000.

I am very concerned that vulnerable people will be persuaded to pay a lot of money and be disappointed. I think stem cells may well be the cure of the future and good work should not be sabotaged by charlatans."

Jane Clarke is affected by Parkinson's



"Stem cell therapies are still in the early research stages for most conditions. The UK is at the forefront of pushing the boundaries, and there is reason to be optimistic, but realistically it takes many years for new treatments to be proven safe and worthwhile. Unregulated clinics take people's money and hope, putting them at risk of complications, even HIV or hepatitis, for no benefit."

Prof Robin Lovell-Badge, Head of the Division of Stem Cell Biology and Developmental Genetics, MRC National Institute for Medical Research



Stop asthma with water!_

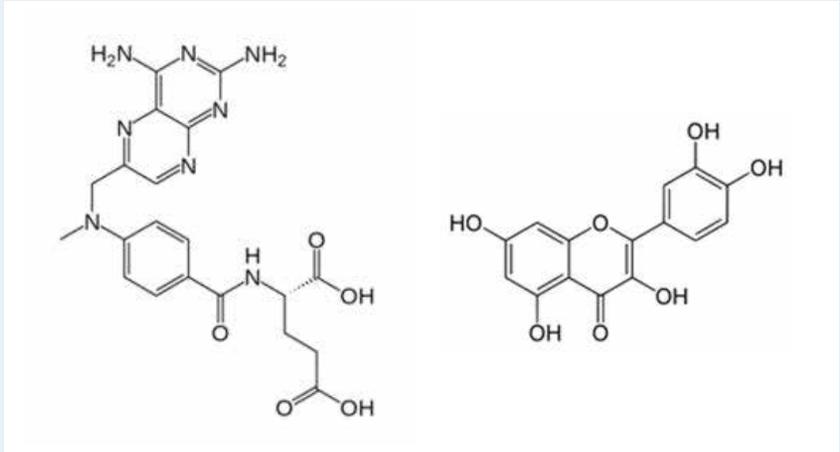


“When I ask patients what they are taking for a condition they frequently don’t report anything that they have been led to believe is ‘natural’. Many of the most dangerous poisons are completely natural.”

Dr Andrew Green,
GP

Products marketed as ‘natural’ or ‘herbal’ are often perceived to be safer than so-called ‘chemicals’. In reality, everything is made of chemicals whatever name it is given.

The substance on the left is a well-researched cancer drug, whereas the substance to the right is promoted as a ‘natural’ alternative called ‘Four-marvels powder’, which has not been investigated for risks and benefits in clinical trials. However, they are both chemicals.



Herbal remedies for arthritis mostly ineffective_

Eight Remedies Treat Diabetes Naturally_

Natural Salt Therapy for Treatment of COPD and Emphysema_

Kill or cure?_

The aloe vera miracle: A natural medicine_

The industry for products marketed as ‘natural’ is not regulated in the same way as conventional medicines, meaning there is not such rigorous testing for effectiveness. Alternative treatments are not so well researched or understood. They can also be very expensive and counterfeit products are common on the internet – people are rightly wary of paying a lot and not knowing what they are getting.



“While many of the treatments promoted on the web are unproven and ineffective, others could be positively harmful for people with epilepsy. For example, some herbal remedies are more likely to cause seizures rather than cure them. When it comes to unregulated treatments it’s very difficult for people to know who to trust on the internet.”

Dr Sallie Baxendale, Consultant Neuropsychologist,
Institute of Neurology, UCL and Epilepsy Society

Emotional costs

Trying unproven treatments costs people time, stress, and energy. One of the biggest emotional costs is the disappointment of discovering you have been sold false hope. Rather than being pushed into trying anything, you can ask some critical questions about what you're really being offered.

For example, a new diet or exercise regime might simply mean a more complicated daily routine, but other more extreme diets – like only eating fruit – run the risk of damaging health through poor nutrition.

John said he tried making so many changes to his eating and living habits that he started to feel bad:

“I ended up thinking I had bad days because of something I was getting wrong. I realised I'd picked up some weird ideas about what the disease actually was.”



“Following all this advice can be exhausting, time-consuming and expensive, but more importantly it can create false hope, which can have a devastating effect – especially when something doesn't work.”

Charlie Fletcher has motor neurone disease

You might find that complementary therapies like massage or aromatherapy help to improve mood and reduce stress. But watch out for alternative or complementary therapists who make claims that they can cure you or treat your condition, or who tell you not to consult your doctor.



Clinic peddles
false hope of
cure_

The public
deserves
protection from
the false hope of
'wonder drugs'_

Wonder drug
'boosts hope'_

Stem cell trial
offers millions
hope of a cure_



Finding a balance

Encouragement from well-meaning family and friends to try anything that offers relief or hope, rather than questioning whether the treatment works and is safe, can feel like a lot of pressure.

The main advice from others in this position is:

- Don't be pressured into trying things, even when people around you mean well – tell them that finding the evidence matters to you.
- Approach new treatments with a wary eye, especially if you are parting with money.
- Be suspicious of websites that blind you with 'sciencey' information.
- And be particularly wary of any treatment that claims to be a cure: if it sounds too good to be true, it probably is.

“There’s so much information about how we can prevent or cure diseases – whether it’s on the TV, in a newspaper or just gossip. Some of it is accurate but lots is either half the story, distorted or just plain wrong. How can we know what’s accurate and what’s not? Keep asking questions and it’s usually possible to sift the truth from the fiction.”

Prof Martin Wiseman, World Cancer Research Fund

“Although hyperbaric oxygen therapy is something you could try, please do not get your hopes up too high. Some people feel that it helps with some of their symptoms but I know plenty of people who have had absolutely no effect from it at all and there is no scientific evidence that it makes a difference to multiple sclerosis.”

Karen MacRae has multiple sclerosis



Cancer treatment
'blows tumours
away in weeks'_

The secret to
healing virtually
all diseases_

“A great deal
of his recovery
down to taking
Aqua Hydration
Formulas”_

3. Looking for the evidence

There are useful questions you can ask to find out if claims have any evidence behind them:

1. Have results been independently researched and repeated?
2. Has the study been published in a scientific journal?
3. What do other experts in the field say?
4. Has there been a clinical trial?
5. Is the treatment licensed? What is it licensed for?

Why do unproven therapies seem to work?

Personal testimonies often give a misleading picture about how effective a therapy is. Just as people on diets look at the scales optimistically, everyone is inclined to look hopefully for any sign of improvement that a therapy is worthwhile. This optimism itself makes some people feel better.

The placebo effect

Research shows that when people take a ‘dummy’ treatment that they believe might work, about half of them will see an improvement in their condition. This is the placebo effect, a well-known psychological response which triggers a physical response. This happens with all treatments, including physical therapies like acupuncture.

Coincidence or causation?

The symptoms of a lot of conditions fluctuate, like the pain with arthritis, which comes and goes. And when symptoms are worse than usual, they are more likely to be followed by a period of normality – this can be mistaken for an improvement. People also improve or recover over time from some conditions. This might coincide with a particular food or treatment.

“I personally think it’s worth trying these exclusion diets, if you’ve got the time and energy. But they definitely don’t help everyone and the people who find they do nothing aren’t always so quick to comment about all the time they wasted following them.”



Denise Ramsay has multiple sclerosis



Do cancer alternatives really work?_

Curry spice can halt spread of liver disease_

Clinical trials

A genuine, trustworthy trial will never expect you to make any payment.

To find out whether there are relevant clinical trials for your condition you can visit www.who.int/ictrp

Of every ten new drugs that enter clinical trials, only one makes it to the market.

The best way to find out whether a treatment is safe and effective is through scientific testing. For treatments this happens in rigorous clinical trials, often involving a large number of people.

New medicines go through clinical trials that assess whether they work better than a placebo (dummy drug) and at least as well as current treatment (if there is one). Clinical trials also test for side effects, and to ensure the advice on dosage is correct.

It can take years to complete the clinical trials process (shown below) because the stages of testing include extensive safety checks and finding out whether the treatment works. It can feel like a long and frustrating process, but if a medicine has gone through this it means we understand the benefits and potential harms.

There are three main phases of clinical trials before a medicine can be authorised for use...

Phase 1: The safety phase



Testing in a small group of around 30 people (who do not necessarily have the condition) to check if the medicine seems safe and what dosage to use.

Phase 2: Does it work?



Continue to look at safety. Compare to a placebo and/or an existing treatment in up to 200 people with the specific condition.

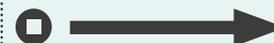
Phase 3: Does it work?



Continue to look at whether it works, but this time in hundreds to thousands of people with the condition. This means that more information on less common side effects can be collected.

After Phase 3 has been completed, an application can be made for the medicine to be licensed as a treatment for the specific condition it was tested on.

Phase 4: Monitoring



Once approved as a new medicine and in general use across the population, it should continue to be monitored and evaluated.

Clinical trials often specify the condition, stage of the condition, and particular group in the population (e.g. women) that the therapy is being trialled for. If these therapies were then prescribed for other groups of people, or to treat other conditions, we cannot say, on the basis of such a clinical trial, what the risks or benefits for other groups are and they could be very different.

Many unlicensed therapies and alternative remedies are not tested to such high standards, if at all. Without evidence we risk choosing treatments that don't work or even worse, that can do us harm.

Systematic reviews: the best evidence

In these special review articles, scientists use a rigorous process to bring together all the available clinical trials from around the world looking at the same treatment for the same medical problem.

The process looks carefully and critically at the quality of the trials to separate out which have reliable results. Were they done well? Did they ask the right questions? Did they include the right sort of patients? This is particularly important because not all individual pieces of research are good quality and not all give a reliable picture.

Finally the systematic review brings all the results together in a summary. Sometimes this is in the form of a mathematical analysis called a 'meta-analysis'. High-quality systematic reviews are considered the best evidence for making decisions about treatment.

So, rather than looking for a single clinical trial to answer the question 'does this treatment work?', it is always better to look for a systematic review.

Read more in '**Sense About Systematic Reviews**' at senseaboutscience.org



"Allowing treatments to be made available which have not been through an established clinical trials process encourages unscrupulous individuals to market ineffective treatments for monetary gain."

Dr Brian Dickie,
MND Association



Crocus drug that can kill tumours in one treatment_

Cancer 'bomb' jab in years_

Hope over heart pill_

Unprecedented Medical Miracle: first MND Patient Cured_



“We owe it to previous participants and researchers who had the patience to begin to reduce uncertainty, to carry on and be patient ourselves.”

Hazel Thornton,
Patient
Researcher

You can find out more about why and how trials are done in **Delving deeper** on page 16

Monitoring new medicines

Medicines are tested under strict conditions in clinical trials, but in everyday life there is a wider range of differences between people, and influences they are exposed to, and so previously unseen side effects are likely to crop up. This is why researchers continue monitoring for adverse reactions in Phase 4. Once doctors can start prescribing a medicine, patients and health professionals then report any side effects through the Yellow Card Scheme, so they can be analysed by the researchers.

This evidenced-based approach to therapies can seem frustrating and bureaucratic – it’s true there may be room for improvement. However, rushing new therapies through is risky: with less testing, more people would be harmed.

So on the one hand, people point to the success of AIDS activists in getting trials of anti-retrovirals cut short so that the medicines could be prescribed. But on the other hand, the slower and cautious approach of the US licensing body to trialling thalidomide in the 1950s spared that country the thousands of cases of babies born with limb defects that occurred in other countries.



Jab to heal the blind_

Daily pill to cure diabetes_

The Miracle Oil for Colitis_

Chocolate ‘good for your heart’_

Could palm oil cut stroke risk?_

Armed with evidence

By asking critical questions and knowing where to find information you can trust, you put yourself in a much stronger position to cut through the hype around unproven treatments.

You can make evidence-based decisions – including deciding not to try something when it carries the risk of disappointment and harm.

The internet and other resources are really useful if you:

- Ask questions
- Know how to spot quackery
- Know what to expect of good evidence

“It is very important that the safety and effectiveness of treatments are evidence-based, otherwise we would be chasing rainbows every day.”

Jane Tomlin has multiple sclerosis

And there's more you can do to stand up for evidence and change things for the better, including:

- **Participate in clinical trials**

Recruitment criteria for trials are often strict so it's not always possible to enrol in research, but you can find out more about getting involved at www.crncc.nihr.ac.uk/ppi.

- **Be involved in making decisions**

Medical research charities, public funders and hospital ethics bodies are worth contacting if you are interested in joining a committee to be involved in shaping the future of research and health and social care.

- **Fundraise to make research possible**

Many organisations fund research into possible cures and new treatments to relieve symptoms, made possible thanks to people's fundraising efforts.

- **Find a network**

Patient groups bring together like-minded people who support each other and are interested in keeping up with the latest research and information.

4. Delving deeper

Trusted sources

NHS Choices www.nhs.uk The online portal of the NHS and the UK's biggest health website. The **'Behind the headlines'** section sets news stories in their research context.

PubMed Health www.ncbi.nlm.nih.gov/pubmedhealth Reviews of clinical effectiveness research with easy-to-read summaries.

Bad Science Ben Goldacre's witty best-selling book (2008) lifts the lid on quack doctors and scaremongering journalists.

Testing Treatments

www.testingtreatments.org How we tell whether one treatment is better than another and what makes a fair test.

Health Talk www.healthtalkonline.org

A unique database of personal experiences and information about over 50 conditions – video, audio and text.

"I don't know what to believe..."

Making sense of science stories

A guide to how scientists present and judge research, and how you can ask questions.

Evidence Based Medicine Matters

A booklet about how evidence-based medicine is the key to the success of modern healthcare.

Both available from www.senseaboutscience.org/resources.php

Reading research papers

If you want to read original research articles, a good place to try is Europe PubMed Central: www.europepmc.org. You can search over 22 million biomedical and health article summaries (abstracts) and find review articles that give an overview of the latest developments in a particular research area.

Over 2.5 million articles in Europe PMC are now free to read. Despite more people being able to access published research, it is aimed at an expert readership. Some journals (such as PLoS Medicine and eLife) now include a lay summary of their research articles.

The Cochrane Collaboration

www.cochrane.org Systematic reviews exploring the evidence for and against the effects of treatments.

UK Clinical Research Collaboration

Available from: www.ukcrc.org/publications/informationbooklets.aspx 'Clinical Trials: what they are and what they're not' and 'Understanding Clinical Trials'.

International Clinical Trials Registry Platform (ICTRP)

www.who.int/ictip A way to find information about clinical trials.

My Medicine www.mhra.gov.uk/mymedicine

A guide to the life-cycle of medicines, from scientific discovery to licensing and monitoring.

Organisations

Organisations that helped put this guide together and can provide more support and specific information

Alzheimer's Society alzheimers.org.uk
Asthma UK asthma.org.uk
Breakthrough Breast Cancer breakthrough.org.uk
British Lung Foundation blf.org.uk
British Thyroid Foundation btf-thyroid.org
Cancer Research UK cancerresearchuk.org
Core Charity: fighting gut and liver disease corecharity.org.uk
Epilepsy Research UK epilepsyresearch.org.uk
Europe PMC europepmc.org
HealthWatch healthwatch-uk.org
INVOLVE invo.org.uk
Motor Neurone Disease Association mndassociation.org
MS Society mssociety.org.uk
Muscular Dystrophy Campaign muscular-dystrophy.org
NIHR Diabetes Research Network drn.nihr.ac.uk
Parkinson's UK parkinsons.org.uk
UK Cochrane Centre ukcc.cochrane.org
World Cancer Research Fund wcrf.org
Science Communicated sciencecommunicated.moonfruit.com

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“Evidence-based medicine is central to providing the best possible care for people with Parkinson’s. Scientific advances in our understanding of the condition and our ability to treat it must flow through into clinical practice, where they can be used to help make the right decisions about care for each individual.”

Dr Kieran Breen,
Parkinson’s UK

“



This matters to me because over the last 20 years I have been encouraged to try so many expensive drugs or treatments. I would have

done better to have a good holiday. It is hope that makes us grab at straws. We need facts not dreams.”

Rita Baillie has multiple sclerosis

With support from our funding partners:

