

To jab or not to jab?

Given that the immune system has been at the centre of suspicion for what may have 'gone wrong' to make us ill in the first place, whether or not to have vaccinations is a big decision for people with M.E. Having appealed for your experiences regarding the effects from a range of vaccinations, Hanne Scrase draws together your responses, while also seeking the views of medical experts, to help you make an informed choice about this difficult issue.

Our immune system has an inherent capacity to recognise foreign material (such as an infection or a flu jab), produce the appropriate defence molecules or antigens, and subsequently 'remember' this contact for decades. This means that antigens can be mobilised much quicker in the future should a similar agent enter the system again – in other words rendering us immune to the invading bacterium or virus.

Understanding the flu vaccine

However, as the influenza viruses change from year to year, a new flu jab is necessary annually in order for an individual to stay protected. The vaccine is made from two or three different, inactivated forms of the virus in order to protect people against those types of flu most common at the time, as decided by the World Health Organisation (WHO).

Because the viruses chosen for the vaccine are inactivated, they cannot cause flu as such, although they may produce flu-like symptoms for up to 48 hours. According to the Scottish Executive Health Department, the influenza vaccine gives 70-80% protection against infection with any virus strains closely matching those in the vaccine.

The chosen viruses are grown in poultry eggs and then killed ('inactivated') and purified.

In contrast, a 'live' vaccine has simply been altered to make it less harmful. Live vaccines include oral polio, MMR and BCG as well as yellow fever and one of the typhoid ones.

Could mercury preservative be harmful?

In order to prevent contamination of many vaccines, a mercury-based preservative, thiomersal, is often added. As mercury is toxic, the presence of thiomersal in vaccines has been the focus of much controversy. The current dose used in the UK is well below permitted levels according to the NHS' own data. What constitutes safe levels has, however, been passionately debated and opinions vary from "no mercury can ever be acceptable" to "tiny amounts have not been proven to cause problems and must therefore be safe."

Proving correlations, let alone causal relationships, with regards to the biochemistry of the body is incredibly difficult. But as it's a matter of genuine concern among the public, the US Institute of Medicine (IOM) and the WHO's Global Advisory Committee on Vaccine Safety have both carried out extensive reviews of research investigating any link between thiomersal and various serious conditions, e.g. MS, rheumatoid arthritis, diabetes, CFS and leukaemia. While no scientific evidence has been found supporting any alleged links, some evidence was accumulated by the IOM to disprove a link between MS onset or relapse with thiomersal.

However, thiomersal preservatives are banned in some countries due to safety fears, particularly in children's vaccines. The US Food and Drugs Administration has also recognised that some children who receive thiomersal-containing vaccines may have, over time, exceeded federal guidelines for single-dose mercury exposure. The United States Public Health Service, American Academy of Pediatrics and vaccine manufacturers have now agreed that

thiomersal-containing vaccines should be removed as soon as possible because of the potential risk of adverse effects from mercury exposure. Similar conclusions were reached by the European Medicines Agency and worldwide research investigating safety issues remains ongoing. For more on this issue, see the wikipedia website listed at the end of this article.

"My doctor told me wisely to work out the odds! Asthma can be life threatening, so I had to go for it"

Feedback on the flu jab: The good

Of 20 people who wrote earlier this year to tell us about their experience with having the flu jab, 13 had no reaction at all or only minor ones (symptoms lasting less than a week). So nearly two-thirds of this very small group of respondents were reasonably okay having the flu vaccination.

The decision about whether or not to be vaccinated is best made in the light of one's overall health and general circumstances. For example, in 2004 Linda had a very bad bout of flu leading to bronchitis, which left her with asthma and reliant on inhalers. She therefore decided to have a flu jab that autumn: "The injection was

Your stories



absolutely fine, as was the following year's; my doctor told me wisely to work out the odds! Asthma can be life threatening, so I had to go for it."

Similarly Carolyn, who had also suffered with a nasty flu in previous years, decided to have the vaccination last November and was fine, too. The jab worked and she had a flu-free winter, leaving her resolved to have a flu jab every year from now on. Jane has had several vaccinations over the last eight years since getting M.E. and explains: "I haven't had any bad reactions – just the normally expected things like a sore arm or feeling slightly unwell for a couple of days."

And the not-so-good...

Unfortunately, four respondents found that the flu vaccination provoked a marked flare-up in their M.E. symptoms, sometimes lasting months, while two others felt that having a flu jab actually contributed to the onset of their condition. "The vaccination had turned being ill with a 'nameless condition' into actual M.E.", explains one member. "At fourteen I had a flu jab. This precipitated a downward spiral that saw me become very disabled and ultimately receive a diagnosis of M.E." She then risked a second flu jab eight years later, triggering a deterioration which distressingly she hasn't pulled out of. Other readers who had experienced a bad time following a flu jab naturally felt that the months of much worse health outweighed any advantage offered by protection against catching flu.

Confusingly, several people who reported a bad reaction to the flu jab had no ill effect from travel vaccinations. So one shouldn't automatically conclude that all vaccinations will cause the same

reaction. A key factor in predicting response to immunisations seems to be the individual's current state of health at the time. For instance one member wrote in who had had two markedly different experiences of the flu vaccination: the first time when she was very ill with M.E. she had subsequently suffered a serious relapse, while the second jab was given at a time when she felt a lot better and in this case she found that the unpleasant side-effects only lasted a week.

The homeopathic alternative

Two readers wrote about their experiences with trying Ainsworth's homeopathic 'anti-cold and flu remedy', produced each year based on current viruses. Christine explained: "Every year I drive myself nuts trying to decide whether to have the flu jab. So far I haven't dared, but recently thought I'd try the homeopathic alternative. It says to take one tablet four times a day for a fortnight. I took the first four and the next day was coughing and spluttering. I felt worse for about a month so didn't try any more! Ainsworths are a reputable company, so I don't blame them for the reaction; I blame M.E."

However, Tina reported finding this homeopathic alternative "really useful". The difference was that this member, who obtained the pills from the Royal London Homeopathic Hospital's pharmacy, took two pills per week with 3-4 days in between because she was advised that "if taken as a 4-pillule dose straight away, it can produce cold symptoms, with sore throat and cough."

This clearly illustrates the problem experienced by many people with M.E. of sensitivity to 'normal' doses of any

medication – including so-called 'natural' remedies. For this reason most M.E. specialists advise trialling any new remedy on a fraction of the recommended dose and, if tolerated, to build up gradually.

Finally, homotoxicologist Rosemary Lawrence from Turning Point Clinics contacted us to say that their clinic provides a homeopathic flu alternative to injections in pill form called Influenzinum, (available to practitioners via www.biopathica.co.uk, which also lists homotoxicologists who can prescribe it; price £15).

Expert views vary

A Canadian review of research considering a possible link between CFS and immunisations (Sleigh et al 2002) concluded that "influenza immunisation appears to provide protective antibody levels without worsening CFS symptoms." However, this line of thinking has been contested by some medics working in the field, including Drs Charles Shepherd and Betty Dowsett in the UK and US specialist Dr Paul Cheney.

Dr Shepherd, author of *Living with M.E.* (Vermillion), is very critical of this Canadian review. Among others, he points out that the report refutes any link between Hepatitis B vaccine and CFS by using results from a one-week follow-up study of 700 healthcare students rather than any longer term investigation. Dr Shepherd's own data also suggests that "approximately 60% of M.E./CFS patients experience some exacerbation in their fatigue and flu-like symptoms (sometimes quite marked) following an influenza vaccine." He advises though that: "if the vaccination is potentially lifesaving, then considerations relating to CFS must take a lower priority." Specifically regarding the flu vaccination, Dr Shepherd's advice is: "If a patient has any medical condition that could be severely affected by an attack of the flu, such as heart disease, asthma or bronchitis, the influenza vaccine should certainly be considered."

Interestingly, Dr. Cheney suggests that: "CFS patients are already immune-activated. Many have not suffered with flu since having the disease. We suspect they are so immune-activated and the anti-viral system so turned on that they actually have a relative resistance to at least initial infection of common agents.

Injecting an antigen into a fired-up immune system may actually make people go into relapse."

All the M.E. specialists we spoke to advised against having immunisations while ill with active viral-type symptoms (such as swollen glands or temperature) unless absolutely necessary. Several of you who have written in also say that your consultants have advised not to undertake vaccinations unless a genuine medical need outweighed any possible side effects. This refers not only to influenza jabs but also travel vaccines.

This advice is illustrated by Martha's case. She explains: "I strongly believe that having polio and tetanus vaccinations together at a time when I was stressed, depressed, run down and underweight contributed to the onset of my M.E."

Mixed reactions to travel vaccinations

Your replies with regards to vaccinations other than the flu jab make for a less clear-cut picture. Out of 11 people who had had a mixture of vaccinations (not including hepatitis B, which we shall come to later), the reactions can be summarised as follows: five people were made worse; four had no or minor reactions; one was much better and feels that in fact the vaccinations "kick-started her limping immune system"; while another considered the vaccinations to have triggered the onset of M.E.

Clearly our sample of responses is too small to draw any general conclusions. Furthermore the fact that travel vaccines are generally given quite

closely together makes it difficult to say which vaccine may have caused a deterioration, or whether it was the combined effect.

One reader with M.E. said that she spread her travel vaccinations over a period of six to eight weeks, starting with her first-ever flu jab. She then had hep A, typhoid, tetanus, diphtheria and polio followed by anti-malarial treatment. After two weeks she had to stop the anti-malarial treatment, however, because she was starting to feel very unwell. Sadly, she got progressively sicker, resulting in her worst relapse for many years.

In contrast, Jane has had several vaccinations since she got M.E. eight years ago, including polio, tetanus, typhoid, rabies, meningitis, and yellow fever, and has been absolutely fine, "only feeling slightly unwell for a couple of days".

Gill's experience was an interesting one, in that she was "knocked out cold for six weeks" following a rabies vaccination but emphasised that she would not have foregone it for any reason. However she also told us that when she had this vaccination a second time, she was absolutely fine.

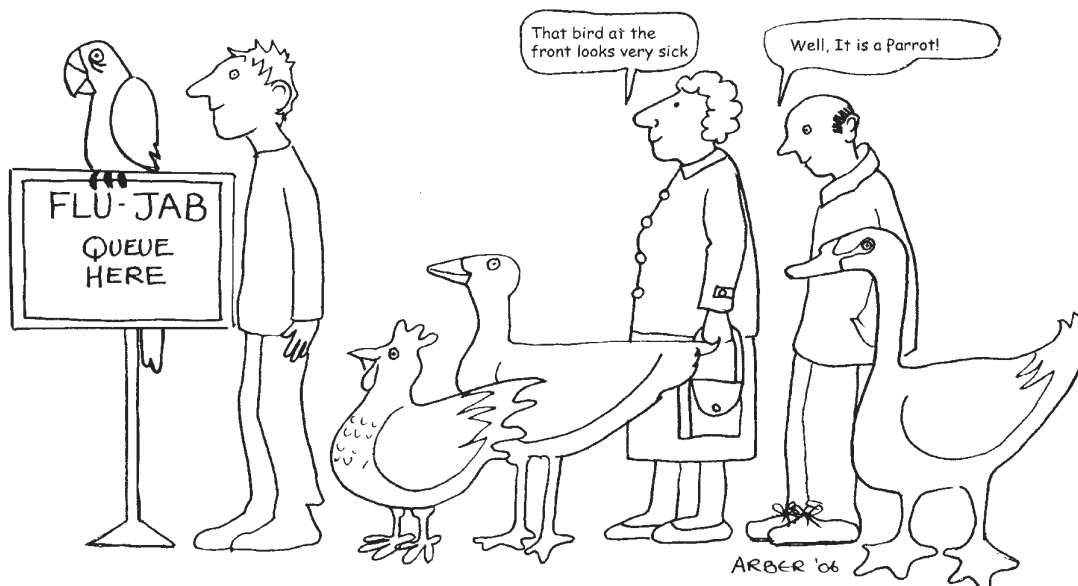
Professor Findley, who heads up the National M.E. Support Centre in Essex, says: "If I am dealing with serious fatigue syndrome, I would advise against the sort of travel that vaccinations are required for, i.e. to tropical and semi-tropical third world-type countries. Travel itself can produce a relapse and if somebody is serious about improving their symptoms, then they should consider alternative types of holidays."

Focus on hepatitis B

We received replies from two nurses and a doctor who became ill with M.E. following immunisation for hepatitis B.

Elaine experienced an immediate and violent reaction to the vaccination. Although the hospital reassured her that it was most likely a coincidental bug, sadly she remains very ill more than two years later. It is important to note that before receiving the immunisation she had been "very run-down" due to a heavy workload on night shifts while looking after her family, having also suffered a nasty virus a few weeks earlier. The other nurse Anne had been well before and during the vaccinations but feels they contributed to the onset of M.E. symptoms 6-12 months later.

It was also a Hep. B jab which caused Dr. Graham Thompson a terrible relapse, having seemingly recovered from M.E. He explains: "I developed hepatitis 18 years ago and then M.E. However, three years later when I thought I'd fully recovered, I had a hepatitis immunisation, which GPs were strongly encouraged to have at the time. I was feeling fighting fit before the jab. Interestingly, it was the genetically engineered Engerix, not the viral one we might have expected to cause problems. Four days later I went down with all the symptoms now covered by the Fukuda & Canadian criteria. This time it took seven years to get back to 90% original function although I relapsed again a year ago for no known reason."



Mixed reaction to meningitis jab

Only two people wrote about their experience with the meningitis vaccination. Jane, who suffered no ill effects, was feeling reasonably well at the time, though she doesn't know if the vaccine was live or not. In contrast, Jo-Anne received a live vaccination and at first felt much improved, but was rushed into hospital five days later with suspected meningitis. Sadly this heralded the beginning of severe M.E., which was to last for six years, though she has since improved over time. The Institute of Public Health in Norway is currently investigating at least 70 cases of people who are linking their onset of M.E. with taking part in meningococcal vaccine trials carried out between 1987-1994. The results should be available in the Spring of 2007.

Weighing up the evidence: some useful tips

Given how little we understand about the immune abnormalities indicated in research on M.E. patients, it's no easy matter for each of us to work out whether the pros outweigh the cons when it comes to having vaccinations for flu, travel or other purposes. All you can do is weigh up the positive versus the potentially negative in your particular situation carefully. For instance:

- With regard to travel, try to avoid parts of countries or times of year when serious infections are present to minimise the need for vaccinations
- Consider investigating homeopathic or herbal alternatives if you're drug intolerant. For instance artemesia has been used for the last 2000 years in China and many developing countries to help prevent malaria (available from Biocare, see page 52), though UK doctors prefer to rely on pharmaceutical protection
- People who are generally intolerant of medication and/or chemically sensitive would seem more likely to react badly to a vaccination than those without such sensitivities
- If you find that you catch flu easily and that this causes a serious relapse in your condition, the potential benefits of having a flu jab may outweigh any reaction

- It is also good advice, where possible, to spread multiple vaccinations over a period of time to lessen the impact on the immune system
- Avoid having vaccinations while you have symptoms of 'active' viral infection

Dr Neil Abbot from M.E. Research UK comments:

The apparent mismatch between patients' reports of development or worsening of M.E./CFS following immunisation and the research literature on this matter is quite striking. The conventional wisdom among many M.E. patients is that vaccinations can make them worse (as illustrated by your survey in some cases), whereas the research literature barely recognises such reports, or underplays them.

For example, the larger reviews say, "There is no evidence of an association between hepatitis B vaccines... and Chronic Fatigue Syndrome." (Zucherman, 2006) and "Upon review of the scientific evidence, none of the serious allegations [of side effects of hepatitis B vaccines] have so far been confirmed" (Duclos 2003). Smaller clinical studies tend to report similar findings in relation to live polio virus immunisation and other vaccinations.

However in 2002 De Becker et al, in looking for possible triggers for CFS, collected data on over 1,500 CFS patients, and found a small cluster (about 5%) in which onset was associated with hepatitis B vaccination. In addition, in his 1992 study examining the appropriateness of flu vaccinations in CFS patients, Dr Sleigh found reports of CFS-related adverse events after flu jabs, though he related them to "overlap of common, post-influenza immunisation symptoms and CFS constitutional symptoms".

What are we to make of all this? The central problem is that adverse effects, particularly isolated and (in population terms) rare ones, such as those reported by M.E. patients after vaccinations, are hard to identify, and even harder to associate with an event on a cause-and-effect basis.

The 'Yellow Card' system of reporting adverse effects to prescribed medication (see below) was designed to make it easier to identify and record such side effects, though this is recognised to be a very blunt instrument. However, the fact that this system was recently extended to allow patients (in addition to GPs) to report a side effect directly to the appropriate authorities is a welcome move in the right direction.

M.E. Research UK is a registered charity with a website at www.mereseach.org.uk

Further information

- **Yellow Card Scheme** – to report an adverse side effect from any drug or vaccination to the Medicines and Healthcare Products Regulations Agency, patients can request a 'Yellow Card form' from their pharmacy or GP surgery, call the Yellow Card hotline on freephone 0808 100 3352 (weekdays 10am to 2pm) or download the form and read more about the system at www.mhra.gov.uk
- **InterAction** ran a 'Dear Doctor' column on vaccinations and M.E. in issue 42 (2002; p38-9)
- **Mercury in vaccinations** – information and a forum for views about mercury in vaccines can be found at www.mercola.com or visit the respected online encyclopaedia http://en.wikipedia.org/wiki/Thimerosal_controversy
- **Homeopathic alternatives** – Ainsworth's remedy is available from some healthstores and chemists or contact the Royal London Homoeopathic Hospital (NHS Trust) pharmacy on 020 7391 8805.
- **NHS Direct** – for 24-hour queries call 0845 4647 or visit www.nhsdirect.nhs.uk to read responses to FAQs on vaccinations
- **Seeking others' experiences?** Make use of the Noticeboard section in *InterAction* or the equivalent e-mail service via interaction@afme.org.uk