

## **The catch 22 in chronic illness**

*Contribution to EuroLyme -*

<http://health.groups.yahoo.com/group/EuroLyme/>

- Catch number 1: You visit the doctor repeatedly, but they don't refer you or make any suggestions other than taking pain killers
- Catch number 2: The worse you get, the more the doctors appear to dismiss you
- Catch number 3: In desperation, you try to find out what might be wrong, including looking on the internet, but the doctor finds this threatening
- Catch number 4: Eventually after time, you get tested for only a very few infections, using tests that are well known to be inaccurate
- Catch number 5: They refuse you treatment on this basis, and deny the need for referral
- Catch number 6: You find alternative tests which show up positive, but these are not accepted by your doctor(s) who ridicule you or the people trying to help you
- Catch number 7: If you are 'lucky' enough to be referred, you have a long waiting list
- Catch number 8: Once you see a specialist chances are they talk about ME or chronic fatigue and then tell you to wait in a que for an ME appointment. Your symptoms do not match what it states about ME in books and policies, are getting worse
- Catch number 9: You are not allowed, to question the lack of diagnosis and the inadequacy of symptomatic treatment, if you do, you are told you may have psychological or psychiatric problems
- Catch number 10: There are very few private clinics, and may involve a cost from reasonable to very high
- Catch number 11: You develop more symptoms, which you know by now are very related to the health condition you know you have, but they dismiss them, again you are treated symptomatically and it doesn't work
- Catch number 12: The more you try to question, persuade, inform, the more you are given slippery words, psuedo-sympathic tones of denial, and evasive statements, that dont link to any of the scientific material they refuse to read
- Catch number 13: You start to understand there are no health rights in the UK, and that even in America, there is more treatment options that is based on good clinical assessment and experimental and medical research

- Catch number 14: You try to complain about the all or any of these events, but you are too sick now to follow through, and the systems of complaint are not easy
- Catch number 15: Some of you, by now have died, some have killed themselves, some have given up, some have now taken to a wheelchair, many of you remain untreated and still having major symptoms, some have worked it all out, been properly treated, and have got better
- Catch number 16: Many of you have known secondary illness (such as heart, hormonal, immune system, etc) clearly linked with the infection you believe you have, however, doctors continue to deny any connection
- Catch number 17: You cry a lot, more than you have ever done in your whole life, and more than most of your friends and family can bear
- Catch number 18: You start to feel you know more than the doctors that arent treating you, and this feels quite wierd, for example, you realise that right back at the beginning, you were given the wrong treatment and it has made you worse
- Catch number 19: You develop more symptoms, but it feels that your doctors are now deaf, and talking to them is painful and distressing
- Catch number 20: You hear from people who have got better, and this makes you hopeful, but you still dont quite know how to get them to listen. You understand the risks involved in treatment, but the doctors dont bother to find out if you understand this, or give you an control over your path to health
- Catch number 21: The medical profession want you to deal with your uncertainty, because they cannot deal with their own. they offer you standard psychological techniques, for this purpose. you effectively then have to take responsibility for all of their uncertainty, all on your own, whilst you are still sick.
- Catch number 22: Having read and listening and learnt, you find the treatment you manage to get access to, works, and you get some of your life back. The doctors dont want to know how and why this happened, because they say it would have happened anyway