



# *The Young ME Sufferers Trust*

## **There's No Smoke Without Fire!**

*Some comments on the tendency to relapse in ME*

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### **Introduction**

**ME commonly follows a virus infection which can, at first, appear to be trivial**

However, the illness soon becomes distinguishable from other forms of post viral debility (including that associated with influenza) because of its prolonged course and tendency to relapse, making it inadvisable for sufferers to return to school, college or work without adequate convalescence.

In a society which rates speed, sport and entertainment so highly, slowing down to rest will be unpopular and most young people will need some persuasion.

## What is a relapse?

**It is an unexpected deterioration in the condition of a sick person after partial recovery**

The commonest causes of such a reverse in ME appear to be mental and physical *over*-exertion and stress or *secondary* illness (usually an infection, possibly a minor one) before recovery from the first.

Recovery from ME depends, as we shall see, upon a very delicate balance between infection and immunity, so it is as well to be informed of other factors which may be detrimental to progress including:

- any upset to the immune system (commonly immunisations and immuno-suppressive drugs such as steroids)
- hormonal disturbance (such as puberty, pregnancy, childbirth, contraceptive and other hormone therapy unless strictly monitored)
- exposure to toxic chemicals and drugs (including those in recreational use such as alcohol and tobacco)
- Other deleterious factors to be avoided if possible, comprise surgical injuries (especially to the head and neck), malnutrition and sudden climatic change.

We do not know why relapses can be cyclical (at weekly, monthly or longer intervals) despite the patients' best efforts to avoid all the above.

## Are young people more at risk of contracting ME now than in the past?

**Yes, of course, because society has changed so profoundly within the past 100 years that many of the checks and balances which maintained**

## **immunity to infectious disease in settled communities have vanished**

It is known that the viruses associated with ME, polio and several similar chronic diseases are programmed to multiply harmlessly in the gastrointestinal and respiratory tracts of infants while, at the same time, providing lifelong *natural* immunisation. Paradoxically, the great sanitary reforms of the 19th century in affluent Westernised countries (where babies were henceforth prevented from early contact with infection) ushered in major epidemics of polio, followed closely by ME in the 20th century. Today, young people are likely to have their first substantial contact with the former 'childhood infections' at school or college and at a time of rapid growth accompanied by hormonal change, when they are less likely to make a smooth recovery without complications.

However, most (but *not* all) young people in the UK are well nourished and, despite many articles written about immunological defects in patients with ME, these changes are inconsistent from person to person and far too slight to explain the chronicity and multisystem involvement of this illness.

Moreover, there is no evidence that patients with ME do not recover normally from other common infections.

## **Why does an illness which can appear trivial at first, take such a long time to stabilise?**

**I am afraid there still remain many misconceptions about the relationship between men and microbes (which are currently considered to be master-minding a mass attack on the human race!)**

We have to be reminded that each one of lives in daily harmony with some trillions of microscopic creatures who undertake most of the heavy housework in the human body, including the assimilation, digestion and recycling of food and waste and the cleansing and protection of body surfaces and cavities by means of natural antibiotics, antibacterial fluids and emollients.

Some 50 years ago it was suggested that the immune system is programmed to attack any material in the body which is deemed 'foreign' because it was not already present *before* birth. A more modern revision of this theory suggests that, in fact, the immune system is primarily programmed only to attack cells or tissues producing a danger signal.

When it comes to microbial invasion, some species are remarkably aggressive whereas others are essentially cautious in making their intentions known. It would appear that African fevers such as Ebola and Lassa, newly displaced from their jungle hideouts by modern logging activities, are aggressive enough to cause 100% mortality in local communities, but then die out spontaneously for lack of new hosts.

At the other end of the microbial scale we have diseases caused by a wide variety of virus species which (through millennia of association with humans) have learnt by various means to persist inside human cells for long periods without alarming the host's immunological surveillance system. Of such are the viruses associated with ME.

The chronic course of this illness charts the various successful and unsuccessful adjustments made on both sides to live in harmony and permit the long suffering host to get on with normal life - an acceptable deal, since both participants survive.

During these adjustments, the virus ceases to replicate early on in the illness, loses one or two genes which code for the outer protective covering and runs for shelter into a sequestered organ (usually the brain) where it can persist indefinitely without alarming the immune defences.

The cost of this to the host cell is the loss of one or two cell functions without overt cell destruction, and the cost to the patient involved is an illness which rarely threatens life but which tends to be *chronic and relapsing before eventual stabilisation*.

## **Are there any implications for management?**

**Yes, these are most important. The main principles of management still rely upon:**

- **Conservation of energy**
- **Reduction of stress**
- **Simplification of work**

This is an illness best managed by the patient at home once it has been fully explained and investigated. However, a great deal of support is required *from an early stage* if stabilisation at a functional level is to be achieved (eg some 70-80% of the individual's former ability).

Since this illness has not yet been studied for a sufficiently long period (years and decades rather than weeks and months, as in most modern studies) or using molecular biology, radio imaging and other techniques coming into common use for other chronic illnesses, there are no reliable 'quick cures' or 'diagnostic test' as yet.

**The most important task is to seek help from relatives, friends and professionals to construct a lifestyle in which it is possible**

**for the illness to stabilise and the sufferer to progress *at their own pace* towards realistic ambitions.**

## **How can a relapse be distinguished from a minor variation from 'normal'?**

**Many patients have told me that this can be recognised by a sudden return of the very distinctive 'malaise' accompanied by a generalised aching, nausea and dizziness (so similar to that of influenza) which ushered in the initial illness**

Although, as the patient gets better, this sensation diminishes in further relapses it is obviously a reminder that the battle between virus and immune system has not yet completely died down.

## **What is the best way to manage a relapse?**

- Immediately seek extra support to remove all stresses (physical, mental, emotional, intellectual)
- Be patient and listen carefully to the signals given by your own body so that you can aim to remain in charge
- Maintain good nutrition (by means of supplementary feeds, on prescription, if necessary)
- Seek to delegate all tasks except those you love to do or which are absolutely essential, till recovery
- Do not ascribe all new symptoms to the relapse; seek a medical opinion if possible as you may have another potentially treatable condition
- Do not despair; in surviving this relapse, you will gain confidence about self-management and quicker recovery in the future.

Always be ready to start again at a different level.

## **Conclusion: A little Allegory**

Imagine, if you can, a tranquil English breakfast table. The kettle steams, the electric toaster is in action, someone forgets to adjust the thermostat. Suddenly the smoke alarm shrills from above and is wrenched from its socket before upsetting the neighbours.

Despite our wonderful self-regulating kitchen gadgetry, all is in chaos! In future, pay careful attention to your body thermostat, your daily variation in energy and activity and remain grateful for the commotion set up by your immunological stress alarm if it prevents another set-back.

Good luck!