





---

## LIVING WITH M.E

---

**M.E is a little understood disability. Most doctors do not accept that ME is a genuine and disabling illness. Disagreements and uncertainties still remain - especially over its name, cause(s) and most appropriate form of treatment.**

*ME (Myalgic Encephalomyelitis) was first described by The Lancet back in 1956. Myalgic refers to the muscle symptoms; encephalomyelitis to the brain symptoms. Research studies suggest that there may be around 150,000 people with ME/CFS in the UK. But a recent study, quoted in The Daily Mail (18 January, 1999), suggests there are up to 400,000 sufferers in the UK.*

*Some form of infection (e.g. flu, glandular fever, hepatitis, tonsillitis) is the most common trigger. Symptoms can vary from Muscle fatigue, pain, problems with short-term memory and concentration, clumsiness and disturbances with balance to sleep disturbance, especially waking unrefreshed. Symptoms are usually made worse by undue physical or mental activity.*

*Myalgic encephalomyelitis (ME) is becoming more and more widespread in Western countries. ME is the name most commonly used in the UK, while in the USA it is now called Chronic Fatigue Immune Dysfunction Syndrome (CFIDS).*

I have suffered from ME (Myalgic Encephalomyelitis) since the age of five years. It is a debilitating and often disabling illness for which there is, at present, no cure. For the first few years of the illness, I tried to continue my education. I would attend school as much as I could, but this did me no good and subsequently made me worse.

I would need weeks, often months, off because my health was so bad. I felt completely exhausted and had no energy; walking was hard as my legs would often feel like lead weights, and my concentration was poor. But against all our better judgement, I was advised to try to push myself and carry on living a normal life, which I did until eventually something had to give and that something was the little energy I had left. At the age of nine, I had to completely give up school and couldn't even manage home tuition for a couple of hours a week. Instead, all I could do was rest; I couldn't see friends or play games, all the normal things a child of that age would do. I also had to use a wheelchair on the rare occasions that I was able to go out, and even this tired me completely.

Things stayed pretty much the same for the next few years. We joined all the support groups going, to try and find out if there was any treatment available for me, which there wasn't. But, although these groups couldn't give us the cure we so wanted, they could give us the reassurance that we were not alone, that there were other people out there who were going through the same thing.

This in itself provided us with some comfort; it's always good to know, no matter what the situation, that you're not alone, and that there are people that understand and know what you're going through. A big part of my life over those years was my pen pals. Although I was too ill to write the letters myself, I would tell my mum what I wanted to say and she would write the letter for me. Through this, I gained a lot of good friends, some of whom I'm still in contact with today.

We started off with the one thing in common, ME, but soon discovered that we got on well, illness aside. ME provided a starting point and we did the rest ourselves; often, we wouldn't mention the illness, other than saying how we were feeling that day, and would then go on to





---

## REPORT ON AGM.

---

This years AGM started with the rather depressing news that our Chairman Ruth Thomson had tendered her resignation with immediate effect. She has also retired as a Custodian Trustee.

**A.G.M 10th November 2001 held in the Boardroom at the Warneford Hospital.**

The Stammer Trust committee would like to offer our thanks for all her hard work and effort over her 2 year Chairmanship. It must also be said that Ruth Chaired The Stammer Trust through some very turbulent, difficult and demanding times with elegance and charm and was clearly instrumental in the recent signing of the lease, thus securing The Apple House's future for the treatment of those who are troubled with speech. We were all greatly relieved when the final outcome regarding the positive future of The Apple House was announced.

***There are now major difficulties to be overcome in the Trust in the year ahead as without a Chairman we are rudderless and have no guide for the future. The existing committee has pledged support until at least July 2002 or probably until next years AGM. The future of the Stammer Trust is still very much undecided and we desperately need new members, new committee members especially those who have attended recent courses.***

During the AGM we briefly discussed the modifications to the downstairs of The Apple House which will create extra treatment rooms and enhance the therapy available to stammerers. This extra space will allow for more than one course to be run at a time or referrals to be seen whilst courses are underway.

These improvements are being funded by The

Stammer Trust and along with extra security will cost up to £5600. A grand opening ceremony is proposed for Spring next year where an open day along with

rounders are also planned.

Also in this newsletter are both Polly Mitchell's and David Ward's report (see page 5). Most important points to note are:

David to date has had 70 adult referrals and Polly has had 124 referrals for children.

During May 2001 Polly Mitchell and Rebecca Ledzion used The Apple House to run a week long course for 12 speech therapists on the Lidcome programme.

The before and after results of two adult intensive courses make for interesting comparisons.

The speech therapists are to present at next years Oxford Disfluency Conference.

The allowable treatment time has now been increased to 2.5 full days for Polly and 2 full days for David.

**Geoff Forward  
Secretary  
28th December 2001**

PS. For those of you on the internet go have a look at the new Stammer Trust website it's fantastic and well worth a visit.



## U SHOP U GIVE!



In October 2000 a new shopping website went online, ([www.ushopugive.com](http://www.ushopugive.com)). This site enables you to raise money for certain predefined charities if you purchase items via their web page.

**Did you know by shopping online, you could support a chosen charity?**

Their web site acts as a window, with links to retailers (approx 100), who in turn pay sales commission on items purchased. The commission goes to “ushopugive”, who in turn pass it onto the charity you selected. There is no extra charge, you pay the same price as you would by going direct to retailers site. Only this way your selected charity benefits.

At present charities receive 50% of the sales commission. It is planned as purchases grow, “ushopugive” will increase the charity’s share progressively to a total of 90%.

You select your charity before you move onto the individual retailers’ sites. There is a wide range of good causes to chose from, ranging from animal charities, the BSA (British Stammering Association) to cancer and medical charities. In fact there are about 90 charities to pick from. There is detailed information on all the individual charities along with the percentage of commission each retailer will give. The average sales commission passed on to “ushopugive” is about 5%.

Using the “ushopugive” website is fast and simple. A small registration form is required to be filled in, but this is only expected. On this form you have the facility to receive monthly updates, via email, on

how much your chosen charity has received from “ushopugive”.

The shopping categories include appliances, books, music, clothing and accessories, computer related items, gardening, home and leisure items, and even travel tickets. All in all it

is a very professional and organised site....

### **On ode to a spelling checker.**

Eye halve a spelling chequer  
It came with my pea sea  
It plainly marques four my revue  
Miss steaks eye kin knot sea.

Eye strike a key and type a word  
And weight four it two say  
Weather eye am wrong oar write  
It shows me strait a weigh.

As soon as a mist ache is made  
It nose bee fore to long  
And eye can put the error rite  
Its rare lea ever wrong.

Eye have run this poem threw it  
I am shore your pleased to no  
Its letter perfect awl the weigh  
My chequer tolled me sew.

The above was sent to me, by a reader. They must have spotted the spelling mistakes in the last Newsletter!



---

# THE STAMMER TRUST WEB SITE.

---

In July of last year the Stammer Trust web site was launched. Although currently only consisting of 4 pages the site has been constructed with the possibility of expansion in mind.

Problems with individual computer screen size's (e.g. 14" to 21") along with individual screen resolutions, (ranging from 640 X 480 to 1028 X 1024) has caused a variety of uneven appearances with the graphics on the right hand side of the screen, even with expanding columns, a certain amount of unevenness can be experienced, this is due to the different screen size / resolution

set up. This along with content changes will in some set-ups, course an uneven base to the page. (e.g. text appearing lower than the graphics)

The best resolution to view the site is 800 x 600 but this is only if you wish to have an even base at the end of the page. (Personally I would not bother to change your settings, as different sites will display differently).

Those who are on the internet my wish to browse the site the address is [www.stammertrust.co.uk](http://www.stammertrust.co.uk)

The Stammer Trust  
Charity Commission Ref No 265938

Apple

Last updated  
05/08/2001

Home Page  
About Us  
Publications  
News

Stammering

Stammering probably affects over 450,000 adults in this country. For some it is a childhood disorder, which can usually be effectively treated, but for others the patterns of bad practice harden, and the stammer continues into adult life in varying degrees of intensity. On the positive side, adult stammerers are usually resourceful and innovative in seeking life-styles that suit them, and in the process they have worked with speech therapists to develop a number of successful treatment programmes containing useful fluency techniques. One of the better known and longest established is treatment at The Apple House, which has been run at Oxford since 1964.

The Apple House

Speech Therapy courses for adult stammerers were started at

Gerda Wilson

Sylvia Davey

The home Page.



---

---

## THE STAMMER TRUST WEB SITE CONTINUED.....

---

The Stammer Trust  
Charity Commission Ref No 265938

Last updated  
11/07/2001

Home Page  
About Us  
Publications  
News

Publications

The Stammer Trust Newsletter is published every four months and carries all news and articles concerning the Apple House and general stammering related articles. It also includes other items of interest.

*A PDF version of the last newsletter can be down loaded by clicking on the apple.*

Apple House story January 2001

### The Publication Page

The site is divided into four sections, the first section being the....

“**Home page**”, which consists of a brief description of Stammering, The Apple House and therapists. Various pictures are situated on the right of the page; this is the same format for all pages.

“**About Us**”, is about the Stammer Trust, a very brief history along with encouragement to join the Trust.

“**Publications**”, is where anyone can download a newsletter or a sample of the Apple House Report. A request form is situated further down the page, where requests for any information ranging from membership, Gift Aid, or joining the committee can be forwarded with ease. In fact any member who wish to contact a committee member quickly can use this for their comments.

“**News**”, is where all the future event details are entered, along with information on Gift Aid etc.

The links to various stammering organisations are situated along the left (not shown).

Although the site is just out of its experimental stage, any suggestion for improvements, or ideas for other items to be included on the site, would be gratefully received!

One possibility open to discussion, is a personal type page, where ex course members would be able to contact other stammerers from their old course, (subject to both parties approval) possibly to see how they are getting on etc. You will not have to be a member of the trust to use this facility.

**RJW.**