

# *The Young ME Sufferers Trust*

## **The Use Of Interactive Virtual Education For Young People With Myalgic Encephalomyelitis (ME)**



### *Family Testimonies*

ME is so disabling that it is the biggest cause of long term sickness absence in schools in both staff and pupils. This was first established by Dowsett and Colby in the Journal of Chronic Fatigue Syndrome (1997). A commentary by Dr Dowsett on this study is at [www.tymestrust.org/pdfs/dowsettcoby.pdf](http://www.tymestrust.org/pdfs/dowsettcoby.pdf).

The school roll studied was 333,024 pupils, and 27,327 staff, in 6 widely spaced English Local Authority areas, making it the largest such epidemiological study available; a smaller study by a community paediatrician replicated the results in one (different) area.

Clusters of ME, consistent with viral infection, are known to occur in schools, families and communities, which was also established in Dowsett and Colby. In the case of the first family quoted in this document, it affected a family of three boys.

In these accounts of how interactive virtual education has changed their lives, the families have chosen to name the official virtual education provider they are using.

#### *Family 1*

*My children all loved school and were very sociable and sporty, when they were well. They are too ill to attend school and it makes their condition so much worse.*

*The home tuition service was exhausting for the boys, the sessions were long and subjects could not be covered as concisely. There was no interaction with other pupils or other teachers and staff, just one tutor.*

*We moved LA [Local Authority] boroughs and the boys were allowed NISAI. [[www.nisai.com](http://www.nisai.com)]*

*After just 2 terms on NISAI, and with no school for 5 years and only a few hours of home tuition my son got a B in his GCSE science. After 2 years of NISAI he got 5 GCSE's in English, maths, history, science and further science. He has been unable to attend school and yet has achieved educationally whilst being really ill. He is now doing A levels on NISAI. My other 2 boys are also on NISAI.*

*The teachers and staff at NISAI all understand ME and have supported the boys enormously. The pre-16 lessons are just half an hour and each subject is 4 sessions a week. So 3 subjects of English, maths*

*and science can be covered comprehensively in 6 hours broken up over the whole week, with breaks between subjects. If a child is unable to attend the lesson it is recorded and can be caught up with later on. Thus sick children are able to keep pace with the lessons and so do not get left behind by missing any. Lessons can be done in a relaxed quiet comfortable home environment in soft clothing.*

*My boys enjoy the virtual classroom engagement with other pupils and different subject teachers. They are supported by a mentor tutor who will discuss any difficulties or ways to support further. The teacher can be emailed directly and assignments are posted on line so they can be accessed and submitted without difficulty. My children are all really intelligent yet very ill. The physical strain of attending school makes them so much worse. By conserving energy by being educated at home they can focus on the lesson with minimal energy expenditure.*

*The class sizes are small and there is good interaction and individual attention. My children have made some fantastic friends via NISAI.*

*There is a 'tribe' system where points are gained for their tribe. There are clubs, such as animals, gaming, debating club there is even an ME club.*

*My children have achieved and felt included and supported. At school they were not wanted, seen as a nuisance, disbelieved, refused basic support mechanisms and purposely not included offering a toxic environment of prejudice and persecution for a sick and disabled child with ME.*

*On NISAI my children are cherished and supported in a fantastic learning environment which best suits their condition. We call it NISAI High, this is the boys' school. They are happy knowing they are receiving a great education, that it is manageable and energy efficient. They are achieving and are able to maintain their ambitions to succeed, not only in education, but in life.*

*Dr Jean McDonald BVSc MRCVS, parent*

## **Family 2**

Having read the testimony above, another parent, Janine Bailey, commented: "My youngest has been studying with Nisai for three years and it has transformed her. She hopes to study English at university and this dream now seems tentatively possible." Her daughter Emily gives her own testimony:

*I am approaching my final few weeks with NISAI Virtual Academy and I can honestly say that I am filled with a level of sadness at leaving them that I would not have thought possible when I, rather hesitantly, enrolled with them three years ago.*

*I became ill with ME/CFS at nine years old and for five years I was determined to remain in the standard educational system. I believed I would, quite simply, get better and be able to resume a "normal" life. I also thought that, if I left my school, I would become isolated and that I would risk losing my friendships; a message reinforced by my consultant who operated upon the guidelines that homeschooling should be avoided. Moreover, I'd only ever seen one interpretation of home education: 1:1 tutor sessions. For someone who loves engaging with fellow students in discussion, this didn't particularly appeal to me.*

*I didn't get better. I was constantly exhausted. I had to drop subjects and rely on strong support from my teachers during my frequent, and rather long, absences. Some teachers were great at helping me, but some really weren't. In the first term of year 11, I relapsed and could no longer manage to get into school for any lessons.*

*1:1 home tuition with the Medical Access to Education team was helpful but an incredibly intense learning environment that I struggled with. I sat my two English GCSEs and it soon became clear that college wasn't an option if I couldn't commit to nine hours onsite each week. I was tempted to abandon my education altogether.*

***I've always looked forward to learning but persisting in a system of education that didn't work with my ME was exhausting and disheartening.***

*It was then that we discovered NISAI, an Ofsted inspected virtual education provider on the Department for Education's Section 41 list of approved schools for post-16 SEND, meaning: they're a school that provide lessons online. They completely disrupted my vision of what home education is. My lessons are timetabled, delivered live by a teacher and attended by multiple students. All of us can interact with each other via microphones or in the text chat and the screen acts as the whiteboard. I always say that it's a normal classroom, just on my laptop.*

*I took a very deep breath and decided to give it a go. It truly turned out to be a God-send for me, in so many ways. On the days when my symptoms mean I am unable to get out of bed, I am able to just log in on my laptop and listen in, and my teachers are always incredibly understanding if I send them a message at the start of the lesson saying that I'm not going to be up to contributing to discussion on that day. On the occasions when I am completely unable to attend lessons I don't need to worry, as the sessions are recorded and I can access them when I feel a bit better.*

***Since falling ill I struggled to achieve even 30% attendance in mainstream education. At NISAI, despite inevitable relapses, I have been able to maintain an attendance level at around 90%. After three years that is still astonishing to me.***

*I have sat one GCSE, one A Level and am completing my second A level this summer. The environment has meant that I'm achieving a quality of work that I wouldn't have believed possible at my previous school, where I was constantly hampered by my physical symptoms.*

*The level of camaraderie between my fellow students and me is so motivating and I have formed strong friendships which I hope to keep for many years to come.*

*Five years ago I desperately wanted to go to school but was unable. My time with NISAI has been so encouraging for me and now, three years later, as I prepare to leave, I do so with offers from two universities: an opportunity I couldn't have imagined when I left secondary school.*

Emily adds: "I wish that I could go back to my thirteen year old self and tell her to make that leap from mainstream education earlier."

Of her teachers, she says: "They rekindled my love of learning. I'd like to just say thank you."

### ***Further Medical Information***

School attendance, which uses a great deal of physical and mental energy, is observed by clinicians to be a key cause of relapse from ME, leading to a recurring pattern of attendance-relapse-absence-attendance-relapse-absence... The following four points help to explain why this should be.

**1 Dr William Weir** *Calibrated studies of oxygen consumption during peak exercise show incontrovertible evidence of metabolic derangement in muscle function in patients with ME/CFS. Such derangement has been demonstrated in more than one academic centre in the United States, a finding further supported in this country by in vitro studies of muscle biopsies taken from affected patients. Such biopsies perform badly when subjected to 'exercise' by repeated electrical stimulation when compared to biopsies from healthy control subjects. [...] These findings perfectly explain one of the hallmark clinical features of this condition, namely exercise intolerance. Furthermore this worsens progressively if the patient with ME/CFS is advised to exercise beyond their (characteristically meagre) level of tolerance; many patients so doing end up bedbound and unable to mobilise for weeks and sometimes months.*

**2 Professor Jill Belch** *We showed for the first time, to our knowledge, that oxidative stress [...] and increased WBC apoptosis [increased white blood cell death] occur in children with ME. [...] The data are also consistent with a reactivating or persistent viral infection.*

*Biochemical and Vascular Aspects of Pediatric Chronic Fatigue Syndrome*

See [www.tymestrust.org/pdfs/ttmeisphysical.pdf](http://www.tymestrust.org/pdfs/ttmeisphysical.pdf)

**3 Professor Jill Belch** *The quality of life of children with CFS/ME was significantly impaired compared with their healthy counterparts and that of children affected by other chronic illnesses (type 1 diabetes mellitus and asthma).*

*Physical and Functional Impact of Chronic Fatigue Syndrome/Myalgic Encephalomyelitis in Childhood*

See [www.tymestrust.org/pdfs/ttmeisphysical.pdf](http://www.tymestrust.org/pdfs/ttmeisphysical.pdf)

**4** *When a student makes an effort, oxygen levels in the brain can fall instead of rising to cope with the demand.*

*Why home based education helps*

[www.tymestrust.org/pdfs/tthomeedhelps.pdf](http://www.tymestrust.org/pdfs/tthomeedhelps.pdf)

*You are welcome to redistribute or reprint this document without seeking our permission provided: 1) you do not abbreviate, add to, or change the text in any way; 2) the authorship information is retained; and 3) [www.tymestrust.org](http://www.tymestrust.org) is credited as the source.*