

# Free essay on living with a potentially deadly condition

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Myalgic Encephalomyelitis is a rare condition which is not at all well known, although in the UK there are over a quarter of a million sufferers. I spoke to Nicola Reiss, who lives in Malta and who was diagnosed with the condition some years ago

ME is definitely a harrowing condition to have to live with. Nicola Weiss does not let this situation deter her, but as one of the founder members of the ME Sufferers Association in Malta, she tries to remain as active as possible in all areas within her limitations. Myalgic Encephalomyelitis is a neurological illness, but chronic fatigue syndrome (CFS) is the most common name given to this variably debilitating disorder that is generally defined by persistent fatigue unrelated to exertion, and which is not relieved by rest.“ I was diagnosed by Dr Charles Mallia Azzopardi and it was an ‘ exclusion diagnosis’. After running a number of tests to rule out other possibilities he told me I had an immune system dysfunction. At first I was delighted to have a diagnosis. After 18 months of feeling awful, losing my job, seeing various doctors and having no idea what was wrong with me, it was a relief to be diagnosed with something specific. My delight soon wore off, when I began to research the illness and I discovered how little doctors know about it and how controversial it is.” A typical example of the disease and its perception was discovered by Nicole when she was working overseas at the time, became ill and had long-term disability insurance coverage.“ My claim was turned down on technical grounds and a lawyer advised me that it was useless trying to pursue it. This is extremely common with cases of ME. Now I’m living a nightmare – too ill to work, no income, no cure, no understanding. I am totally dependent on my ageing parents who are both

well into their eighties. At least I have no dependents of my own; I cannot imagine the distress of young fathers, diagnosed with ME, with children to support, or other young people who have only a bedridden life to look forward to. This illness is far more common among the young and active, and their lives are being destroyed by it.” With her two Masters degrees, Nicole worked in several countries around the world, including working on the UN mission in East Timor. At the time she became ill, she had already been in East Africa for four years working as a project manager responsible for developing and monitoring education projects for children affected by war in the Democratic Republic of Congo. But her life today is obviously much different, as the simplest of things becoming a daily struggle. “ My work was fascinating and challenging and the job came with some great benefits, including a lively social life. It wasn’t something I wanted to give up. These days I have learned to pace myself – to manage the energy available to me so that I can look after myself without assistance most of the time.” It takes all my energy to do essential activities such as grocery shopping, cooking, and laundry. I rarely do other housework because I’m not able to. I take frequent rests and use that time to read or do research on the internet. In the afternoons I have to lie down for around three hours and nap or listen to the radio. There are days when I’m not able to get up: orthostatic intolerance is a problem, as is dizziness and generally feeling awful.” Around 25% of people with ME are completely bed-bound, with severe pain and extreme sensitivity to all noise and light. But what is worrying is the perception of the disease and the treatment methods being used which according to Nicola are totally wrong, as even doctors have been known for giving the wrong

advice to patients suffering from ME. “ Although I was grateful for a diagnosis, my doctor had no advice on treatment or management of my condition. I had to do my own research and soon discovered that exercise makes the illness worse, and that the natural tendency to push oneself is highly detrimental. Indeed, for the preceding 18 months I had been pushing myself to work and to exercise and my health had only deteriorated. Everyone needs to know that exercise and pushing oneself to do more actually make the illness worse.” Nicola insists that the health authorities in Malta must ensure that medical students and doctors receive correct bio-medical information and are kept up to date with the most recent research into the disease. “ The medical authorities also need to begin tracking cases of ME so that proper epidemiological studies of ME in Malta can be carried out. Prof. Luc Montagnier, who won last year’s Nobel in medicine, says ‘ scientists have already uncovered a lot about ME, but this information does not reach professional healthcare personnel, and the disease is still not taken seriously. It is about time this changes’.” Nicola is also critical of the government’s commitment to help disabled people, maintaining that ME sufferers are being completely ignored and left out in the cold.”

Government’s commitment should apply to all those who are disabled; social services should not be allowed to pick and choose whom they serve. At present people with ME are discriminated against. Even those who are bed-bound receive no disability benefits and no social services. This is simply not right – and it is certainly unchristian.” Child sufferers represent another area of concern: often too unwell to attend school, apparently no extra provision is made for sufferers of the disease. The Young ME Sufferers Trust in the UK

has a series of information leaflets designed specifically for children and teachers ([www.tymestrust.org/tymespublications.htm](http://www.tymestrust.org/tymespublications.htm)). “ All teachers and head teachers in Malta should be aware of how this illness affects children,” Nicola says. “ Well-informed teachers could be enormously useful in helping identify children with the illness. Early diagnosis and proper care for children can lead to their eventual recovery. I hope the government of Malta will choose information, fair treatment, and health over misinformation, prejudice, and permanent disability for the children and young people of the islands.”

Although Valletta is considered to be a beautiful city, it obviously has had its fair share of dark and mysterious episodes over the years like any capital would. The range is quite varied from infanticide to family members, from theft murders to simple quarrels which escalated in deaths. The first murder which I would like to take a short look at occurred on the 23rd July 1851 in Frederick Street.

Marija Baldacchino was known as ‘ Il Furficetta’ and was apparently a well known prostitute. At 2pm on that fateful day, the police were called to Baldacchino’s dwelling after cries for help were heard coming from the inside. Upon arrival the officers heard no further cries and decided to enter the house where they found traces of fresh blood everywhere. A Turkish man by name of Hamet bin Mabruk was arrested in connection with murder and after a while he revealed that the badly mutilated body of Baldacchino was located in a well from where it was later extracted. Mabruk was tried and found guilty of this grisly murder and was hanged in Floriana on the 1st September 1851.

We move forward almost 120 years to the murder of Marija Grech which occurred in Fountain Street on the 1st August 1970. Grech was found stabbed to death and naked by some children who entered her apartment after neighbours were worried about her whereabouts. An American sailor, Hustone Featherstone was arrested and after evidence was found to incriminate him, he was found to be suffering from mental illness and was sent back to the US where he spent his life in an institution. A couple of years later, another barmaid, Irene Johnson was also found stabbed to death and naked in her apartment in the same Fountain Street but this case was never solved by the police.

Another grisly murder took place on the 19th of September 1978 in Irish Street when Ersilia Farrugia was found stabbed to death on the roof of an apartment block. After police investigations, Anthony Cassar a 59 year old man who also lived in the same block of flats was arrested and in his testimony, he explained that he had various arguments with the victim and on that day she had attacked him with a rifle cartridge after which he defended himself by lashing out at her with a pointed instrument. The jury ended with a self defence plea and Cassar received a relatively light six year prison sentence.