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Swine flu And MS

The indications are that people with multiple sclerosis are at no greater risk of contracting the H1N1 virus (swine flu) than the general population. However, as the effects of flu may worsen MS symptoms, it is sensible for people with MS to try and reduce their risk of infection.

At time of writing, there is no specific information about swine flu for people with MS. The general advice from the Department of Health (DH) is to try and prevent the spread of germs as much as possible by washing hands regularly with soap and water, keeping surfaces clean and using tissues to cover your mouth and nose when coughing or sneezing.

The DH also advises that people prepare now in case the swine flu becomes widespread by:

- establishing a network of 'flu friends' - friends and relatives who can collect medicines and groceries for you if you fall ill
- making sure that you have an adequate supplies of cold and cough remedies in your medicine cupboard
- people who act as carers should consider contingency plans in case they are unable to carry out this role for a time

People taking immune suppressant drugs should talk to their neurologist or MS nurse about any changes to dosage that may be required. Medication should not be stopped before speaking to a doctor.

The beta interferon drugs (Avonex, Betaferon, Extavia and Rebif) and glatiramer acetate (Copaxone) are immune modulators and not immunosuppressants and so do not raise the risk of contracting the virus in the first place.

The beta interferon drugs can cause flu like symptoms as a side effect. If this occurs, contact your GP or MS nurse.

Antiviral medication is currently only being given to people in close contact with people who have contracted swine flu. When a vaccine becomes available, the Joint Committee on Vaccination and Immunisation has advised that people in clinical risk groups, which include some people with a long-term (chronic) condition and their carers, will be priority groups for treatment.

Experience with vaccinations for seasonal flu vaccines suggest that it is safe to take these whilst still receiving disease modifying drugs for MS.

Department of Health swine flu information line - 0800 1 513 513

DISCLAIMER

The articles in this Bulletin are meant for the sole purpose of information only, and do not necessarily reflect the views of the committee.

Dignitas: I couldn't let him die alone

Four years ago Laura McDaid made the hardest choice of her life: to accompany her former boyfriend to Switzerland's Dignitas clinic to escape the pain of MS

It was lunchtime. There was nothing to distinguish the apartment block or the plain room within it. The colours were neutral, the furniture a single bed and a table holding a vase of flowers. On the bed a 30-year-old man drank a draught of liquid. It was bitter so immediately afterwards he had a piece of chocolate.

"I lay beside him and chatted," says Laura McDaid. "I said, 'How do you feel?' He said, 'Happy'. I think he did. I hope he didn't say that just for me. After about a minute he stopped talking." By the time Martin Barry took his life in the clinic run by Dignitas in a suburb of Zurich his physical condition was poor. In 2002 doctors had diagnosed an aggressive form of secondary progressive multiple sclerosis; by April 2005 he was unable to walk, he had tremors, his eyesight was failing and he had an infected bedsore on his back that embarrassed him because of the smell. He was in great pain, he was incontinent and he knew that living alone with a visiting carer would not be an option for much longer. Faced with a choice between further deterioration over perhaps another year in a care home, and managing his death, he chose the latter.

"He didn't want to die in Switzerland, in an unfamiliar apartment," Laura explains. "He wanted to die at home with his family and friends around him, but that wasn't going to happen."

Martin lived in Cork, Ireland, where the law on assisting suicide is similar to the UK. At the Dignitas clinic 115 Britons have ended their lives and although it is illegal to help terminally ill people carry out the act painlessly, none of those who have accompanied them have been prosecuted.

Laura accompanied Martin because she respected rather than condoned his choice and because she did not want him to die alone. She stresses that in talking about his illness and death she is not advocating assisted suicide or euthanasia. Rather, she is telling a story — for her a profoundly emotional one — that has had such a searing effect on her that it has become the foundation of an eloquent - and fictional - play that she has written for Radio 4.

She met Martin in January 2001; both were newspaper journalists working in Dublin. She was 23 and had grown up in a supportive middle-class family in Coleraine, Northern Ireland. Martin was adopted and had grown up on a council estate in Cork and, at 26, he was handsome and had the force of someone who wanted to be noticed. He challenged Laura; she was entranced and soon they were in love and living together.

"He was a huge character," she says, speaking in Belfast where she now works for the BBC.

"He had views on everything, he was passionate about journalism and he was happiest when he was the centre of attention. He was funny and he battled MS with humour and strength."

The diagnosis was a shock. He had tried to ignore, and even deny, symptoms over several years. "I could see him losing weight, he'd sometimes lose control of his bowels and bladder, he was thin and frail and had trouble walking," Laura says. "He was in a wheelchair within three months. The prognosis was pretty bad but he tried to be upbeat. I was his carer and we were both able to work part-time. But it got worse and I found that emotionally very hard."

In 2004 Martin was told that he probably had two years to live and that it was likely that, having lost the ability to swallow, he would choke to death. "He got frustrated not being able to do the things that he loved doing," Laura says. "He was gregarious, he loved being out, loved a drink. He couldn't do any of that any more." Neither could he be active in the profession from which he had drawn his sense of identity. "He wrote when he could but he didn't have the energy to go out on stories. He felt that everything around him was just as it used to be but that he was an outsider looking in on it. He didn't feel part of the world as it was."

This sense of isolation affected both of them. Some friends found his disability hard to witness, and Laura blames herself for her inability to support him full-time. "He got more and more depressed and that put a strain on us. We already had a volatile relationship — he was a volatile character! — and our relationship became more like carer and patient than the way it had been. I felt that I didn't have anything to talk about because we were living in this enclosed world.

"I left in April 2003. I felt guilty because I was leaving my best friend to cope with that, and I loved him. He was so angry at me and felt betrayed but he came to realise that we hadn't been helping each other. We became much better friends after that."

Martin attempted suicide by overdosing with pills and failed. About nine months later he told Laura that he planned to die at the Dignitas clinic. Sensing that his decision was based on his emotional state rather than his physical condition, Laura was unable to accept it. He needed counselling, she believed, though none was available at that time. In January 2004 he travelled, alone, to Zurich. "I felt I'd let him down," she says. "No matter what my views were on the issue I had let him go to Switzerland and he was going to die on his own."

At Dignitas a doctor asked Martin if he was certain that he wanted to end his life. He wasn't. He phoned Laura and told her that he had changed his mind. "When he came home he had a new zest for life," Laura says. "He said, 'I'm going to live this life as best I can until I need to go back there'. Just knowing that it was there for him, knowing what was going to happen, that he had an element of control, was a huge comfort. He was a changed person, back to the old Martin." Over several months Martin developed a telephone friendship with Ludwig Minelli, the human rights lawyer who founded Dignitas - until Martin received a vast phone bill that his disability allowance couldn't meet and stopped phoning. Minelli contacted him to ask why he hadn't been in touch. When Martin explained, Minelli sent him a cheque for €1,000 (£850) and told him to pay off the bill and stay in touch.

Martin's improved emotional state made Laura revise her view of his decision to take his own life. "I realised that the decision wasn't mine, it was his to make. This was something he was going to do whether I agreed with him or not. It was just a question of could I let him die alone? I couldn't let him do that."

In October 2004 Martin contributed to a radio debate on assisted suicide, announcing his intention to end his life at the Dignities clinic.

"MS happens in ten stages. I went from stage one to stage seven in less than five years," he explained. "I did not want to end up in a nursing home requiring constant care in my thirties. I did not want to endure a painful, cruel death propped up with morphine. My choice ... has released me from the terror of facing a horrible and painful death. It is an act of self-deliverance."

When he returned to Zurich six months later, Laura went with him. On the evening of their arrival, they had a convivial dinner with Minelli and his partner. The next day Martin met a doctor at the apartment and asked Laura to leave while he signed the consent forms - for legal reasons he did not want her to witness it. She was distressed; Martin was calm and happy, Laura says. As he had requested, after his death she phoned his mother, who knew of his intention though not the timing. A devout Roman Catholic, his mother was upset and disturbed by the nature of his death, though she has since come to understand his decision, Laura says. Laura knows that she may be questioned by police as a result of talking about Martin's death, but her decisions to write about assisted suicide and to talk honestly about Martin have been supported by her husband, whom she married last year. "I wrote this play because I had this experience," she says. "I didn't write with any agenda."

"Before I met Martin I had a rosy view of the world. What happened to him made me see that it's easy to forget about disabled people. And anybody who sees assisted suicide in black-and-white terms isn't putting themselves in the position of either the person who is at that stage and has decided they want to go, or the vulnerable person who feels they should make other people's lives easier and is put under pressure to go. I think it's a grey area."

How Dignitas operates

Dignitas was founded in 1998. By the end of 2008 it had almost 6,000 members and had assisted in the suicide of 947 people - 115 Britons have now died with its help. It works with clients who are terminally ill, who have an "unacceptable incapacitating disability" or who are suffering unbearable and uncontrollable pain. Some doctors have expressed concern that some of the people who have used the service were not terminally ill and had conditions that could have been treated.

The founder, Ludwig Minelli, likes to stress that for many members knowing that an assisted death is available to them is enough. Speaking in Amsterdam in March he said: "About 70 per cent of members ask for a green light but, having been given it, most people never contact Dignitas again."

Dignitas, a non profit-making organisation, charges clients a fee of up to SwFr10,500 (£5,900) for an assisted death. This covers administrative procedures, a consultation with a doctor who prescribes the drug used for the suicide, rental of the Dignitas premises and funeral and burial or cremation services. The joining fee is SwFr200 (£111); annual membership is SwFr80.

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Smoking may speed progress of multiple sclerosis

Multiple sclerosis (MS) patients who smoke have a speedier progression of the disease, a new study in the Archives of Neurology suggests.

Dr. Alberto Ascherio of the Harvard School of Public Health in Boston and his colleagues also found that smokers with MS were more likely to have the progressive form of the disease, in which symptoms steadily get worse, rather than the relapsing-remitting form, in which a person has MS symptoms intermittently.

"Most of the adverse effects were seen for current smokers, which in some way is good news because it suggests that stopping smoking can help," Ascherio told Reuters Health.

People who smoke are known to be at increased MS risk, but research on whether smoking affects the course of the illness has had conflicting results, he and his colleagues note. They followed 1,465 MS patients, 17.5% of whom were current smokers, for an average of just over three years to investigate.

Of the 891 patients the team followed for that period to determine the rate of progression from one form of disease to the other, 72 saw their MS progress to the worse relapsing-remitting form: 20 of 154 smokers, 20 of 237 ex-smokers, and 32 of 500 never-smokers.

That meant that the smokers were 2.4 times as likely as non-smokers to have primary progressive MS, and those who had relapsing-remitting disease were 2.5 times more likely than never-smokers to develop secondary progressive MS during the follow-up period.

At the study's outset, the smokers had more disability, more severe disease, and more atrophy in their brains. Over time, they also showed a faster increase in the total amount of injured brain tissue and their degree of brain atrophy.

The mechanism through which cigarette smoking could worsen MS isn't clear, Ascherio said. Smoking has been linked to some other autoimmune conditions, such as rheumatoid arthritis, he noted, but not others, so the habit's effects on the immune system could be a factor; another possibility would be that cigarette smoke is toxic to the nervous system.

There are currently no proven risk factors for progression of MS that a patient can do anything about, Ascherio noted.

"Although causality remains to be proved," he and his colleagues write, "these findings suggest that patients with MS who quit smoking may not only reduce their risk of smoking-related diseases but also delay the progression of MS."

SOURCE: Archives of Neurology, July 2009.

Drug curbs severe facial pain: study

Results of a small study suggest that the drug pregabalin (sold as Lyrica) can reduce stabbing facial pain and other symptoms stemming from a condition called trigeminal neuralgia.

The condition occurs in the trigeminal nerve, which affects perceptions of touch, pain and temperature in the face and jaw. People with trigeminal neuralgia experience shock-like or stabbing facial pain that may be triggered by everyday motions such as talking, tooth brushing or chewing. Few medications relieve the condition.

"Our findings suggest that pregabalin could be a first choice therapy when treating painful trigeminal neuralgia under 'real world' conditions, because it not only reduces the pain, but also its benefits extend to the associated symptoms of anxiety and depression and sleep disturbance-related symptoms -- in a well-tolerated fashion," lead investigator Dr Concepcion Perez told Reuters Health.

Pregabalin, a drug that calms nerve cells, gained U.S. regulatory approval last year to treat another pain condition called fibromyalgia.

Dr Perez, of Hospital de La Princesa, Madrid and colleagues examined the effect of pregabalin in 65 patients with trigeminal neuralgia who had not received the agent before and had been resistant to previous analgesic therapy.

Of this group, 36 received pregabalin alone and the remaining 29 used it in addition to their current therapy, mainly with non-steroidal anti-inflammatory drugs.

Following 12 weeks of treatment, both groups showed a greater than 55% reduction in pain intensity. Almost 60% of responders showed pain reduction of more than 50%.

There were also significant improvements in a variety of other measures, including a reduction in anxiety and depression and enhancement in sleep and in functioning.

The team calls for further studies, but concludes that in spite of the small sample size, the results "support the effectiveness of pregabalin for the improvement in pain and related health symptoms."

With pregabalin, doctors "have the opportunity to increase their options to clinically manage this condition, which is good news both for patients and physicians," Perez added.

Scottish MS sufferers to vote on independence from UK charity

THOUSANDS of people with multiple sclerosis in Scotland are set to vote on whether to break away from a national charity following a massive row that led Harry Potter author JK Rowling to quit as patron.

The Scotsman has learned that an extraordinary meeting of Scottish branches of the MS Society has been called to debate a possible split.

The charity has been beset with internal acrimony that has led the UK board of trustees to suspend the devolved Scottish council appointed to run the MS Society Scotland (MSSS).

The move, triggered by infighting between the charity's Scottish and London-based leaders, caused a furious Rowling to announce in April that she would no longer carry out her high-profile fundraising role that has generated hundreds of thousands of pounds for the charity.

Rowling, whose mother died from multiple sclerosis at the age of 45, helped to set up a £2.5 million MS research centre in Edinburgh.

Announcing her decision to end her ten-year association with the charity, she said she could not continue to be the public face of a charity that was "changing beyond recognition".

"With mounting frustration and disappointment, I have witnessed resignations of immensely dedicated people within MSSS and the increasing demoralisation of staff whom I have come to know and admire over the ten years of our association," she said.

Eleven of Scotland's 35 MS Society branches have called for a meeting in September to discuss the way ahead.

And one branch has already drawn up a motion calling on Scottish members to break from the UK body.

That motion reads: "The Caithness branch committee move that the Multiple Sclerosis Society in Scotland should be independent of the Multiple Sclerosis Society in the rest of the UK and should have its own constitution."

The motion could trigger a ballot of Scotland's 3,500 MS Society members. A two-thirds majority would be needed to carry the motion.

Caithness branch chairwoman Pat Stanley said: "I think independence should be seriously investigated.

"If the members decide they want to be part of a larger organisation with a bigger voice, it needs to be one that people have confidence in."

An MS Society spokesman said: "MS doesn't respect national boundaries and we believe there are strong arguments for staying a UK-wide charity, but as always we are happy to discuss the pros and cons of independence.

"We get the best results when we work together. For example, being a UK-wide charity means we are more effective in bringing together scientists across Scotland, England, Wales and Northern Ireland in the fight against MS."

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Why repair of brain's wiring fails

Scientists have uncovered new evidence suggesting that damage to nerve cells in people with multiple sclerosis accumulates because the body's natural mechanism for repair of the nerve coating called "myelin" stalls out.

The study, published July 1, 2009, in the print edition of *Genes & Development*, was conducted by scientists at the University of California, San Francisco and University of Cambridge. The research was led by co-senior investigator David Rowitch, MD, PhD, a Howard Hughes Medical Institute investigator at UCSF.

The investigation, conducted in mice and in human tissue, showed that repair of nerve fibers is hampered by biochemical signals that inhibit the development of cells known as oligodendrocytes, which function as repair workers in the brain.

Oligodendrocytes form a protective sheath, known as myelin, that insulates the fibrous cables, or axons, radiating from nerve cells. In multiple sclerosis, the immune system's T cells and B cells attack oligodendrocytes, ultimately damaging the myelin sheath to the point that the electrical signals transmitted by the axons beneath it are disrupted.

Remarkably, the brain generally is able to recruit fresh, immature oligodendrocytes to the myelin sheath to repair the damage, for a time. This explains why, in the most common form of the disease, known as relapsing remitting MS, the symptoms - which range from tingling and numbness in the limbs to loss of vision and paralysis - disappear or are greatly reduced, for some times months or years at a time.

Ultimately, however, the repair process falters and the disease progresses. In their study, the team set out to see if they could determine what was slowing down myelin repair. They lesioned a small region of white matter in healthy mice, then monitored the repair process, examining the tissue after five, 10, and 14 days.

To find out which genes were contributing to three key stages in the repair process - the recruitment of oligodendrocyte precursors to the site of injury, the maturation of those cells into functional oligodendrocytes, and the formation of a new myelin sheath - they measured the activity of 1,040 genes. All of the genes they studied encode transcription factors, which regulate the activity of other genes. Their experiments showed that 50 transcription factors are working during key steps in myelin repair.

The team then honed in on a gene called Tcf4, because its expression was strong in damaged areas where repair attempts were under way.

Tcf4 is involved in a cascade of biochemical events known as the Wnt (pronounced "wint") pathway, whose importance has been well recognized in normal development of many tissues, including the brain. Until now, however, Wnt had not been linked to myelin production or repair. "This is the first evidence implicating the Wnt pathway in multiple sclerosis," says lead author Stephen PJ Fancy, PhD, a postdoctoral fellow in the Rowitch lab. "We consider this an exciting development in our efforts to understand why the repair process often fails in the disease."

To glean further evidence about Wnt's role, the researchers hyperactivated the Wnt pathway in the oligodendrocytes of mice, which caused a profound delay in repair. Further analysis suggested that the Wnt pathway activation was creating a roadblock that prolonged oligodendrocyte precursor development.

"While the animals eventually showed repair, it was delayed compared to normal mice," says Fancy. The researchers also tested human tissue for the presence of Tcf4, and found the protein in areas damaged by MS but not in healthy white matter. Further, the researchers examined available data from another study and found that many signaling molecules of the Wnt pathway are overactive in lesions of patients with MS.

"This is an important step that we hope will lead to targeted therapies involving the repair process," says co-senior author Robin Franklin of the University of Cambridge.

Now the team is starting to examine some of the other genes it found to be active in the myelin repair process, and is developing new mouse models to help test potential therapies that might manipulate the Wnt pathway to improve myelin repair. Given the pathway's role in so many different processes, however, Rowitch cautioned that targeting Wnt could cause unintended side effects.

The new work may also have implications for another neurological disease, periventricular leukomalacia, which can lead to cerebral palsy in extremely premature infants, says Rowitch. Recent studies by Rowitch and colleagues show a similar inability of oligodendrocytes to perform their important repair function.

"The researchers have made an encouraging finding that could open a new window into the cause of failed neural repair in multiple sclerosis," says Dr Patricia O'Looney, Vice President of BioMedical Research at the National Multiple Sclerosis Society. "Understanding such mechanisms should help advance the efforts to find valuable treatments for this debilitating disease."

The work was funded by the National Multiple Sclerosis Society, the United Kingdom Multiple Sclerosis Society and the National Institutes of Health and Howard Hughes Medical Institute. Co-authors of the study were Sergio E Baranzini, Karen-Amanda Irvine and Nader Sanai, of UCSF, Chao Zhao of University of Cambridge and Dong-In Yuk of Dana-Farber Cancer Institute

Author: [Science Daily](#)

Abdominal massage shown to benefit constipation in MS

Trial results have highlighted the benefit of abdominal massage in the management of constipation – a common symptom in people with multiple sclerosis (MS).

In the latest study, reporting in the International Journal of Nursing Studies, 60 people with constipation were split into two groups and given a combination of laxatives and abdominal massage, or were given laxatives alone for eight weeks.

It was found that the group of people being treated with a combination of laxatives and abdominal massage had reduced severity of abdominal symptoms, including constipation and pain, than the group taking laxatives alone.

The MS Society has recognised the importance of finding new ways to manage common MS symptoms such as constipation.

Last year more than £120,000 was spent on a project to help develop a better approach to managing a variety of bowel syndromes for people with MS and formed part of the MS Society's **Symptom Relief Research Initiative**.

MS sufferer who pioneered specialist treatment commits suicide

An academic who pioneered a treatment for multiple sclerosis has committed suicide because she feared being sent to a care home as her condition worsened.

Cari Loder, 48, a former university lecturer who had lived with the neurological disease for the past 17 years, killed herself at her Surrey home by inhaling helium gas that she had ordered over the internet.

Police are investigating the circumstances of her death on June 8 and believe she may have received help to commit suicide from an elderly neighbour, who has been arrested and bailed. Miss Loder discovered a treatment for MS by accident in 1994. Having developed the disease at the age of 31, she went to her doctor for antidepressants and, shortly after taking the drugs, along with others prescribed for the MS, found that all of her symptoms went into remission. At the time of the discovery, Miss Loder said: "One day I had been hardly able to walk without crutches; the next I was able to dance to Top of the Pops."

The cocktail of drugs - including an anti-depressant, vitamins and an acid found in Diet Coke - became known as the 'Cari Loder regime'.

She wrote a book, *Standing in the Sunshine*, about her temporary recovery and 138 other MS sufferers volunteered to take part in a trial of her treatment, which found that patients underwent slight improvements in their disabilities and symptoms.

There are several disease-modifying treatments for relapsing remitting MS - the most common type - but scientists are yet to come near to developing a cure.

Miss Loder's own condition advanced to the stage where she feared being sent to a care home, which she was "determined" to avoid, according to friends.

Her death reignites the debate about euthanasia. Campaigners for the introduction of medically assisted suicide say she may have lived longer had she known that doctors would have helped her to die when she felt she could no longer endure her illness.

Dr Libby Wilson, a retired GP and member of Friends at the End (Fate), a pressure group in favour of assisted suicide, said that she spoke to Miss Loder days before her death.

"She thought it was monstrous that she had to do all this herself when she would have much preferred to have been able to just swallow something that would put her into a sleep from which she would never wake up," said Dr Wilson.

"She said, 'I have always been very independent. I have always been in charge of my life, I live here alone despite my disabilities'.

"She was absolutely determined that she was not going to go into any kind of residential care." Miss Loder is understood to have left a note explaining that her suicide was unaided, however detectives are continue to investigate.

A spokesman for Surrey police said: "A man in his seventies from the Godalming area was arrested in connection with the incident and has since been released on bail pending further inquiries."

Author: Sunday Telegraph

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Biogen enrolls patients in new MS trial

Biogen Idec has enrolled its first patient in a phase 3 trial for a potential multiple sclerosis treatment that, when compared with existing therapies, would reduce the number of injections patients must receive.

The trial, called ADVANCE, will determine the efficacy and safety of Biogen's drug target, called PEGylated interferon beta-1a, in reducing relapse rates in patients with multiple sclerosis (RMS).

The global study will enroll more than 1,200 patients with RMS between the ages of 18 and 55. The study's goal is to determine whether the drug reduces the annualized relapse rate in patients with RMS at one year. The study will also examine if, over time, the potential treatment can slow disease progression and lead to a decrease in the number of a certain kind of brain lesions commonly seen in MS patients.

The treatment is a combination of interferon beta-1a, which has been used successfully to treat MS for more than 10 years, and PEGylation, which can extend the amount of time a drug remains in a patient's system. If the trial is successful, the treatment has the potential to reduce the frequency of treatment injections and provide patients with an effective and more convenient dosing option.

Author: Boston Business Journal

MEMBERS COMPETITION

A £5 prize will be given to the member whose entry has the most correct answers. Even if you can't answer all the questions, send in those you have answered – you could still win!

The first letter of each answer will spell out the name of a London Underground line.

- 1/ Which naturally occurring substance measures a maximum on the Moh's scale of hardness?
- 2/ Who wrote Rip Van Winkle?
- 3/ On the Statue of Liberty how many spikes are there on the crown?
- 4/ Where was the 1998 winter Olympics held?
- 5/ Who commanded the Confederate armies during The American Civil war?
- 6/ Which semi transparent substance is used for clarifying alcoholic beverages?
- 7/ Which film star has a statue in Leicester Square?
- 8/ How many compartments are there on a roulette wheel?

Name:

Address:

Send Completed Forms To:
Mr D Henderson
74 Windermere Road
Stockton-On-Tees
Cleveland TS18 4LY

All entries to be received by the next social. The winner will be drawn from entries received with the highest number of correct answers.

Answers to last quiz:

- 1/ Silvio Berlusconi 2/ Acid 3/ Katydid 4/ Eight 5/ Rowling 6/ Leningrad 7/ Omaha 8/ Octopussy Line: Bakerloo