

## Blogs I'm watching by Mark Ivory

American blogger Silverfox has a problem. Apart, that is, from his Lewy body dementia, which he describes as a terrible disease that he's tired of fighting. But in this instance his problem has a cure or at least a partial cure, namely the blog itself. "I realize that my emotional control system is compromised," Silverfox says candidly. So there's an all-important issue – every now and again you understand – about "Blowing off STEAM!!" as the headline to a recent blog entry puts it. When he used to be on active duty in the US Navy, there was always the option of a little R & R while on shore leave - "since we all shared the same stress levels from the same problems, it was a 'Support' group for stressed out sailors." But now? Screaming, punching the walls and hurling random abuse are non-starters, he thinks, but there's always the blog. "I have written about this before, at length. You need to realize this is THE ONLY avenue I have to vent. And short of beating the ship (sic) out of someone right now, it will have to do." Silverfox has just been hailed as one of the "Best Alzheimer's Blogs of the Year" by the American website Healthline for what it bills as a "heartfelt and insightful look into the patient experience." A worthy winner.

<http://parkblog-silverfox.blogspot.co.uk>

For a sense of what it's like to live with dementia there can be few better places to go than Alzheimer's Society's Talking Point online discussion forum. I clicked through to the "I care for a person with dementia" forum, which had 125 people viewing it at the time. Under the headline "Sue had a fit/seizure today" a family carer calling himself stanleypj shares his discovery that there are always new experiences to be had in dementia care. It was, he says, "the first time I've seen anything quite like this." Having found Sue sitting on the toilet apparently unconscious and "twisted up" he

tells of the interminable wait for the ambulance, the long hours in hospital while a battery of tests were carried out, and his relief when word eventually came that they could go home. “As [Talking Point] members will understand, these events are always shocking. I know things might get worse again but at the moment I’m fairly hopeful that this might just be a one-off.” What impresses is the volley of reassuring responses to stanelypj’s story. Admittedly, few have expert advice to offer, but what they do offer is great moral support. “Hi Stanley – sorry no advice – just a hug,” says one.

<http://forum.alzheimers.org.uk/forum.php>

While we’re on the flourishing genre of family carers’ blogs, I found one encouragingly entitled Adventures with Dementia. The blogger’s wife has Alzheimer’s disease and he relates how he found himself saying to a friend “that I would find my wife’s condition very interesting if I wasn’t so involved.” But, in fact, involved or not, he *does* find it interesting, something that clearly comes across in the blog as he unravels the meaning of this or that set of research findings. There’s a new post most weeks and one in particular caught my eye headed “New Hope for Alzheimer’s Research”. Underneath is what he labels a “staggering quote” from the *Guardian*: “Between 2002 and 2012, 99.6% of drug studies aimed at preventing, curing or improving Alzheimer’s symptoms were either halted or discontinued.” It is indeed a breathtaking statistic, succinctly described by our blogger as “possibly the biggest, most expensive and most pointless wild goose-chase in the history of medical research.” But all is not lost because the article holds out the hope of a different approach to treatment that may even result in the restoration of vanished memories. Finding that really would be a great dementia adventure.

<http://adventureswithdementia.blogspot.co.uk>

In the last issue I mentioned prolific dementia blogger Beth Britton's rave review of the Oscar-winning *Still Alice*. Well, she is someone with plenty of experience of caring too, having cared for her father who had vascular dementia. To mark Carers Week, in June, she took up its theme of 'carer-friendly communities.' Just as she celebrates the film while noting down a few reservations, so she celebrates the "vital contribution" carers make to society while putting on record the "multitude of issues and problems" they face. A meager Carer's Allowance, workplace prejudice and patchy training for the health and social care workforce are just a few of them. What's more, she says, "social care is on its knees." So what's the answer? Value our family carers! "My personal view is that as a country we don't value carers enough. Time and time again the huge contribution they make to society and the immeasurable problems that would be created if every carer decided to stop caring are conveniently forgotten." Hear, hear!

<http://d4dementia.blogspot.co.uk>