

The Unscripted Carer – 23rd April 2009 – “Screaming in a Vacuum”

More years ago than I care to remember, one of my school teachers recommended a book that was built around the theme of “screaming in a vacuum”. The main idea being that no matter how hard you tried, nobody actually listened, or even heard you. The same theme has since been captured in numerous Science Fiction films and stories, and has remained strangely relevant to me over many different periods in my life.

I am feeling strangely reflective as I “celebrate” over two years of having to give up work to become a 24*7*365 carer. During this time both of our lives have been totally transformed – not necessarily a totally bad thing as work seemed to be a very prominent and often all consuming element. We have both learned new skills, which includes the very difficult one of living with each other 24*7 in the same house with little, or no, opportunity for us both to leave the house together (my wife is basically housebound and needs someone with her all the time). We have become more aware of the social side of the internet, and have learned from others about the potential dangers of the “web”. The “web” has given us access to some marvellous things, such as the pictures sent back to NASA from space, something we could not have dreamed of only a few years ago, but we have also found just how easy it is to lose many hours idly flicking through pages of “interest”. At least when I used to spend the odd Saturday morning in the library, I could usually claim to have met some “interesting people” – a really good excuse for “wasting” a few hours!

However, without this access to the outside world, my wife would be totally cut off from all the valuable “research opportunities” (such as shopping!) that she was able to do in person a while ago.

Unfortunately, “research” can be a little soul destroying, as one finds crumbs of comfort for people with disabilities and their carers, only to discover the age of the article and realise that nothing has actually changed in the “real world” since the article was initially published many years ago. I have also found many very supportive ideas for carers from various Cabinet Ministers, it is only when you read the fine print that you realise that this is “in the next ten years” - as another year passes with no concrete changes. One also discovers the insensitivities and prejudices about anyone who is different, whether this be a recent joke in the Metro about Steven Hawkins; quotes from overweight politicians about obesity in children; or simply the indifference casually demonstrated on a daily basis by able bodied people parking in a disabled parking space. An American friend of mine has the saying “you can take my parking space if you take my disability” – which sums it up rather neatly. To quote from a recent Radio 5 phone in “I pay for their disabled car, why should I not park in their space” – fortunately, other callers and the presenter were not supportive of this view!

There is the other side of “research”, when you are approached by “market research organisations” (who quickly point out they are not trying to sell you something!) who are able to accept all your answers, until the vital one of

“what do you do?”. The term “carer” is not on the list, and you are then put “on hold”, while they consult their line manager, sometimes this all knowing person comes on the line to ask if “carer” means you do domiciliary work – but usually they have no idea at all!

Rugby Council has a wonderful scheme whereby “carers” are allowed discounts at the local, council owned “gym” (the Ken Marriott centre) – these discounts can be unlocked if, for instance, you can demonstrate that you work for Crossroads – who provide a care support service for “carers”. You cannot unlock this discount if you are merely a “carer”, so perhaps it is a little unfair to criticise market research call centre staff when our own council does not really understand the term “carer” either. It is also only fair to point out that this “official” view of a “carer” is not restricted to Rugby council – at the last AGM of South Warwickshire Carers, one of the guest mayors recounted a “hilarious story” of how a “carer” looked after his mother – he actually meant somebody that came in to help with the house work!

“Screaming in a vacuum” – despite all the best attempts of many people to explain and support carers, if our elected representatives do not actually understand what it is about, then any support we do get is either accidental; tokenistic or the result of a few very hard working people. (Fortunately we are blessed with many very hard working people in the council and carer support organisations in Warwickshire.)

Many years ago people with disabilities were often ignored, even in their physical presence – something that the BBC successfully addressed with their radio program “Does he take sugar?”. Fortunately we seem to be moving away from this attitude (?), but the condescension seems to be transferring to carers. There are any number of web sites / emails / forums seeking carers opinions and assistance, but they never then follow up by publishing the resulting actions that arise from the “consultation”, or even summarise the returns. This can easily be seen as yet another example of “screaming in a vacuum”, and certainly justifies the jaundiced views of many carers who routinely accept that genuine carers views will be disregarded, unless these views align with the current policies. We also see this on Radio and TV phone ins, where there is an apparently open discussion about carers’ issues, but, perhaps inevitably, the “experts” are working to a restricted amount of actual knowledge that soon becomes evident, as callers’ points are answered to reflect an expected question, rather than the question that was actually posed.

Fortunately, there are some silver linings. For example, our local GP surgery actively supports carers and has representatives of Guideposts in their various surgeries at nominated times. These sessions have already benefited a number of carers, and the local Practice Manager freely admits to having a better understanding of the caring role.

On a very personal level, we had spotted an article in the local paper about the benefits the residents of a local care home were deriving from the donation (from Nintendo) of a Nintendo Wii and Wii fit package. Nicola contacted the care home before Christmas, and they very kindly offered us an

invitation to join them for a “Wii session”. About 23 days ago (that seems a bit exact!) Nicola was finally able to leave the house and attend a session – which was very instructional for us, and we were warmly welcomed by the staff and residents. We were surprised that Nicola was able to participate in the Wii fit session, despite her extremely restricted mobility, and we enjoyed being able to share in the general fun and well being that the residents derived from it.

Nicola survived the session remarkably well, and was able to reset her back on our return home without any longer term problems. Once we were fairly sure that there actually were no longer term repercussions we decided to take the plunge and buy one. Inevitably we researched the web (!), but found the best deals (and stock availability) were from our local Gamestation shop – they had much better offers than their central web site!

The Nintendo was very easy to set up, and Nicola has been able to do a little bit every day since we bought it. We both enjoy the shared activities and Nicola is already benefiting from both the fun element, and the gentle exercises. Nicola has had, literally years of physio treatments, until Walsgrave finally gave up on her, and so she has learned what to look for in exercises, and to understand what her body is telling her. The Nintendo offers a large number of short term exercises, some as short as 1 minute, and disguises some of the exercises as “Balance Games” and less subtly as “yoga”. One of these exercises manages to achieve what her physio had been trying to achieve for ages, but Nicola and her had never quite managed it.

We are not naïve enough to think that this is a magic cure, but the gentle exercises do help reduce the issues with fluid retention in the body, as well as introducing an element of fun; a small “exercise challenge” and something that we can share in our own home. The Nintendo offers excellent feedback and “small rewards” that encourage you to participate in “its games” – and we have actually found it more encouraging than the gym we used in our past.

One of the unexpected bonuses of being up at all hours of the night in a caring role, or simply suffering from the stresses of day to day caring, is hearing the “dawn chorus”. I had only ever heard this before “at dawn”, but I am now hearing a few birds signing their hearts out about an hour or so before dawn – some of them even come round looking for bird food before dawn actually breaks.

As a footnote, the same school teacher also introduced me to the mock Latin phrase “nil carborundum illegetimi” (don’t let the bas***ds grind you down”) and pointed out that you can always try to change the world! Although it is sometimes very hard to maintain an optimistic approach, support comes from the most unexpected places, whether this be in the form of the help we recently received from Overslade House with the Nintendo, a recent friendly enquiry from a young lady at a recent carers meeting – and, of course, the unstinting love and support of our two dogs!

Bye for now

Graham

PS – there goes the early dawn chorus!