

## **Gerry Robinson and Dementia Care in Nursing Homes**

**'Can Gerry Robinson Fix Dementia Care Homes' was a two-part series which was screened on BBC 2 on December 8<sup>th</sup> and 15<sup>th</sup> 2009.**

Gerry Robinson is a hero and I am a man who works through his heroes – Bob Lister, Stan Cullis, Billy Wright, John Johnson, Tom Arie, Bernard Isaacs, Brian Clough, Gordon Brown, Mary Marshall, Pat Smith, Beverley Hughes, Dudley Ainsworth – these are a few of the people I hold in awe and whose style and purpose have influenced and sustained me.

Gerry Robinson's salvation of (a part of) the NHS and his follow up to see that it had remained fixed assured him of a place in this honourable roll. So the prospect of his attempting to answer the question:

'Can Gerry Robinson fix dementia care homes?' made for 'this is a must' viewing (all-be-it with the assistance of the new technology which allows us to see programmes at times other than those advertised ie BBC iPlayer.)

I have been through sadness and anger and back to acceptance and endurance – for Gerry Robinson found he couldn't make much of an impact on the dementia care he saw in the time and budget allowed him. Compared with the NHS series, this two part programme felt cheap and shoddy – touching on insights and possible solutions but without the time and commitment to turn things round – making bricks with what had seemed to be inadequate straw - as he did at Rotherham.

He was working to a brief which echoed the spin of recent initiatives to raise the profile of dementia – some of which fudges the figures and facts too far – apparently feeling justified by exaggerating the scale of things because this might grab attention more effectively – as in the most horrid of horror stories.

'The whole system of dementia care is broken': I think not – much good work is done and people are quietly grateful for this. There are problems and these must be addressed – and can be if we have vision based in reality, work carefully and make progress stepwise (Stan Cullis, Billy Wright, Tom Arie).

'Half of us will end up put away in dementia care nursing homes': not so – even when we survive into our eighties and beyond, only one in five of us will develop dementia and at any one time less than half of individuals with dementia are living in Care Homes – not all of which provide an exclusively dementia dominated milieu.

So dementia is not as common as some agencies would panic us to believe. When it occurs many people live with it for years in the setting of a home life which they and their family have constructed, accepting the changes which it and other age-related pathologies bring with grace and determination. In this they are sometimes helped by modest extra benefits and support from statutory and voluntary agencies or the private sector. For the most part it is only when matters have become hazardous, too worrying or exhausting that

people turn to 24 hour care. It can then be a very positive experience for both patient and carers (remember the final months of Iris Murdoch) though sometimes it becomes a prolonged vigil with very few obvious positives (see Alan Bennett in his 'Untold Stories').

The programmes concentrate on the lives of people with dementia in specialist dementia care nursing homes, which cater for people with the most marked and difficult changes in ability and behaviour. The business of running such homes is referred to in the programmes as 'Granny Farming'. This is not a term of respect and sets the scene to present the industry as brutish, uncaring and profit focussed.

Gerry Robinson enters this world, with his actions and interviews captured on camera, as a very open and concerned human being – sensitised by the experience of his own father's dementia and equipped with experience and knowhow of management applied in many settings.

The methodology of the programmes was to visit a number of Nursing Homes of variable quality and reputation, to observe and interview staff, managers or owners and residents and to reflect something of the milieu and activities offered within the Homes. There were no interviews with family carer/visitors. It is a puzzle to me how far informed consent was obtained from any of the individuals interviewed. Certainly some of the staff seemed frightened and it is doubtful they were aware of their rights in such a situation.

Inevitably the scenes and interview samples broadcast were selected and edited to make best television and to tell a story. Gerry Robinson was helped in his task by David Sheard and colleagues who were able to offer models and advice on the very best of dementia care in residential settings.

The one good Home included in programme one (December 8<sup>th</sup>) achieved its excellence at a cost of £39,000.00 per annum per resident. This is a great deal more than any Local Authority will pay for a placement.

The other Homes ranged from poor to very worrying.

Gerry Robinson was perplexed that residents remained indoors rather than spent time in the garden. He found that staff knew very little of the life-stories of those in their care and that even the senior nurse lacked knowledge of dementia or even the administrative jargon of the business within which she held a responsible role. Time was demanded by paperwork designed to monitor safety and quality but which was effectively squeezing hands on care and listening to patients out of the time table. He was troubled that for many residents there was no regular plan for activities of any kind beyond the basic round of feeding, toileting and bathing.

This sensible practical man could see that priorities must be revised.

Professional care staff must be chosen and appointed for their caring aptitude and potential and they should be supported with appropriate training and ongoing updates and appreciation of their skills and ideas. They must be valued and they will value themselves, the work they do and the people they care for.

He was able, with David Sheard's help, to demonstrate that with an enthusiastic, sensitive programme people with quite severe impairment could

become engaged and become happier and less prone to distressed and resistive behaviour.

In programme two, which focussed on one home which was in great difficulty, he declared at one point that such transformations could be achieved at no extra cost (remember the £39,000.00 pa).

I think he was carried away.

His approach to staff (and patients) as one human being to another was admirable. But the extension of this to address members of staff and managers as professionals of equal standing and competence to himself took the model too far. The differences in their constitutional gifts of intelligence grafted to education, training and experience were starkly evident. Where his challenges to NHS managers and clinicians had met with creative responses from individuals who had previously not understood or not dared to use their own gifts; here the challenge was to a threadbare fabric. Unable to cope, these people were cruelly exposed to a national audience and had not the wit or resource to counter the attacks or to raise their game to use the advice to improve their performance. They were destroyed.

There was perhaps the matter of time – perhaps given more time the situations could have been rescued.

In the event everyone was damaged. Many members of staff were clearly very troubled, some turned on others. With little delay a story or stories emerged which were so worrying that the authorities (who had also received a pasting by report) called a halt to all this by closing the Home. So residents were to be moved. The move itself would add hazards of physical or mental deterioration, a risk balanced by a hope that the next place might be better. The thoughts of families on this were not included in the broadcast, nor have we knowledge of the outcomes, yet.

Gerry Robinson too was damaged: for all his gifts, for all his humanity and good heart – he had not fixed dementia care – not even in this one place.

If a man as great as this is rebuffed – retired hurt – we must know that this is a very scary monster to be taking on.

The programmes have generated a good deal of response: 10,700 references on Google so far (6.1.2010) which compares with 3,360,000 for his NHS series.

Chris Manthorpe wrote in Guardian Society quite positively immediately after the first programme and then more critically after the second. In the latter commentary he pointed to some of the weaknesses and unfairness which I have mentioned. Comments (17) on this more critical review were truncated after three days but were allowed to run on longer (31 in six days) for programme one.

Other references identified by Google also found the December 15<sup>th</sup> programme difficult to swallow. This is a very difficult business.

These programmes add to the current discussion of ideas which includes the National Dementia Strategy and the recent report on the use of antipsychotic medication in dementia in Care Homes.

One of the hopes of the National Dementia Strategy is that early intervention will reduce our dependence on Care Homes and be cost-saving. I doubt it will for there is not much sound evidence to support the idea.

The most encouraging fact which may reduce the need for Care Home admissions is the increased longevity of men. This will mean less older women with dementia are alone with their condition – so they have a better chance of being supported at home for longer.

The availability of Extra Care Housing may also prove to be a workable alternative to Care Homes for some people.

There remains a need to improve the status and quality of care for people with dementia (and others) within Care Homes. This requires a change in valuation by the people who authorise payments: At present a middle-aged or old person with dementia with a profile of dependency and behavioural disorder will receive a fraction (of the order of one quarter) of the funding made available to support an individual with a similar profile derived from a Learning Disability. Thus it is that Care Homes actually make little profit (and many go out of business as consequence) while providing inadequate care within the budgets available to them. The suggestion within the National Dementia Strategy that outreach teams from Old Age Psychiatry Services be sponsored to provide support and education to Care Home staff is sound and to be welcomed. Experience tells us however, that exhortation and advice from out-with the organisation finds it difficult to achieve an effective and lasting grip on practice and culture. The programmes demonstrated this on a small scale in the frustration of David Sheard's ministry.

Not even Gerry Robinson can fix Dementia Care Homes within current constraints – time for a wake up.

David Jolley

for dementia plus January 2010

References:

Banerjee S (2009) The use of antipsychotic medication for people with dementia: Time for action  
[www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/documents/digitalasset/dh\\_108302.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_108302.pdf)

Bayley J (1999) Iris A memoir of Iris Murdoch. Abacus, London

Bennett A (2005) Untold Stories. Faber and Faber, London

Department of Health (2009)  
[www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/documents/digitalasset/dh\\_094051.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_094051.pdf)

