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Great Aunts and Armadillos

A Glimpse into Dementia

D. B. LEWIS



For the friends and family of Pat Botley

SRN BTA Cert H.E.

(1931-2017)

and

*for all those who face the care of relatives suffering
with dementia*

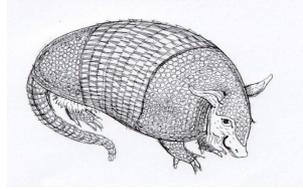
'And midst the fluttering legion

Of all that ever died

I follow, and before us

Goes the delightful guide...'

(A.E.Houseman 'A Shropshire Lad')



The image of the armadillo used in this book is by Scarborough based artist and writer, Jo Reed Turner, to whom sincere thanks are given.

In aid of



Fifty percent of the royalties from this work are being given to help further research into dementia by the Alzheimer's Research UK.

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Also by D.B.Lewis

A Little Bit of Trouble in London

Plotting Shed (Ed.)

Return to Premantura

A Wedding in Hoar

One Day in December

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Preface and Acknowledgements

This is essentially the story of one person's journey through dementia as well as a tribute to a much loved relative; who, with her own great aunt, are wonderful examples of that fine breed of seemingly armadillo-skinned aunts of the title. It has been written to provide the family and friends of Pat Botley SRN, formerly an 'old school' nursing sister of formidable repute, with a first-hand insight into her last years together with some of the issues involved in caring for someone with this debilitating condition. It also poses the question as to whether there is any link between 'eccentricity' in younger age and later dementia.

The story, which spans the years 2009 – 2017, may also be of interest to anyone who is faced with the care of relatives or friends with dementia; either now or in the future. The title was chosen because Pat Botley was a much loved 'favourite aunt' in the great British tradition; tough on the outside in a determination to overcome all travails, but warm hearted and soft-centred underneath her hard armadillo-like exterior. Dementia is a shared journey for most families. It is not just the sufferer who is affected but all those who have a concern for that person's life and welfare. This story, with all its comedy as well as its tragedy, has been written with the same love and care that Pat showed to the world in her own idiosyncratic way and is dedicated to her memory and to her example. She was a very remarkable woman so this personal reminiscence of her life through the stories she told whilst she was ill is offered as

a testimony to her life and work.

It would be remiss not to acknowledge Pat's own painstaking work in collating the '*Botley Family History*' she produced in 1993, together with its 1995 amendments, and in particular to acknowledge the many wonderful details supplied by the research undertaken with, and through, members of Pat's extended family. A big thank you to everyone who has contributed, either knowingly or unknowingly, in the hope they will forgive any shameless usage of their own research in this book. I must give enormous thanks to Sonia, my wife, who was a large part of this shared journey of looking after my aunt. She also was a great help in bringing the book into being and thanks are due to her, and to our eldest daughter, Kate, who both helped with correcting the errors.

The Photographs

The majority of the photographs have been taken from either Pat's or our own family albums. Where this is otherwise, the credits are shown accordingly. The photograph at the front of the book was taken at the Gala Opening Night of Scarborough's newly re-built Open-Air Theatre in 2010 featuring Dame Kiri Te Kanawa, an event Pat was then still able to thoroughly enjoy.

Notes on '*A Shropshire Lad*'

'*A Shropshire Lad*' is the best-known work of poet and

scholar Alfred Edward (A.E.) Houseman (1859 - 1936), and probably amongst the most oft-quoted works from that time. It was written whilst Houseman worked in London and was first published in 1896. It has remained continuously in print ever since. The book consists of 63 separate poems, all beautifully and atmospherically linked to the Shropshire areas Houseman later came to know well, although he was actually born at Bromsgrove in Worcestershire. The extracts are taken from a 1920 reprint of the 1908 illustrated edition; the first copy to be so illuminated. Sonia gave me this copy as a memorial present shortly after Pat died so it seemed appropriate to place the very fitting extracts into a work about the life and times of a true 'Shropshire Lass'. The archaic spellings of certain words are as they appear in the original and have been left as such. The Roman numeration is as it appears in the original text.

A Note about Factual Accuracy

In the nature of Pat's, as in anyone's dementia, well remembered stories became distorted as the disease progressed. The stories recorded herein are as they appeared in our conversations with Pat over the eight years of her illness. Where possible I have recorded the stories as she constantly repeated them early on in her dementia, and I have used her own words written in the Family History on occasion as the clearest version of the tale available. There is, therefore, a need to accept that the stories may over time have acquired inaccuracies both in fact and in effect. Perhaps it

is a little ironic that Pat opens her Family History of 1993 with these words;

'The human memory is very complex. Sometimes we see things through "rose-coloured spectacles". At other times, it's easy to exaggerate or over-dramatise events, but in either case, we are really sure, in our own minds, that it was so in reality at that time. I promise I will try to keep to facts to the best of my ability!'

(Family History. Page 10)

In testimony to Pat's lifelong quest for factual accuracy and the absolute truth of any matter as she saw it, I have tried to do likewise and record, as faithfully as I can, the experiences Pat endured during the years of her dementia between 2009 and 2017. I have recorded extracts from Pat's 1993 history as 'FH', followed by the page number where appropriate.

Preamble: The Last Letter. March 2009

'Dear Mr Smith,¹

What on earth made me do such a stupid thing by signing and ticking that form as I did? Not at all what I wanted – this job needs doing – and soon if possible. I think I must have had some sort of “panic” – not like me at all. I really do feel awful – and very worried about how careless I was.

The “ Rep.” and I had a pleasant chat and cup of tea. He looked at his watch and realised, I think, he was running late for another appointment. While he was out of the room to spend a penny, I saw to the form – far too quickly. I just cannot understand what made me do it as I did. I did not think to ask him to check it.

Would it be possible to start again please? I’m not usually careless. Since then I have nearly gone mad with worry and sleepless nights. The old blood pressure has also been a bit naughty, but that has settled down thank goodness.

The good news is (I hope) I have been to the bank and can manage to pay by cheque if this is at all possible? Or? A loan? All I can say again is how very sorry – and awful – I feel to have caused this problem for all of us – especially my nephew who has recently been very ill.

Re the work already done so far. The back brick of the house – 2 men working on it. Can you please check exactly how far over they have got to in this area? I'm not sure if they did the area below the window where my swinging seat is. This had obviously not been moved and there was not room behind it to work. Thank you.

My nephew David Lewis will be in touch with you after his holiday. I do hope sincerely we can resolve this problem. I certainly do not want this sort of thing to cope with?? Never have been in serious trouble. So hope my message will be acceptable.

Again, sincere apologies for all the trouble caused – to you and me; and David.

P.M. Botley.'

¹ Not his real name.

I

Dementia's Turn: The Last Great Challenge

*Before this fire of sense decay,
This smoke of thought blown clean away,
And leave with ancient night alone
The steadfast and enduring bone.'*

(‘A Shropshire Lad’ XLIII)

I had not seen my aunt for more than four months, the longest period without such contact for many years. I had been in China leading a youth programme for the British Council whilst ‘on loan’ from the Metropolitan Police Service where I was a Community Police Inspector based at Charing Cross. During my trip I had picked up a serious bile duct infection that saw me crawl home to spend several months of hospitalisation, operation and recovery. There was no indication anything was seriously amiss with my dear mother’s younger sister. I had still spoken to her every week by ‘phone. She was, as ever, lucid, a little pedantic, exact, no nonsense. Very black and white; very Pat Botley. Very much the old eccentric Aunt I knew and loved. When we had last seen her, she had her business and family papers spread about the house which was unusual, but she seemed in good spirits claiming that, at long last, she *‘was having a good sort out’*. It just did not register

with us that this approach to the 'sort-out' was in fact, out of character. We were misled maybe by Pat's regular 'clear out' sessions which could reach unbelievable levels of obsessive thoroughness. Sadly, it was a sign missed. But when she rang in great distress one Sunday morning four months later saying she couldn't see, we knew something was obviously wrong.

Although I hadn't completely recovered from my operation and was still being employed on 'light duties' with the police, my wife and I set off immediately for Croydon from our then home in Essex. It was September 2009. We entered the familiar terraced house Pat had lived in for nearly fifty years to find a battleground littered with papers on every conceivable surface. Upstairs and downstairs was a confused mass of jumbled correspondence. My aunt sat amongst it all, confused, distraught; her right eye heavily bloodshot, the hand written copy of a letter she had intended sending to the director of the cladding company, which appears above, tightly gripped in her hands. This was to be the last intelligible letter she ever wrote.

Pat was the most organised, detailed and punctilious person I had ever met. Before or since. She was as precise as the hospital corners on the beds she had ruthlessly required the junior nurses under her charge to maintain in her early career as a nursing sister. She paid all her bills on the nail. She had lists of every major purchase she had ever made. Every book she had ever read was listed; every film she had ever seen, every place she had ever visited. Every letter she had ever sent or received was meticulously recorded; every visitor logged in her fascinating 'Visitors Book', often with poetic notes from

those who had the good fortune to come to stay. Since her first, at the Wolverhampton Civic Hall in 1948, she had listed every single concert of classical music she had ever attended; thousands of them; sometimes three or four a week, for sixty years - all logged down and often annotated. All these things and many more such as her holiday diaries, were detailed in exercise books ruled up for the purpose and appeared with additional notes in Pat's almost totally illegible handwriting. This was the subject of much of our shared mirth for Pat smiled to think we would need to decipher it all once she was gone. In her house nothing was ever out of place. No single item was ever allowed to gather dust; if any household utensil remained unused for three years exactly, it was discarded. If it had no immediate practical use to her then that article had no place in Pat's life.

On closer examination that day in East Croydon, it seemed Pat had not paid a very large bill for some exterior cladding work to the house that was almost certainly unnecessary in the first place. To incur a debt or not pay a bill was tantamount to high treason in the life of Cedar Road. Clearly, things were awry.

The immediate issue was to have her eye seen to. We took her straight to 'Mayday', the old hospital of her nursing sister days in Croydon. There we found a long waiting time was predicted. We had arrived at the 'A and E' in the early afternoon and we were still waiting at the hospital at 11 p.m. that same night. After what seemed like an eternity, we were referred on to the specialist eye clinic at Denmark Hill Hospital in nearby Dulwich where it was arranged for Pat to see a specialist the following morning. It was decision time. We arranged that

Sonia would return home to Essex to sort things out there and I would stay with Pat and try and establish what on earth was going on.

Sadly, it was dementia that was going on. And quickly. The eye specialist found that Pat's blood pressure had built up behind the eye severing the optic nerve, causing almost complete loss of vision in her right eye. Back at Cedar Road, I found Pat's unconsumed blood pressure pills; she had been forgetting to take her tablets. The facts were beginning to fall into place. Clearly she could not be left alone just then and it was going to be necessary to look after her until we could stabilise the situation. I rang David, my Shropshire cousin, and explained what had happened. He spoke with the other nephews and nieces and before long we had a schedule of family care worked out for the immediate future.

The following morning, I heard the doorbell ring. I answered it and my 30 years of policing experience sent every warning bell in my brain ringing full blast. There, standing on the pavement beyond Pat's gate and front wall, in 'getaway-quick' mode, was as disreputable looking a character as you could ever not want to meet. His only words, '*Come for me money*', were more than enough to confirm the instinct. His dishevelled, tarmac-marked clothing, his battered knuckles, his paunch and the vicious line across his face that passed for a mouth, gave every clue to his background.

He was indeed so disreputable that he was able to make the instant reverse conclusion about myself. It was a mutual recognition formed by long exposure, each to the other, that he was a villain and I was a copper. He was away on his toes.

I was in a dilemma. I suspected he might well be a member of what we called a 'distraction burglary' team, and whilst I dealt with him at the front, a fellow 'ne'er-do-well' might be round the back removing the 'swag'. I rushed back in, made sure the back door was locked, told Pat not to move one muscle, locked the front door and I was off after the man. By this time, he was two streets away and gaining. I dialled '999' as I went. This slowed me and the man made good his escape by the main Addiscombe Road roundabout; the one known locally as the 'Wedding Cake'. I returned and spoke to the attending officers. We drove around the area in the patrol car. There was little to go on and, as they pointed out, up to that moment no crime appeared to have been uncovered. I spoke to Pat. "Why had this man, *'come for his money?'*", I asked. Pat mumbled something about 'gutter work'. I put two and two together and for once made four. I looked into her bank statements. Every day for weeks past, Pat had attended her bank and withdrawn cash. Usually £100, sometime larger withdrawals. Over £4,000 in total. I questioned Pat closely and, I hope, sensitively. She said the man had to be paid for cleaning out the gutter. Each day he had called she had forgotten she had already paid him the day before. I went straight to the bank, taking Pat with me. I asked to see the manager. They checked. *'Yes, we thought it was odd but didn't like to say anything'*. I asked them to check the CCTV. Sheepishly, the manager eventually returned to say it seemed a heavy, unkempt, middle-aged male had brought Pat to the bank each day where he waited outside until she handed over the cash. The description tallied. I was furious. Even the slightest duty of care, properly exercised, would have prevented much of this loss and distress. The bank were full of apologies and perhaps

I should have followed it up with a negligence claim. But Pat's condition was pressing hard and I had to be content with filing a crime report for the loss.

Some weeks later I was relieved to take a call from Croydon CID, who told me the man had been caught at a similar deception in an adjoining street and had asked for several other offences to be 'taken into consideration', including Pat's. When he came up for trial, my account would be used as a 'victim impact statement'. He eventually had a two-year prison sentence for his misdeeds; but there was no compensation. People with dementia are easy victims for ruthless criminals devoid of any empathy and this crime added to the urgency of care need for Pat.

Pat was to live on with much care, and at her own great personal and financial expense, for another eight years. In that time she deteriorated mentally from an exciting, if 'edgy', full-of-life individual of complete and unwavering independence, to a totally dependent shell of human suffering with moments of shockingly aware lucidity. The decline was excruciatingly painful to watch. How much more painful must it have been for her to experience? It is hard to tell. Amidst all this suffering there were brief, but great, moments of fun; the old humour never deserted her to the end - the twinkle in her only sighted eye remained to the very last breath. Before she lost the ability to even know who I was, or who anyone was, she asked me to write the story of her final years for her family and friends. This is it.