Experts by Experience

Home: Four Ways (1/2 volunteer visits)

Date: October 2014

What is Experts by Experience?

Several WCS homes have been scrutinised by Age UK Warwickshire volunteers to find out what life was like for people living there. Volunteers explored all aspects of home life, from atmosphere and cleanliness to mealtimes and culture.

As well as using discreet observations, the Age UK also volunteers mingled with people who lived there to find out how they felt about their quality of life. Each volunteer filed a report rating things like cleanliness, staff attitude and atmosphere from poor to excellent, and also commented on how each score was derived. A first round of visits gave 16 'excellents', 16 'goods', and 3 'adequates', however more visits are planned throughout 2015. **Volunteers' names have been redacted, but here are their comments published in full.**

Note: All volunteers' comments are black, while their instructions from Age UK are in Magenta.

Sections:

Home Enviornment

Staff Attitude

What was Happening in the Home?

Eating and Mealtimes

Quality of Life

Home Environment

Score: 4/5

Describe your own experience of the quality of the home environment. Please consider things like:

How clean the home was, how it was decorated, how homely and comfortable it was, how the home was personalised to the people who live there, how the home smelt and whether the facilities were comfortable, pleasant and easy to find.

Care homes cannot be 'what they are not'—they are 'what they are'— I question the very ethos of care homes endeavouring to provide or promote the ' 'home from home' perception. It is an illusionary concept to believe that the 'lived home experience' of each unique resident, prior to their residency in a care home, can be replicated substantially, in or by, a care home. Whether the home environment, that a resident has come from, was good, bad or indifferent- it was 'THEIR' home environment, with all that encompassed. The deeply embedded 'knowing' expressed as 'not my home'- felt like a common foundational touchstone of deep sadness and phenomenological truth which was not acknowledged, and therefore 'direct experience' felt somewhat denied.

However, many residents appeared to try, in their own way to make the best of their situation-- However, the ' situation' has to be realised before adaptation/adjustment can occur . To this end, I found 'gimmicky pretences'- like the 'front door' substitutes, unhelpful. It sort of felt like a cruel game' using 'visual deception' , which I found hard to comprehend set against 'Dementia awareness'. 'Survivors of life' should not be underestimated- in their 'knowing'- nor their capacity to accept 'reality' and move forward in the best way for them- but at the very least, it feels only fair, to 'not add to confusion' whilst endeavouring to make for a pleasant physical environment.

A couple of residents were found wanting a tissue- they were passed a serviette- to accommodate their needs- but I noted there were no boxes of tissues to be found in communal areas- and I wondered whether this basic requirement was a resident responsibility?

This said, the environment also provided a scope of 'spaces' from which to choose from (i.e. conservatory) Choice, in itself, promotes a feeling of freedom and this helped counterbalance the institutional reality somewhat.

All areas, I am sure , met health and safety standards as a priority for communal health.

Staff Attitude

Score: 5/5

Describe your own experience of the attitude of staff. Please consider things like:

How you and residents at the home were treated, whether residents were listened to, whether people were treated with dignity and respect, whether staff were polite and courteous? Whether they had a rapport with you/residents, how you/residents were addressed (eg what name was used and whether you were asked what you'd like to be called), how you and residents at the home were treated, whether residents were listened to and whether people were treated with dignity and respect.

In absolute, the task of 'caring' is immense- and the subtle 'power' of delivering 'care' within an establishment to enable maximum human potential to flow – is largely down to one human attribute- Compassion

Within the care home environment- compassion felt central for both the smooth running of the environment and the physical, psychological and emotional well being of individual residents. The individual predicament of each resident was none the less- for the superficial visuals of aesthetic value --which were largely ignored – but what made the horrendous burdens of residents bearable- was the experience of human compassion. The staff gave this in great bucket loads—and not from a learned or taught way—but with a genuine spirit and willing heart. I saw the tender way a hand was held- I saw eyes saying much more than words ever could- I heard tones of voices with depth of real feeling and sincerity- I saw courage to 'see and be with' extreme personal challenges- which showed me a passion beyond 'just doing the job'. It was heart warming, to witness, sincere human compassion to vulnerability, frailness and distress.

The residents appeared to express, in an assortment of ways, that they were well aware- this was not their 'real home' and there was an undoubted sadness evident regarding that for some.
People are not just there heads- their minds, but their hearts and their souls- and connecting with those parts of a person was evidenced by the very sharing and connections of the hearts and souls of the staff- I saw the heart and souls of staff- shine through—and this is what makes a HOME---
It is not the physicality of the structure, or the surface aesthetic appearances, the constructivist elements- the policies and protocols that uphold and 'give the care that makes a difference'- but the human resources within the construct--- the human element is what helps heal the losses experienced by the residents------- and give a reconciliation and peace which helps with the life position and thus, the reactions to it.
To 'not see' behavioural difficulties' also said something- I saw no 'fear' –
To that extent- it may be- that in their final experiences, in life- they experience a relational quality— which touches the core of their own existence- of what it is to be a human being. I think most would agree that 'home is where the heart is'- where we feel we 'want to be'--- none of residents elected for their position- none truly want to be, where they are- but the hearts of others help them to experience a type of home- where they felt wanted. This felt paramount.

Amongst residents, it was evident, without question or doubt, that the commonality experience was one of receiving compassionate care.

What was happening in the home?

Score: 4/5

Describe your own experience of what was happening in the home. Please consider things like:

What people were doing – whether it seemed to be their choice, whether people were doing what they might have been doing living independently, whether people's interests and hobbies were being supported, the organised activities you observed, how were people encouraged to join in activities and could people choose not to join in.

The 'unspoken' pain of family/home fragmentation and instability of life transitions, was aptly demonstrated during a 'mealtime drama' which compounded the 'huge sense of loss' among the residential group. Residents identified with the existential pain of hopless-ness, within their life position. 'I would rather slit my throat than stay here' came the verbal plea, to visiting family, by a resident. This, I understood WAS NOT, a detrimental comment regarding the
'care home'- but a verbal, existential crisis expression and acknowledgement of immense grief coupled with feelings of helplessness and hopless-ness she was experiencing . It was not heard, by relatives – who merely commented 'what's wrong with it here?' The physical environment appeared primary to subjective experience and well-being.
The exposure of 'the truth' resulted in one man leaving the table, another was taken to her room for her 'safety', by a member of staff who admirably noticed and empathised with the delicate situation which had presented.
I would challenge, that the profound awareness expressed in a display of tears, was 'part of the dementia diagnosis', as was suggested--- - and/ or to be taken as a reflection of success/failure on the part of the care home--- in fact, I would argue the reverse- that is showed a level of 'normality' and psychological well-being (honesty, awareness and phenomenological comprehension) in the resident despite diagnostic/ pharmaceutical interventions. To this end, I wondered how 'psychologically supported' residents are as 'persons' rather than dementia patients? I wondered how adequately the 'up beat-ness' impacted upon the underlying anxieties. Part of the human experience, is the ability to experience, and the capacity to express, the whole sphere of human emotions , not just the selected 'nice ones'. Its OK to cry, its OK to express, all manner of emotion as part of well-being- its not 'wrong'—its 'how it is'-- it helps process grief and the realisation/acceptance of a given 'life position'.

Likewise, its ok to not always—'look perfect'.
One resident expressed a frustration 'I do my bed, but they re-do it. I let them, but its not how I like it"

The hair dressing team , who offered their services to residents were polite and courteous. However there felt a 'social pressure' within the community—and I questioned the ethical stance of a 'captive market'------ could residents really say 'No Thank You' ? Especially when the 'treat' had been paid for by relatives?—I noticed one resident did—but she had to repeat her refusal, which I saw as a courage, maybe not all would have had !

The physical appearance of residents felt important to portray a level of care through visual image. One resident was found to have a broken nail, by relatives. It became a point of concern that demonstrated or even dared to hint at questioning levels of care. Whilst the resident paid no attention to the broken fingernail, it felt that the staff were under pressure to address it immediately- which gave the relatives priority power over the wants or desires of the resident.
I became aware of the stressful position of the staff, and home manager- to deliver ethically based care that was acceptable and appropriate for both residents and their relatives.

Eating and mealtimes

Score: 4/5

Describe your own experience of the meals and eating. Please consider things like:

The comfort and atmosphere at the mealtime(s) you participated in, the quality and quantity of food offered and the way it was presented, whether residents got choice about their food and could they serve themselves, how staff supported people during the mealtime, whether people could choose when and where to eat, whether people could help themselves to drinks and snacks whenever they wished? Whether there was a variety and were they visible to residents and the comfort and atmosphere at the mealtime(s) you participated in.

The communal are for eating was experienced as open and spacious.
The food was plentiful, served hot and nicely presented. The dining table was decorated with small vases of flowers which were appreciated by the residents.

One resident clearly had been used to having bread with her soup at home and commented 'there's no bread' - the response of relatives was 'no-one has bread' - but the staff went to the trouble of fetching her a slice of bread.

At a time of high demand upon the staff, it felt like the presence of relatives, added greatly. However the staff exampled their flexibility and professionalism and managed admirably.

They catered for the individual needs of the residents above and beyond the obvious. Their diligence and aptitude to endeavour to 'give' all that they possibly could, was heart warming to experience.
Their knowledge of, and bond with each resident verified the very genuine relationships that had been established. The trust which the residents showed in the staff, equally showed quality relationship experiences.

Quality of Life

Score: 4/5

Describe your own experience of quality of life for residents. Please consider things like:

The general appearance of residents (clothes, hair, teeth, glasses), whether people's personal appearance choices and preferences were supported (eg men wearing their tie, women wearing makeup or jewellery), whether call bells were intrusive? Were they answered in good time, whether significant events and anniversaries were observed, whether the staff know the residents (their interests, preferences, life histories, family) and whether people were enjoying themselves in the home? Was there an atmosphere of calm, laughter, fun?

A care home, in its very nature, is providing an 'alternative environment'—and cannot be 'the physical home' from whence a resident came. Its efforts at providing the very safety and security within and for communal living, demonstratively shout out the 'difference'. Fire practice began a stark reminder of the 'institutional life' as bells rang and doors slammed. Key coded zones accepted or denied access and 'uniformed staff' made the 'them and us' divisions. The constancy of audible 'alert calls', bleeping and flashing through the environment and the visible bulk of the drugs trolleys trundling along, medicalised the establishment.

In order to promote a 'nice, up beat environment'—modern day 'values' such as wide screen TV,s and music appear to dominate many spaces. My subjective experience detected these 'noises' tended to impede upon the instigation of conversation or interpersonal communication or add to the 'confusion' with those already struggling with 'hearing'. I noted, that if a 'gap' or some quietness occurred---- inter resident connections occurred. Although they were tentatively offered or minimal, these opportunities allowed for a sense of own identity and self worth to be experienced and brought some residents together . I noticed how residents supported each other, in sharing biscuits, eye contact with silent acknowledgements- to empathic understanding. Inter resident connections felt really valid for recognition of self and others in the shared environment which served to de-isolate and establish the 'new family' as OK. These interactions appeared to reach somewhere very different and more substantially than the 'daily sparkle' leaflet as a 'given construct' to induce a smile! A sense of unity, amongst even the most distressing of circumstances, can be a great comfort. A sense of unity can promote a sense of purposeful belonging and give point and purpose. This can help with a degree of meaning reconstruction and help toward experiencing some fulfilment and healing.