

Letters for the next issue of S&S should be sent to the Editors by 21st January 2012 - Eds.

Dear Self and Society

Time bomb ticking

Media attention has once more turned to the old – their care in hospitals, their care in nursing homes. It's not a pretty picture, and one that bodes ill for the impending boomer generation. How are we going to cope as individuals, as generations, as a society?

A while ago we began writing an article from our personal perspectives to discuss care home provision. We hoped to raise awareness and open a space for sharing readers' experience, both personal and professional. Perhaps AHP might collaborate with movements that support and encourage humanistic approaches to a societal blind spot that is fast threatening to become a crash scene.

Since our original article, hospital care and nursing home scandals have hit the headlines, and the Dilnot report has appeared. So we are starting again.

The issue is urgent.

The Dilnot Commission recommendations, which included capping individual contributions to funding care and an approach to sharing costs between the individual and the state, received a warm welcome from the Care sector. This is the money bit and as the King's Fund concludes, "With the number of over 85s set to double over the next 20 years, the question is not whether we can afford the Dilnot proposals but how can we afford not to."

As we are all too aware, finances are not the whole story. Treating people on an individual basis is more than giving them an individual budget.

Commenting on the Demos Report on personalization that they funded, the Sue Ryder charity came to many of the same conclusions we had reached through our own experience and that of people we know. Steve Jenkin, Director of Health and Social Care at Sue Ryder, said:

“We need a true democratic revolution across the nation’s care homes, building on great work being done in some quarters and ensuring decisions are made by residents, for residents. Personalisation is about more than giving people the purse strings. It’s about recognising all of the areas where we can pass control back to care users, and ensure they are given back their independence, autonomy, and quality of life”

This conclusion matches the personal solution that one of us has drafted for herself:

Grow Your own care system whilst you are still active enough to do so:

She has worked as part of a group of friends on developing a specification for what they would want from a care home. This would be a ‘one stop shop’ from assisted living through to a nursing home, with like minded people, spa facilities and a restaurant and bar. The next stage of implementing this is much more difficult, and for the present the group decided that they are too young to do so. This delay may later prove to have been a mistake.

Not many people have the luxury of finding themselves amongst like-minded folk once in a care home, and individuals are required to “fit in”. But as the writer of the Demos report says, *“we must never lose sight of the individual, which is the danger of letting systems take over.”*

“Personalised care” needs to be both individual and person-centred. This is what the author of the demos report calls the “personal touch”, and she finds the critical factor is a staff culture that supports this approach. Training should ensure that staff have “the right enabling and empowering attitude”

Turn around current provision in the care home:

One of us has personally experienced that there much to be done in this area. Luckily she was available for her mother as an almost ever-present advocate, both during an almost six-month hospital stay and the ensuing first year in a nursing home. Without this constant advocacy the outcome for her mother may have been a very sorry one, as it seems to be for many people already and threatens to be for countless others. In this case the solution turned out to be simple and time-intensive.

After the hospital stay her mother again became ill and frail shortly on moving into the nursing home, and the author spent several hours with her every day. There were several “events” resulting from inadequate or inappropriate care, some serious, which needed addressing. Yet this home had a top rating.

Over time the author observed that some of the problems arose from carers’ lack of awareness (due to lack of training, not hard-heartedness) and over-work. Some seemed to have low self-esteem and grappled with cross-cultural and language issues.

On a management level many problems arose from chronic short-staffing and lack of communication between reporting levels.

The author tried two simple approaches – on the one hand wanting to learn more about the carers as individuals and on the other to give them more detailed information about her mother as an individual. Informal chats with each carer revealed much about their own background (at least 12 different nationalities were represented by the eighteen or so carers in the unit), how they felt about their work and about the people in their care. Relationships developed with individual carers. She was also able to provide detailed information about her mother, not only biographical but also behavioural minutiae such as the way she would never complain but responded non-verbally to pain with slight changes in facial expression. This somehow resourced the carers to respond with more awareness to minimal cues and develop a more intimate relationship with her mother. Over time the quality of care improved dramatically. What for some had been detachment and just a job became in many cases commitment and a real relationship. Simply by talking, sharing and caring about carers who themselves sometimes had come from very difficult life situations, a vicious circle turned into a largely virtuous one. Resources used were time, attention, caring. People stuff. So things are still not perfect - management issues remain, and training and staff levels still need far more attention.

Next Steps

There are some excellent projects around to help people working in care homes to better see their cared for clients as real individuals. There is no space here to enumerate those or give our ideas – and anyway, we want to hear from you.

Let's share through 'Self and Society' our further ideas on these matters, and explore together how we can contribute to tackling these issues. We know that many of you have extensive experience of these areas, and we would love to hear from you. Who knows, we may also come up with some solutions for ourselves, our families and society.

Warm wishes

Marolyn Burgess and Alexandra Chalfont

See the King's fund briefing on the Dilnot report at: http://www.kingsfund.org.uk/events/past_events_catch_up/beyond_dilnot.html

Sue Ryder charity comments on the Demos Report: http://www.sueryder.org/news.php/606/sue_ryder_and_demos_call_for_democratic_revolution_in_care_homes

The Demos report can be downloaded at: http://www.sueryder.org/data/files/publications/Tailor_made_-_web.pdf