CARE BEYOND WALLS

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Damn them they outvoted me

How are we to grow old? This might be another way of thinking about what we should be doing today to support older people in society.

If we ask ourselves that question, I don't suppose that any one of us would answer "in an old people's home". Institutional care is not the choice we would make for ourselves. So how has it come to be the service we have designed for our elders when they need care?

The specialists among us in packaging efficient care regimes will no doubt tell us that it is the only way to deliver care cost effectively.

My own view is much more sceptical. I think that Nathaniel Lee, a 17th century playwright may well have been nearer the truth when he protested against his consignment to Bethlam, "They called me mad, I called them mad, and damn them, they outvoted me." [1] Just as Nathaniel Lee felt powerless to influence his own fate, so older people today believe it is forces beyond their control that place them in residential and nursing homes.

In its evidence to the Royal Commission on Long Term Care Help the Aged presented research that drew on the perceptions and aspirations of 'ordinary people'. It confirmed that people have a strong preference for remaining in their own homes. It went on to say: "The option of residential or nursing home care was viewed very much as the choice of last resort, and participants criticised situations where people were 'pushed into nursing homes too soon'. It was believed this happened because of the inadequate development of alternative services which could support people in their own homes, and the perverse incentives whereby it is cheaper for local authorities to admit people to residential care than to provide intensive packages of domiciliary care and personal support."[2]

From the Isle of Wight to Ikea

However, things are changing. Two demographic changes and a cultural shift in the older age group will alter the balance of power.

The demographic changes are rising longevity and falling birth rates, which year on year will shift the population distribution closer to an average age of 50 in most developed countries.[3],[4]. This new found power will not only be in the numbers of older people, who will, of course, have politicians courting their votes. It will also be in their purchasing power and their youthful attitude to living. Many will move into retirement with index linked pensions and they will be well accustomed to maintaining their lifestyle by buying what they want, when they want it.[5]

Today's silver haired people grew out of the baby boom era that shaped the youth culture of the 60s and 70s. It is the generation that slipped effortlessly from the pop culture of festivals in

Hyde Park and the Isle of Wight to consumer culture in the aisles of Tesco and Ikea. It is a generation that has floated through life in a self-indulgent way that will become the silver boom generation of the first few decades of this century. When it creates the silver culture as its lifestyle for the next three decades it will not accept the implied self-denial of an old folk's home.

The fact is we are talking about planning the services that will support us in our old age. Being a self-indulgent lot, what other motivation do we need to create new patterns of care for the 21st century that reflect our self-image? The chain event approach to services of the latter part of the last century which moved people from their own home into sheltered housing, then into a residential home, and then into a nursing home or augmented care and possibly on to a continuing care ward in a geriatric hospital, have no place in supporting the lifestyle of tomorrow's silver generation.

Steam powered or solar powered care

We know that people living in institutions and those living in their own homes can have broadly similar levels of disability. We know, also, that when people are moved from their own home to an institution their rate of dependency increases and their physical and mental health declines faster than before. Why do we continue to put such faith in the services that no one would want for himself or herself?

Pete Ritchie, of the Scottish Human Services Trust, has likened the institutional care services to steam powered services. But he describes the services we need in the future as solar powered.[6] He describes solar powered services as person-centred, reliable, liberating, grounded in the real world, with a light touch that is responsive to the people they serve. These services manage to be ordinary by making use of smart circuitry buried inside, with back-up safety systems, feedback loops that enhance effectiveness, repair and renewal mechanisms and infrared connections to the wider community. They have the gift of helping ordinary people achieve extraordinary results.

By contrast steam-powered services are regimented, disempowering, stigmatising and immune to the wishes and aspirations of the people they serve. Somewhere between the two we have electrical services. These have been starting up everywhere in the name of care in the community. They are plugged into a service grid, facing the community but firmly rooted in service dogma and while outwardly homely they succeed in being no-one's home.

Steam powered and electrical services are both part of the legacy of the last century. They are easy to manage and easy to cost with a 'one size fits all' power pack to deliver the energy to the appliances and staff that make up the service. Pete Ritchie argues that to run individualised, person-centred services you need to manage things that you can't control, work with fuzzy boundaries, and keep on the edge of the possible.

Digital futures

In the last decade we have witnessed the revolution that the microchip and digital technology have brought to the work environment but so far our home environment has remained immune.[7] For example, our cars have more built-in new technology than our homes.

When we go out to our car we unlock all the doors with one press of a button. We get in and if we want fresh air we open the windows and the sunroof by pressing a button. As we drive along the road the radio automatically switches channel from the music we have been listening to, to warn us of road congestion in the vicinity. With an in-car navigation system our position will have been tracked by GPS and we will be given an alternative route that our routemaster

advises us to follow. The same in-car diagnostics that tell us when a light bulb is not functioning will also let us know when we need to take the car for a service or warn us if the brakes need adjustment (and no doubt a booking will be made by the mobile phone e-commerce services). If our mobile rings during a journey we do not need to stretch a hand out to receive the call, we can just tell our hands free phone to connect us to the caller and we can talk to them as if they were sitting in the passenger seat next to us.

We call at the services to fill up with fuel and we are greeted by a remotely controlled petrol pump that asks whether we would like to pay at the pump or the kiosk. We might at first look at it in confusion, which buttons do we press and how do we pay? Never worry the assistant has spotted us on the video (and by the way the video has also noted our registration number for security purposes) and she speaks to us to explain the system and guides us step by step through filling up and paying. Having bought our petrol we move off to the shops. As we approach the doors they open automatically and when we go to the toilets the lights also increase in intensity. Even washing our hands becomes a new experience since the taps seem to recognise our presence and a warm stream of water flows out at just the right temperature.

All of these things can be translated to provide control and communication for us in our homes. And much more is possible with the technology available today. However, there are also more tailor made solutions being developed too for older people and disabled people. Devices that detect falls and track the pattern of activity around the home can create alerts to summon assistance. Other risks such as the bath overflowing, the pot boiling over and a gas leak can all be identified and safety measures can be put in train. Even physiological measurements that we often think as being the preserve of the doctor's surgery or the hospital are also going to be available in our homes. We might even, if one Japanese company has anything to do with it, have a robot pet that greets us with a good morning, asks us how we are today and reminds us to take our drugs and put our coat on when we go to leave the house.

Working with the grain

The Royal Commission on Long Term Care, in recognising the role new technology can have helping people run their everyday lives, said "Getting such products to market will help shape the future".[8] Does this mean that George Orwell's 1984 has arrived, sanctioned by a Royal Commission? I don't believe it will be like that.

First, we need to go for the solar powered person-centred services with their feedback loops that encourage the older person and all who are close to them to question practices as they develop. Second, we need to ensure that new technologies are developed on principles of inclusive design. Third, we need to create an ethical culture within which the new technologies act as aids that help us gain control and autonomy in our lives. In creating this ethical culture we may well come to regard the person with dementia as helping us set the most rigorous standard.[9]

Some will no doubt say that technology might be all right for a person with physical disability but how can it help us if we get dementia? Technologies such as memory joggers and hazard alerts will be of use and in my view every small assistance that we can provide to help people remain in the familiar environment of their home is worth pursuing. By contrast, when we move people with dementia into institutional accommodation we remove them from all that that is familiar – all the physical things, the emotional connections and the people in their life.

But although technology will help, what matters most is the way we support people with human care services. In our services for people with dementia at Edinvar we used an approach called Gentlecare. This can be likened to working with the grain. Moyra Jones, in introducing her

book on the technique, explains how her father had been a keen gardener and when he got dementia he started to dig up the garden he had loved. Rather than stopping him from doing this Ms Jones would reinstate the garden after these digging sprees so that he could repeat the pleasure he so obviously experienced from digging the garden again and again. In her words "Gentlecare advocates using existing skills and abilities to create satisfying experiences".[10] Similarly, I recall a woman at Edinvar who used to get so much pleasure from ironing that staff would bring in their own washing for her to do!

How are architects to design?

If information and communication technologies are to provide the nervous system that supports person-centred patterns of care, how will it affect the architecture of our homes? When I first became involved in studying the potential of new technology as an aid to independent living in the early 1990s, I believed we would need a new infrastructure similar to those that distribute electricity and running water around the house.

I have now changed my mind because there is an alternative. And that is the mobile telephony and wireless revolution which is gathering such pace that it will make cabling unnecessary for transmitting even large amounts of data within very few years, if not months. In Europe, we are about to be swept by the craze for Internet capable mobile phones. These phones will have huge data transfer capabilities and will soon be installed with another technology called Bluetooth that will connect appliances without the need for cables. It is said to have the potential to create the "truly networked house full of gadgets talking to one another".[11]

Does care beyond walls need architecture?

Will architecture need to adapt to join this brave new world of technology in support of care? In my scenario architects will not be sought to build more monuments to institutional care and the infrastructure requirements of services connected by wireless technology is unlikely to place high demands on the fabric of the building. However, I do believe the role of architecture is important. And the most important part of the role remains what it always should have been – the adoption of the principles of universal design. Regrettably, the profession seems to have had a blindspot when it comes to viewing design for all as an important design objective. The result has been to add further to the exclusion older people and disabled people in society experience.

Inclusive design is the first of three areas that I commend to architects. The second is to look at how we design the components of our homes so we can ease the path for the introduction of new technologies. For example, if we are to have electrically operated windows and doors, are they best operated by a mechanism that swings them to and fro or one that slides them from side to side or up and down? The third is the need to adopt a different approach to the manufacturing process. Can we really expect to produce high quality, high tolerance, high technology homes if we piece them together brick by brick and cable by cable on a windswept field, lashed by rain and bathed in gloom for much of the year? The Rethinking Construction agenda put forward by Sir John Egan's Task Force that commends more off site production techniques will be the third important area for architects to get to grips with.

But universal design is the key design feature for care beyond walls. The architectural profession needs to embrace barrier free environments that are welcoming to people with the widest range of abilities. Last year level thresholds, wider doors and conveniently placed power sockets and switches became a requirement in new homes in England and Wales. We anticipate following suit soon in Scotland. But this only places a toe into the water of universal design.

Our attention to design for all compares unfavourably with Japan where they are already wading up to their knees in creating ageless design. This is a country that has embraced design for all, or "Kyoyohin" as they call it, as the bedrock to the design of housing and appliances and fittings for the home. At government and industry level Kyohohin is regarded as a central plank in the policies that are needed to provide care for an increasing population of older people. We need similarly to embrace inclusive design in our design of the living environment in this country.

At Edinvar, we produced a design guide that we called 'Every House You'll Ever Need'.[12] In it we suggested that to lower the barriers, design should meet the requirements of four groups of people: those who have problems with mobility and reach, those who have sensory impairment, those who have manipulation limitations, and those who have disorientation difficulties. We need a better understanding of what good design can do to lower barriers for each group and there is a lack of research and development work. One interesting recent demonstrator project that is seeking ways to make an ordinary Council flat dementia friendly has been developed as part of Glasgow 1999 UK City of Architecture & Design.[13]

So how are we to grow old?

Of course, some 70% of us will remain reasonably fit and healthy until just before we die. But three out of 10 of us will experience failing health and fitness over time and require help to do even the most ordinary activities of daily living. We will get the assistance we need in our own homes. The housing environment will be responsive to our changing needs, assisted by new technologies that will provide us with control and communication beyond our wildest imaginings.

But whether we create true independent living or merely exchange the walls of Victorian institutions for the webs of virtual institutions will depend on what we do now to put in place a new paradigm of care. In this new paradigm we will place the individual older person at the centre of a care plan that draws its structural strength from families, friends, community, and services from near and from far, brought to us by new technologies and personal carers.

This new approach will require us to join up services in more ingenious ways than ever before. Architecture's role will be to replace its passion for designing monuments to institutional care by a new passion for the fine grain architecture of inclusive environments. In this way it will discover its role as an important design pillar of the new paradigm of person-centred care.

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