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Committed To The Asylum? The Long Term Care of Older People

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About the author

Malcolm Johnson has been Professor of Health and Social Policy at the University of Bristol since 1995. He is now Director of the new International Institute on Health and Ageing, having also served as Director of the School for Policy Studies. For twelve years before that he was Professor and Dean of the School of Health and Social Welfare at the Open University. He has also taught at the Universities of Leeds and London and been joint Head of an advisory body to the government – The Personal Social Services Council.

His research interests spread across the fields of health, social care and policy analysis. Of his more than one hundred and thirty publications, including six books, over half concern ageing, the lifespan and old age. A former Secretary of the British Society of Gerontology, Professor Johnson was the founding Editor (1981–1993) of the international journal *Ageing and Society*. His current research interests focus on regulation and assessment in long term care and end of life experiences in institutions, changing patterns of work and retirement and on inter-enerational equity.

Professor Johnson's research on long term care goes back over twenty years. He is a principal author of *Home Life* and has monitored changes in the sector over the intervening period. His advocacy of the Single Registered Care Home, a single assessment tool, a national regulation framework across all of long term care and greater attention to the quality of management are well known. His latest book is *Managers in Long Term Care: Their Quality and Qualities*.

Foreword

Professor Malcolm Johnson delivered the second Leveson lecture on 24 April 2002 at the Leveson Centre for Ageing, Spirituality and Social Policy at Temple Balsall. His lecture is an important contribution to the debate on the future for long term care of older people. He responds to the attack on the institutional care of frail and vulnerable older people and the prevalent view that we can, and should, get rid of care homes. He argues that the case for abandoning institutional care is poorly thought out and against the evidence. He suggests that we need to rediscover care homes as places of asylum for older people worn down by 'the heroic maintenance of a private dwelling into which invading helpers are present for perhaps four or five hours out of the 24 hours of each day'. He points to the origins of our care system in the Church's provision of sanctuary, love and spiritual support which the Foundation of Lady Katherine Leveson aims to provide in its sheltered housing and residential care and recognises that the needs of a growing constituency of very old people, many suffering from dementia, can often only be met by collective living. He concludes with a plea that we 'reconstruct our thinking about institutions and put them back in the valued spectrum of human living arrangements'.

As well as publishing the text of the lecture in full we have included a response by Professor Roger Clough who was present at the lecture and adds his perspective to the continuing debate which we hope to encourage at the Leveson Centre and through our Newsletter.

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The Long Term Care of Older People

Introduction

Old age and spirituality are frequent companions in the stories of past times. Solomon, Simeon and Abraham spring to mind as biblical examples of old men who were respected for their wisdom. The strongest theme in the writings of Confucius 2,500 years ago was that of filial piety – respect for the old. Christian, Jewish and Muslim traditions all embody their own versions of filial piety. The common notion is that those who survived to be old (as only a few did) were skilled survivors whose knowledge of life was to be valued and nurtured. In their celebration of old age these narratives praise the old and invoke moral obligations to support and care for them. But it was always the responsibility of the family. And the older people were meant to be calm, grateful pools of spirituality and good will.

Cicero, the Roman statesman and philosopher, in his essays *On Old Age and on Friendship* presented his thinking as a dialogue with the great Roman, Cato, to whom he writes:

> I have expressed admiration, Cato, at your eminently correct philosophical attitude towards life's problems, but perhaps most of all because I could see that old age was never a burden to you. To most men, you know, it is so distasteful that they swear they carry a load greater than Mount Etna. (Cicero 1967)

Cicero chose to celebrate the ideal of old age whilst recognising that for many it is a trial and for some an unbearable misery. (Cicero never saw old age. His wisdom let him down when he challenged the warrior Anthony, who chopped off his hands and his head.)

In the 21st century we still rely on the family to provide for the old who lose their independence. But long gone is the correlation with wisdom and status. In its place is a new respect for those who breach the conventions: hang-gliding grannies, growing old disgracefully and following the famous words of Jenny Joseph's poem 'When I Grow Old I Will Wear Purple'. This combines with a dread of old age as disability, disintegration and dependency. Cicero saw it and wanted to avoid it. So do we. Our society is still coming to terms with its demographic inheritance. We retain the biblical rhetoric but have progressively lost the willingness and the ability to provide well for the oldest old.

So my lecture will take this ambiguity as its subject. Can we again become committed to providing whole person, loving care of the kind provided by religious communities for the indigent and old? Or are we destined to provide sanitised versions of the dehumanising institutions of Victorian Britain which

brought the wonderful word asylum (which means 'sanctuary', 'place of refuge and safety', 'institution for shelter and support') into such utter disrepute.

Origins Of Old Age Care

The care and support of older people in the developed world has always been a tension between lofty religious ideals and a desire to punish those who grow to be old, weak and poor. The Judaeo-Christian tradition and theology of respect for age and wisdom, faithfully carried out, is one honourable dimension of our collective past. But so too is the often inhuman treatment meted out to the aged poor down the generations. The patterns of health, social care and social security at the beginning of the third millennium reflect this ambiguity, giving rise to serious questions about ethics, services and resources.

Christian teachings about the importance of elders within the family have been the enduring foundation of European society. There is good evidence of loving care for the old within the family setting. Yet the historical stereotype of multi-generational families living in harmony in the same dwelling is not one supported by historians. It was one pattern within a spectrum. Those with wealth and surplus accommodation found it easiest to meet the family living ideal. The poor, the majority of the population throughout recorded history, were hard pressed to supply the needs of those who could no longer be productive and did the best they could. But the determining factor has almost always been resources.

To meet the needs of those who were left destitute, two agencies offered support of a minimal kind – the Church and the local community, two moral entities, linked by a shared Christian ethic but with differing motivations. The Church offered asylum to the frail and the sick. The community offered the lowest level of survival, with regimes established as a deterrent. Throughout the last millennium fear of becoming an elderly pauper permeated the lives of those among the labouring classes who survived into late adulthood. Failure to be able to support yourself or to have the support of kin was seen as a sign of social incompetence and failure in the sight of God and men. It was to be punished, if also to be pitied.

During the second half of the twentieth century these philosophies of personal responsibility for poverty and illness were replaced in western Europe by the welfare concept, which addressed need rather than causation. The welfare state was as much an ethical as a political revolution. Yet now, fifty years later in the midst of great prosperity, the demographic explosion has provoked governments into re-appraising those principles under the pressure of mounting costs.

The Historical Context

It is never wise when examining any aspect of social or medical services to ignore history. It would be particularly unwise in the case of long term care for

elderly people. Over the past decade significant changes have taken place which have shifted the balance from public to private and voluntary services. Yet the essential mixture is recognisably one which we have inherited from the Poor Law established by Queen Elizabeth I in 1601 and refashioned during the so-called industrial revolution in the Poor Law (Amendment) Act of 1834.

Both pieces of legislation contained elements which are prominent in current policy and practice. They were promulgated out of recognition of the needs of the aged poor who had no viable means of support. Maintenance of life had to be provided for those who could not sustain it for themselves. At the same time there were strict limits to the generosity of this contribution to personal welfare. The motives of the parliamentary drafter were control of both the behaviour of elderly paupers and the financial burden they put on the rest of the population. Therefore access to parish support either in the workhouse or in the 'out-relief', which the Victorian legislation brought, was provided only at great cost to personal dignity and with virtual loss of citizenship. Once 'on the parish' there was little prospect of independent living. Personal freedom was forfeit.

In *The Last Refuge*, a landmark study of old age institutions, Townsend (1962) showed that those most likely to end up in them were the widowed, the never married, and those without family. Searching through the historical evidence of occupancy patterns a century earlier, Thomson (1980; 1983) confirms that this is an enduring pattern. Very few elderly couples were ever admitted because the policy has always been to maintain them in their own homes by providing outdoor relief (a regular payment to some one living outside a Poor Law institution) of a few shillings a week. He also shows that the proportion of elderly people in England living in institutions in 1870 was the same as it was in 1970 – between 4 and 5% of the population over 65.

The development of historical demography at the Cambridge Group for the History of Population and Social Structure has totally reconstructed our notion of old age in times past. As Laslett points out, abandonment of elderly people by their families 'is false because research on the family relationship of the elderly shows it to be so today, and because historical work fails to show that familial support has declined over time' (Laslett 1984). From the work of the Cambridge Group we learn that pension payments ' … in the late twentieth century are of no greater relative value than earlier twentieth century ones and rather less value than mid-nineteenth century ones … ' (Thomson 1984). Further, it has been found that in the late nineteenth century, elderly residents in multigenerational households were more likely to be giving care than receiving it (Robin 1984). Such evidence is broadly corroborated by Stearns' work in France, which portrays attitudes toward the old as having gone through a 'golden age of age' which falsely idealised their role in earlier centuries (Stearns 1976).

It is not our purpose to dwell on history, but it is instructive to start with it, for it is the ideas of the past and the human constructions they led to which have

shaped British long term care. The Elizabethan Poor Law of 1601 established a framework which has had durable if curious consequences for current policy and practice. It laid responsibility for the relief of elderly people on their children. Only when this system of support failed or proved non-existent did responsibility fall on the local community in the form of the parish. Once an individual made claim on the parish, he or she could only be an inmate of a poor-house, where a regime of shamed subsistence was the normal if not exclusive pattern.

Because of the rapid urbanisation occurring from the mid-eighteenth century onward, the twin forces of population growth and geographic mobility placed unmanageable strains on the parish system and its institutional provision. The able-bodied poor were increasingly allowed to remain outside the poor-house, existing on the meagre financial support provided under the 1834 Poor Law (Amendment) Act. Here were the origins of our social security system. But for that seemingly irreducible minimum of the old with no means of support (it has remained around 4 per cent for the over-65 population for as long as records exist), the institution was their fate. For a small minority, group living was provided by the Church and, as the nineteenth century progressed, by a growing array of voluntary societies, which stemmed from Victorian middle-class benevolence. They co-existed with another longer-lived ecclesiastically provided institution, the alms-house. Small cottages, usually with one bedroom, were built in a terrace near a church or Christian community which supplied simple but good housing for the infirm but 'deserving' elderly, who received regular aid from clergy and parishioners.

In these early arrangements we can see the origins of state-provided long term care, the voluntary (non-profit) sector of residential and nursing homes and of sheltered housing. When local authorities took over responsibility for elderly people by the enactment of the 1948 National Assistance Act, the Poor Law was terminated. In Part III of the Act local government was required to provide 'old people's homes'. The inherited stock was made up of large, overcrowded, badly maintained, dehumanising institutions. Townsend (1962) described them with graphic precision and compounded the effect with data from a massive national survey of 800 homes. His work closely followed Goffman's *Asylums* (1961). This seminal work gained currency far beyond the sociological community. It became a benchmark which rejected all collective living as bad. It set up a strong reaction against institutional care in all its forms. In Britain the disaffection was further fuelled by the publication of *Sans Everything* (Robb 1967) in which a group of doctors and nurses wrote of their revulsion at the treatment meted out to elderly patients in long stay care.

Townsend's descriptions provide their own testimony:

> The first impression was grim and sombre. A high wall surrounded some tall Victorian buildings, and the entrance lay under a forbidding arch with a porter's lodge at one side. The asphalt yards were broken up by a few beds of flowers but there was no garden worthy of the name. Several hundred residents were housed in large rooms on three floors.

> Dormitories were overcrowded, with ten or twenty iron-framed beds close together, no floor covering and little furniture other than ramshackle lockers. The day-rooms were bleak and uninviting. In one of them sat forty men in high-backed Windsor chairs, staring straight ahead or down at the floor. They seemed oblivious of what was going on around them. The sun was shining outside but no one was looking that way. (page 4)

> The women seemed to be more resilient and less depressed than the men, despite their greater age. A number sat and joked outside on a bench. In the day-rooms a few were knitting or exchanging conversation. They too were wearing rather shapeless clothes supplied by the local council. Flowered aprons, dresses buttoning down the front and carpet slippers seemed to be the rule. (page 5)

Anti-Institutionalism

Erving Goffman's studies (1961) were published in America a year before Townsend's. He focused on very large psychiatric hospitals, but generalised his interpretations to provide an analysis of all 'total institutions' which by his definition are 'places of residence … where a large number of like situated individuals, cut off from the wider society for an appreciable period of time, together lead an enclosed, formally administered round of life.' His detailed scrutiny of the physical and social patterns which exist in such places produced a searing critique of all long term care establishments. He described a total institution as 'a natural experiment on what can be done to the self' where 'inmates' suffer 'forced deference patterns' to staff and where staff invade personal space by the use of over familiar names and through their access to the most private parts of their bodies.

Goffman's systematic exposure of the social world of institutions was so powerful that it became a cult book. For over a decade its messages became the received wisdom. In the case of old people's homes and nursing homes – though they were not included in his studies – the ready availability of corroborating evidence from empirical studies sustained the unremittingly negative view.

Despite evident improvements in the physical characteristics of homes and increased training for staff, from the 1970s onwards long term care received a continuously bad press. Commercial exploitation and fraud in the United States produced broadsides of criticism from the likes of Mary Adelaide Mendelson. In her book *Tender Loving Greed* (1974) she wrote:

> I began to see the evidence of collusion among nursing home operators, doctors, caseworkers and others in schemes to procure maximum reimbursement for patients needing only minimal care.

And Timothy Diamond, as late as 1992, was able to write from his participant observation study of a Californian nursing home:

> Every day and night, the care takers try to build a rest home. But each day the factory-like schedule starts up the production of patients and tasks and timed and measured units of service at the crack of dawn. (page 243)

Sadly Diamond's comments precisely reflect the observations of Tim Booth in his 1985 study of English local authority old people's homes. He concludes:

> Sociologically, the differences of regimes must, in the light of this study, be seen as a veneer that decorates the massive uniformity of institutional life. Underneath lies the same crushing panoply of controls over the lives and doings of residents. Changing the wrapper does not change the contents. (page 206)

Perhaps the lone voice in the 1980s arguing for the role of care homes was Roger Clough (1981). Whilst his own detailed accounts of care home life provided for the confirmation of poor standards, he fell short of supporting wholesale condemnation. He writes:

> It may well be that, with family around and strong neighbourhood ties, a residential home seems abhorrent; is it so abhorrent when one is old and lonely with many friends already dead? (page 13)

His call for better staff training and more rights for residents was largely lost at the time, and has only slowly entered the public agenda.

Anti-institutionalism from the 1960s onwards eventually provided part of the basis for legitimising community care policies. Yet throughout that decade most of the elderly residents of Part III homes lived in poor-law institutions. Even homes in the voluntary sector were very large and forbidding places. The building of new smaller homes (at first the desired norm was 60 places, falling later to 30 places) began slowly. Local authority homes continued to be the poor neighbour – an inferior service for inferior people (Means and Smith 1985).

Throughout the story of long term care, there is a set of themes which, for most of the time, have been in tension. The Poor Law was a benevolent piece of legislation in conception, but its concern for human welfare was predicated on a mixture of financial economy for the provider and social ignominy for the recipient. Social control and humiliation has characterised much of British public social policy. Yet in its execution there has always been the exercise of private humanitarianism. In the 1945–1975 period this heightened concern for the well-being of the person in need became more prominent and official. Since then what had emerged as a set of rights has been redefined to fit within an economic framework where 'rights' are rationed by 'what the economy can afford'. Bornat *et al* (1985) put it succinctly:

> Elderly people face a special crisis because of the condition facing the construction of social policy in the 1980s. There is a political and ideological attack on the legitimacy of their claim to state support.

Despite the derailing effect of the Goffman/Townsend assault and the consequent public wariness of old people's homes, they have both improved and changed. Following the 1984 Residential Homes Act, the expansion of the private sector and the parallel reduction in local authority provision, the experience of life in a home is markedly better. Single rooms, better equipped, more personal, often en suite facilities and spacious, more inviting communal areas, and decent food have transformed the typical residential and nursing home. Staff are more likely to be trained (though most, still, are not) and the day is more likely to contain activities, hairdressing, therapies and visitors.

Even at a time of indefensible public under-funding of long term care and chronic staff shortages (as we are experiencing now), homes for older people in Britain are in my view – as a close observer for over twenty years – markedly better. The average home provides more privacy, careful treatment, agreeable food and attention to personal needs, than at any time in recorded history. Of course, there are still too many which come too close to Townsend's miserable institutions. And there is still much to be done to improve the quality of life for residents. Yet this is a good moment to reflect on a betterment which is being achieved against all the odds. As we reflect, it soon becomes evident that there has been a seismic change in the population of residents.

Long term care is now rarely about socially dysfunctioning old people who are still capable of active citizenship. The combination of policy alternatives based on the home and public finance has made it a place for the very end of life. Laslett's notion of the procession of the generations is in fact a convoy of cohorts travelling down the path of history but the latest cohort is wearing significantly different biographical and collective clothes.

Those in the late Third Age, who ache for the restitution of a life past and a life often beyond reconstruction, expect to be supported at home largely by a mix of kin and paid strangers. Residents in care homes are now predominantly in the Fourth Age. Between 1985 and 1995 the average age of entry rose by ten years to 81. They are predominantly female, depressed, demented, demobilised by chronic illness and in evident need of maintenance.

Many of the old old have lost any spiritual capability they might have had and find security if not pleasure in the presence of others, old and young, who populate their world of shared living. For them living alone is neither possible nor desirable. They fear the aloneness.

But the prevailing ideology, in its full blown state of anti-institutionalism garnished with postmodern concepts of the centrality of the disconnected self, presumes that the privacy of the personal living cell remains a dominant ideal in all circumstances. Yet the lived experience of people at the far end of life is characterised by a frequently untreatable discontinuity or shrivelling of activity

and manifest disengagement – due not to a conscious social distancing from the socio-economic arrangements of the Parsonian world view, but as a result of serious functional decline.

In such circumstances, the heroic maintenance of a private dwelling into which invading helpers are present for perhaps four or five hours out of the 24 hours of each day (a generous provision by present standards), becomes another kind of punitive existence. People who are non-ambulant and seriously confused find the periods of aloneness frightening and distressing. Their reduced capability has stolen the pleasure of expectation and anticipation of the arrival of human concern and practical help. In its place lives a combination of fitful sleeping and angry distress at the continued absence of people and comfort, food and help with the conduct of bodily functions.

In our societal commitment to Activity Theory – 'use it or lose it' – we subscribe to the myth perpetrated by Milan Kundera in his novel *Slowness* (1996) where he depicts the arrest of the speed of modern life as a great blessing. Yet he fails to see it is only desirable as a respite from the hurly-burly of modern life. Slowness in the Fourth Age is often a burden of 'heavy time' and painful biographical reflection.

Is Secular Society Spiritually Literate?

We live in a society which has experienced a century of decline in participation in organised Christian religion. From a high point in late Victorian Britain, when the overwhelming majority of the population were regular church attenders or at least nominally attached to one Christian denomination or another, only about one in ten today have a demonstrable Church affiliation.

This continuing decline in Christian association has been accompanied by some revival in evangelical sects and the stronger presence of other world religions as the ethnic population grows: Muslims, Hindus, Buddhists, among others.

Nonetheless the secularisation processes heralded by the American Harvey Cox (1965) in the 1960s have largely come true – in our society and across Europe (if less in his). The institutions of British society have moved increasingly away from their traditional Christian roots or attachments. Schools have had to distance themselves from religious teaching, and universities have long left behind their origins in religious foundations. Charities, even those with a religious basis, operate on essentially secular lines, and even re-brand themselves to hide the religious connection. Communications and the press treat organised religion as a relic of the past, and in the daily conduct of family life, work and community activities, there is likely to be no spiritual content.

Secularisation has had two significant negative influences on religious spirituality – but has generated new forms, some of which are of doubtful worth. The

first negative is the sharp decline in religious knowledge: the Bible; its moral precepts; the concept of faith in an omnipotent God; prayer – intercession, confession – redemption, forgiveness. There is a residue of what Towler (1974) called Common Religion, but it is diluted by the poorer grounding in religious principles and practices. Its lack of reference renders it 'tradable' into any moral universe.

The education system which once reflected and reinforced family religious values is no longer capable of 'religious instruction'. Young people graduate from the educational world into adulthood with the sketchiest notion of the Bible – though they may have acquired snatches of other world religions. They know little or nothing of the Bible, hymns, prayers, liturgical practice, theology or religious ritual.

The second negative is the lack of access to the rituals and symbolism of religion, which mark the rites of passage:

Baptism
Confirmation/Confession of belief
Marriage
Funerals
Eucharist/Communion

These are vehicles for engaging with the religious principles of love, obedience, community, and transcendence/otherness, so we are left with a society which espouses a plurality of values and has a large gap in terms of rituals.

There is a growing awareness of the need to create secular rituals and this has led to the recent emergence of new forms:

The Baby Naming Society
Civil Funeral Celebrants
Secular Marriage
Faith in Science/Medicine/Money/Fame

Spirituality

The core meanings of spirituality are religious. They are integral to a pattern of being which acknowledges godliness – power beyond the human, a sense of God as spirit. Christians and believers of other faiths learn the vocabulary and the practices of spirituality in and through their personal and collective lives, a learning which is capable of growing throughout life.

What of secular spirituality?

The argument so far is familiar: our society is losing its religious underpinning and has all too little to replace it with. It is an argument of declining influence and lost heritage. One of the losses is undoubtedly the institutionalised

framework of spirituality. But is this the whole story? There is a burgeoning of 'other spiritualities' both generic and specialised: the Green movement; meditation, yoga, self knowledge; the health and healing movement; the talking therapies; counselling; psychoanalysis; holistic health care and feminism.

But is there secular spirituality?

I hear a distant voice saying this is arrogant Christocentrism, there are other spiritualities, they too are valid. But how do we evaluate the valuable and the 'valid' spirituality? Clearly some, perhaps much, of contemporary spirituality is bogus – some of it harmlessly so but some of it iatrogenic. It is the Carbolic Smoke Ball of the late twentieth century – a potion which claims to cure all ills, but which is no more than a placebo.

Its attractiveness is that you can sample these spiritualities in the way you might try a different breakfast cereal or change your brand of toothpaste. But my test in this context is: Will it sustain you when your mind is deeply troubled?

Biographical Pain at the End of Life

Early in this lecture I referred to Cicero's acknowledgement that for many the later stages of life are problematic and times of suffering. Everyday experience of living or working with older people, particularly those who have lost their independence, reveals that the ones who maintain a positive hold on life are outnumbered by the depressed and the disappointed. For a sub-set of this unhappy group, the sequence of losses they have experienced leads to a state of anguish which steals from them many if not all of the former pleasures of living.

In my own work I have interviewed many older people who have come under this unlifting shadow. These experiences have occurred throughout my professional life, but are currently re-appearing through interviews with older people with severe visual impairment. Here, the most prominent finding is of almost unrelieved isolation combined with a grieving for the losses which come with blindness and infirmity. For a group, which numbers almost one million across the UK, there is a disturbing paucity of services.

Inevitably, many of the most frail and dejected are to be found in residential and nursing homes. Entering reluctantly and distressed by the deprivation of their life's acquisitions and freedoms, such people are deeply unhappy despite the best possible care.

Recent research by Professor Peter Coleman and his colleagues (Coleman *et al* 2001) on the spiritual beliefs of older people showed that those who had strong religious convictions were less likely to be depressed and more likely to be at ease with their personal past and the prospect of death. Moderate believers and those with little or no religious faith revealed low estimates of

personal worth and a proneness to depression. These results, added to the research-based estimates of declining levels of belief in later life, indicate two broad observations. Firstly, religious belief and spiritual capability are positive attributes in dealing with the decrements of old age. Secondly, there are indications of low levels of spirituality – even though today's old people have had a much greater exposure to religious and spiritual experiences.

In seeking a solid platform for a proposition to capture this type of anguished experience I have turned to the analysis of personal biography. The distilled, refined, polished but often flawed and jagged story we fabricate from the recollections of life lived, has been one of the tools I have used in attempting to explain the processes of ageing, for over twenty five years. It was in 1976 that my paper 'That Was Your Life: A biographical approach to later life' was first published, discovering, as did Kierkegaard, that life can only be understood backwards though it must be lived forwards.

Biographical perspectives help to deal with the inevitable challenges about my low estimates of the epidemiology of spirituality, even in contemporary societies which host obsessions with 'discovering one's inner self' and searching for holism in nature, alternative medicine, the 'talking therapies' and the rise of evangelical sects – let alone the largely spurious search for self revelation through drugs.

A painful story

The starting point for me was the now received wisdom, created by leading figures in the hospice movement, that palliative medicine could deal with all kinds of physical pain, but that there was also a neglected dimension of pain which it would label spiritual pain. It grew as a concept from the mixture of motivations and convictions of the pioneers of the modern hospice movement, notably Cicely Saunders. The hospice idea predates St Christopher's Hospice by many centuries, but Dame Cicely's creation of this establishment marks the acknowledged commencement of the 'modern hospice movement' and the serious beginnings of the medical speciality of palliative medicine.

Soon spiritual pain became a portmanteau term to deal with all pain which was not physical or demonstrably psychiatric.

In recognition that many people have little or no spiritual vocabulary, let alone experience of practice, I felt there was need for another category and another descriptor. Aware that the pain I have observed appears to grow in intensity as individuals get closer to death – either because of terminal illness or advanced old age – I created the term Biographical Pain, which is defined as:

> The irremediable anguish which results from profoundly painful recollection of experienced wrongs which can now never be righted.

When finitude or impairment terminates the possibility of cherished self-promises to redress deeply regretted actions.

The presence of serious biographical pain is characterised by the surfacing of deeply buried fractures in the life biographies of individuals who always intended to 'put things right', but have now run out of capability to bring about that resolution. They will no longer be able to apologise, seek or give forgiveness, deliver restitution, deliver a good to balance out a bad or evil act. The opportunity to redress wrongs has passed by and the individual is left with an overwhelming sense of guilt.

It is the very slowness of late life which provides the opportunity for such life reviews to surface. During the busyness of independent living, we are able to submerge our worst worries and fears deep into our inner selves. Sometimes the repository becomes covered over; then the re-surfacing of wiped-out recollections is all the more painful (the giving away of a child born out of wedlock, the cheating of a relative or friend out of their business, the break up of a trusting relationship).

Biographical pain is something we all experience in some degree. Sometimes we can 're-frame' the events and see them in a better light, or provide a personal accounting which balances them out. Those who have religious faith may seek forgiveness through a priest, by prayer or by redemptive good works. But for the many who are spiritually unlearned, the options are less available.

In the case of old people there is need for a spiritual care which embraces biographical pain without claiming it as a religious entity. We need to create new social rituals for this 'putting right' and here is perhaps a task for the Leveson Centre.

When the churches and Christian communities in pre-industrial times provided asylum to those in desperate need, they offered more than food and shelter. Their Christian task was to help mend the broken spirit, through love and service and prayer. In our day this task is still needed and the best old people's homes provide something approximating to it.

Secular society will not welcome a wholly religious formulation for addressing the spiritual needs and the biographical anguish of people coming to the close of their lives. But, as we re-think the care of those who must live in grouped settings, ways of supporting residents with biographical disturbances (for which there are no drugs or potions) should be high on the agenda.

In Conclusion

The essence of my argument is that sociological and gerontological theorising have conspired with the empirically-based rejection of poor 'collective care' to discard institutions as valuable ways of living, for some people.

Collective living arrangements which provide a combination of supported private space with uninhibited access to the assurances provided by shared living can be a premium option. It might be the least worst way of living at the far end of life. It could be optimal – and I know of long term care homes where it is.

So my plea is that we rediscover the beneficence of the asylum. We need institutional living – for some – in the 21st century. We need to reconstruct our thinking about institutions and to put them back in the valued spectrum of human living arrangements.

I hope to have persuaded you that we as individuals and our society need long term care and that we should all be committed to the asylum.

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Response by Professor Roger Clough

Roger Clough is Emeritus Professor of Social Care at Lancaster University. He held the chair from 1994 to 2002 before retiring to concentrate on writing and social reserach. Before that he had been Chief Inspector of Social Services with Cumbria County Council. His career has included extensive experience of residential work and social work teaching. He has written widely on work in residential settings, inspection, and other aspects of social and community care. In 1997 he delivered the Graham Lecture 'Living in someone else's home' which looked at the concept of negotiation, the process of ownership and the role of relationships in homes for older people. Currently he is Research Director for a Community Fund financed project run jointly with Counsel and Care into Housing Decisions in Old Age.

Living with others in old age

Malcolm Johnson presents a powerful case for 'collective living arrangements which provide a combination of supported private space with uninhibited access to the assurances provided by shared living'. I share much of his perspective. I hope that Malcolm, and readers, will forgive my starting this comment with a personal reflection on my own ideas. I am using it as a way of responding to Malcolm's argument.

As recognised in the paper, I have argued through all my work life that residential homes could be good places in which to live and noted that glib simplifications of Goffman's 'institutionalisation' have been taken to mean, mistakenly, that living with others in some form of 'institution' was intrinsically bad. It is also vital to remind ourselves that some of what is disliked about residential living is that in residential homes we are confronted with the indignities of ageing in the UK faced by so many people; such indignities may be as profound (maybe more so) hidden in one's own home as in a residential home. In part these indignities may result from what Malcolm calls 'biographical pain', an insightful term which captures the inability of some people to live with their own past. In part also, the indignities may stem from a sense of purposelessness, created in a society which fails to value ageing.

My personal reflection serves the purpose of reminding me that I have swung from emphasising the potential of residential living to trying to understand the reasons why, in spite of so much change and progress in residential life, most of us still do not want to live in homes. At that point the personal reflection must stop, though recognising that Malcolm has moved, as he would describe it, from being 'a friendly critic of residential homes' to arguing for their importance.

In this scenario lies the kernel of Malcolm's thesis: for numerous reasons related to our own histories – our understanding of being and spirituality, coupled with society's attitudes towards elders and resources dedicated to

them – some people would profit from collective living. He is recognising that most people in some parts of their lives thrive from contact with others, indeed can become whom they want to be through such interaction. Others, or maybe the same people, will want loving assistance in managing their lives – indeed, the best of asylum: sanctuary, peace, acceptance and support.

Living with others in a place designed to provide housing and loving service is living in an institution, using the word institution in the neutral sense of an organisation and its building. Malcolm Johnson's focus demands that we escape from platitudes and from popularised (and distorted) social science to the important questions: that we escape from the 'live at home or in a home' polarisation, with the assumptions that 'at home' is good and 'in a home' an indication of sadness and failure, to considering the ways in which people at different stages may choose to live with others. In particular, he calls for a review of the sorts of living arrangements that best suit numbers of people who want (and may well thrive on) support from others.

I am reminded of a former colleague, Chris Beedell, whose work life centred on promoting the healing of residential life for disturbed children. Before his death last year he had spent periods of time in a hospice. The good experience of hospice life led him to conjecture on what makes institutions work well, or perhaps what makes them good places in which to be. He had an idea that it is 'space for loving kindness' that is the critical element in producing a 'good' institution.

We ought to use Malcolm's paper to extend our search for an understanding of what makes some living arrangements satisfactory (even good) and others awful. We must free ourselves from the policy drives that insist that 'home is best', challenging as we do so the societal attitudes that demand inappropriate, impossible self sufficiency and independence.

The hope is that the challenge of Malcolm Johnson's Leveson Paper could lead to re-consideration of the arrangements for living, not in the sense of demanding more of this or less of that, but of recognising the complexities, indeed the seeming contradictory forces at play:

we want to be ourselves and we want to be for others;

we want to be self-focused and other-focused;

we want to do things for others and, forgetting others, to concentrate on ourselves;

we want help and support, and we want to manage on our own;

we want our own place and we want to share;

we want to live with others around us and we want to be away from the noise of their children and lawn mowers;

we want to live with others and we want to live on our own.

The solutions in social policy terms are not to be found solely in making residential homes a fashionable alternative, nor indeed in my own current favoured notion of clusters of housing with services provided and allowing for different combinations of contact with others. The best answers will be found in allowing, indeed encouraging, different groups of people to develop the solutions that suit them and their communities, whether geographical communities or communities of interest. Such solutions must not be available only for the wealthy and powerful.

Malcolm Johnson asserts the place of religions in praising old age and invoking moral obligations to support and care for older people. He notes too the suggestion that people with strong religious convictions manage old age, and impending death, better than others.

Coming from a strong Methodist background and personal religious involvement, but currently inactive, I am not sure where this cluster of points takes me. I recognise the importance of the tradition of responsibility and caring derived from religious experience. I recognise the strong religious underpinning of the hospice movement, providing for patients and staff who are religious and those who are not. I recognise the description of people's 'biographical pain'.

However, I am uncertain of the link between what I take to be the central argument of the paper, the call for a re-valuation of collective living, and religious faith. The two may be intimately connected in that religious communities may give special consideration to the valuing of elders. But forms of collective living can be considered without religious underpinning. Of course religious people may have a distinct role in spelling out the characteristics and systems for successful living and support, as I think has happened with such marked success with hospices. One of the gifts of religious people could be to construct places with spaces for loving kindness.