

## Standing Commission on Carers

c/o Department of Health  
Area 116, Wellington House  
133-155 Waterloo Road  
London SE1 8UG  
Email [SCOC@dh.gsi.gov.uk](mailto:SCOC@dh.gsi.gov.uk)  
Or [prussell@ncb.org.uk](mailto:prussell@ncb.org.uk)  
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### Response from the Standing Commission on Carers to the Consultation on Delivering Dignity in Care

#### **Introduction to the Standing Commission on Carers**

The Department of Health established the Standing Commission on Carers in December 2007 at the request of the Prime Minister. The Standing Commission is an independent advisory body, providing expert advice to Ministers and the Carers' Strategy Cross-Government Programme Board on progress in delivering the National Carers Strategy (a ten year Strategy published in 2008 and 'refreshed in 2010) and on a broad range of other policy issues relating to carers and support for their roles.

The last Census (2001) reported that there were approximately 6 million carers in Great Britain (around 5.2 million carers in England and Wales and almost 500,000 in Scotland). 58% of carers were women, 42% men. 68% of carers care for up to 19 hours a week, 11% for 11-49 hours and 21% for 50 or more hours. Over-65s account for a third of all those carers providing more than 50 hours a week. 58% of carers are obliged to give up employment because of caring responsibilities, with a corresponding number reporting a range of health problems relating to their caring roles. With changing demography and family structures, there is an increase in the number of families with multi-generational (and sometimes distance) caring roles.

The contribution of carers is vital to the delivery of both health and social care and to the wider economy and the Standing Commission on Carers is concerned that their role and their own health and well being should be fully acknowledged within the current debate.

### **Responding to the the draft report on Dignity in Care**

The Standing Commission on Carers warmly welcomes the opportunity to contribute to the consultation on *Dignity in Care*, recognising the importance of raising aspirations and creating positive opportunities for older citizens (and their families) to lead valued lives in their local communities – whether or not they are living in a family home, care home or NHS care.

We support the recommendations of the *Joint Committee on Human Rights (2012)* that maximum independence should be the goal for all older or disabled people, but note that greater independence will also necessitate more *inter-dependence* with families, carers and services in many cases.

We consider that the recommendations, if implemented, would have a major and positive impact on the quality of life enjoyed by older citizens. However, we see challenges in implementation and we would also like to emphasise the importance of prevention, ie the need to consider why vulnerable older people are admitted to care homes or NHS care and what support might have been available to prevent admission or facilitate a successful discharge back home.

### **Responding to the recommendations.**

We consider that the key recommendations are correct and, if acted upon, would make a significant impact upon the quality of care offered to older people, whether or not they are in hospital, a care home or indeed living in a family home.

However, we have some comments on the implications of the recommendations and the conditions for ensuring that they are acted on.

### **Securing major reductions in hospital admissions by delivering care at home or in the community**

We fully support this proposal but would welcome a greater emphasis on prevention (ie the avoidance of unnecessary or premature admissions or readmissions to residential or NHS settings because the carer or family are unable to cope at home). We note and welcome the emphasis on reablement to support recovery from trauma, stroke or other significant in-patient period of care. However, we are also aware that without support for carers, early transfer from

hospital to home can lead to rapid readmissions. The King's Fund (2012)<sup>1</sup> found lack of continuity of care (ie multiple admissions and discharges, together with shifts between wards in hospital) as a major factor in poor outcomes for patients and a likely factor in admission to long-term care.

The Princess Royal Trust for Carers (2011)<sup>2</sup> found that key factors in care breakdowns and readmissions to hospital or admission to a care home were:

- Breakdown in relationships (feeling isolated and unsupported)
- Poor health, tiredness and interrupted sleep
- High levels of intimate care, particularly double incontinence or invasive personal care
- Frustration and lack of understanding of the treatment or support: key concerns lay in the lack of a key worker, designated care coordinator or 'navigator' to advise, explain and help identify support.

An Australian study (Drose and Rees, 2006)<sup>3</sup> found that 3-5 sessions of personal care training to carers (each lasting around 30-45 minutes) resulted in a higher proportion of stroke patients achieving independence at an earlier stage and reduced the need for physiotherapy and occupational therapy. Importantly the numbers of hospital readmissions were substantially reduced with carers reporting that they now felt 'confident, valued and understood the short, medium and long-term outcomes of the reablement programme and the family's role within it.'

We note that a survey from the Princes Royal Trust for Carers<sup>4</sup> found that 65% of older carers polled said that they had significant health problems or a disability in their own right. Only 50% felt capable of now providing the care their relative really needed (eg lifting, going out, and managing complex medical procedures) without additional support. Their relative was therefore at much greater risk of multiple admissions to NHS care without a coherent and integrated care plan from community and acute NHS services and the local authority.

We also note that the right to a family life is a key right set out within the International Convention on Human Rights. *Delivering Dignity* notes that '*working with families is not always*

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<sup>1</sup> Cornwell, J et al (2012), Continuity of care for older hospital patients: a call for action, Kings Fund, London

<sup>2</sup> PRTC (2011), Supporting Carers, the Case for Change

<sup>3</sup> Droses, R et al (2006), University of Sydney, reported in 2012 SCIE review of research on outcomes in reablement, SCIE

<sup>4</sup> PRTC (2011), Supporting Carers: the Case for Change, Princess Royal Trust for Carers and Cross Roads Care

easy 'but rightly recognises the importance of families and the stresses that illness, dementia and anxiety about rapid changes in circumstances can put upon them and their relationships. We hope that *Delivering Dignity* can help to break down some of the often artificial barriers between carers and users and recognise that support for the *family* as a unit will often be the most effective way of maximising quality of life for the older person. In this context we see the National Carers Strategy (refreshed in 2010)<sup>5</sup> as setting out similar ambitions about choice, control and maximum independence for carers, whilst recognising that the best support for carers will always be the best possible personalised support for their family member or friend.

Older people may enter residential care or nursing homes for a variety of reasons and the quality of care in these settings should be a priority. We also note (as in the case of Winterbourne View) that the NHS continues to provide some residential care for small groups of older or disabled people with complex needs. Their family carers frequently report a major breakdown of support prior to admission. Hence there is an urgent need to consider both the positive use of residential settings (ie residential by choice) but also the use of expensive specialist provision often because of a lack of advice and support to families at an earlier stage.

### **Achieving integration and continuity in care**

Improved integration and continuity of care are key ambitions within the Government's ambitions for reforming both the NHS and social care. Both are important for all groups of patients and for all citizens needing care and support in any aspect of their lives. However, as Freeman and Hughes (2010)<sup>6</sup> have noted:

*'Continuity of care becomes increasingly important for patients as they age, develop multiple morbidities and complex problems or become socially or psychologically vulnerable.'*

Such continuity is particularly important for older people and their carers because not only are they are likely to have multiple problems but negative assumptions may be made about older people's expectations and abilities and in turn these may have a negative impact on the support offered. We absolutely agree with Dignity in Care's emphasis on the need to change attitudes and language towards older people, who are too often seen as 'bed blockers' or 'burdens' rather than people who have made significant contributions to families and community and who in many cases can continue to make a contribution if properly supported.

With increased life expectancy, older people will present with a range of inter-locking conditions and challenges. Equally their family members may be ageing and less able to manage

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<sup>5</sup> Recognised, Valued and Supported: Next Steps for the Carers' Strategy (2010), HM Government,

<sup>6</sup> Freeman G and Hughes, J (2010), *Continuity of care and the patient experience*, Kings Fund, London

escalating care needs. Hence it is not surprising that the proportion of hospital beds occupied by older people is rising. Two studies (Hoogerduijn, 2007<sup>7</sup>, Lafont, 2011<sup>8</sup>) suggest that older people not only spend longer in hospital because of their age, but are also more likely to be readmitted within a short time of discharge. They are also more likely to be moved between wards once admitted to hospital with some (ie the over 85s) particularly likely to spend additional time in hospital with the inherent risk of loss of mobility and independence and being unable to return home or to a care home.

Continuity of care is crucial to dignity in care, with some carers describing their older relatives as being treated *'like parcels'* and shunted around wards. Carers have described their relatives being called *'bed-blockers'* and felt pressured to accept premature discharge without arrangements made for a smooth transition back to the home or care home environment. One carer told us that:

*'My mother, aged 87 and with mild dementia, had been admitted to hospital with a urinary tract infection. Whilst that was being treated, she was moved to another ward where she caught the norovirus. She recovered but was confused, not eating properly and very unsteady on her feet as the nurses had apparently not had time to get her walking properly again. We expected her discharge plan to include a physio assessment, maybe for an OT to visit her house and at the very least to be lent a wheelchair and one or two pieces of equipment. When we visited her on a Friday evening, we found her in the relative's room with her belongings in a plastic bag. The bed was needed, we were told. My mother was crying because nobody had thought to ask her if she needed to go to the toilet and she had wet herself. She also has diabetes, had missed her tea and was becoming very confused and disorientated. We got her home and she lasted four hours before she fell. We didn't know how to lift her safely, though we tried, and we had no wheelchair to move her around. She banged her head, it bled and we rang 999. The paramedics treated her with dignity, couldn't be nicer. When we got to the hospital she asked them if she could stay in the ambulance 'because it was just like home' and cried when they said no. She was readmitted, the doctor said mild concussion from the fall but nobody could find her notes – or the discharge plan we never got. We had to start again. Nobody talked to her; they talked over her and at us. We were made to feel a nuisance and one nurse said 'other people manage a fall without dialling 999'! Just as well we did because of the concussion. She is and was an intelligent and independent woman and she sat there crying. After we left her, we went and looked for a good care home. We found one and she is happy.*

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<sup>7</sup> Hoogerduijn, et al (2007), A systematic review of predictors and screening instruments to identify older hospitalized patients at risk of functional decline, Journal of Clinical Nursing, Vol 16, No 1, pp46-57

<sup>8</sup> Lafont, et al (2011), Reducing 'iatrogenic disability' in the hospitalized frail elderly, Journal of Nutrition, Health and Aging, Vol 15, No 8, pp645-60

*But what happens to people who don't have carers to fight their corner? And what happens to people who can't afford the 'top-up' which is what buys you quality? We needed a navigator and an advocate and we had neither – apart from the local carers' centre which was fantastic.'*

### **What do older people want – and how do we check their views about the quality of care and support?**

We welcome the emphasis in Dignity in Care on ascertaining the views and wishes of older people themselves and of the family and friends who care for them. The past months have seen big debates about the future of both health and social care, with much emphasis upon accessible information and active participation in decision-making by those using services and those supporting them. However, as the Joseph Rowntree Foundation notes in a recent study<sup>9</sup>, the experiences and views of older people with high physical or mental support needs (and their carers) have often been neglected because:

- There has often been an undue focus on specific health and care needs at the expense of wider quality of life issues.
- Assumptions are often made about older people that ignore their social roles, their individuality and their ability to make choices.
- Stereotypical views of older people can lead to disrespect and a disinclination to try and improve quality of care.

The Joseph Rowntree Foundation concluded that quality care should embrace three key (and often over-lapping) areas of life, namely:

- Physical needs and well-being
- Social well-being and relationships
- Psychological well-being (including maximum self determination).

As the Royal College of Psychiatrists has noted<sup>10</sup>, 55% of surveyed residents in care homes were not aware that they had a care plan in place to meet their needs (and had not therefore been consulted about its contents). 38% of residents felt that they were not consulted as to how their continence needs might be best managed (including the all-important right to have a

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<sup>9</sup> Joseph Rowntree Foundation (2011), A Better Life – What older people with high support needs value, JRF

<sup>10</sup> Royal College of Psychiatrists position statement (2009), Age discrimination in mental health services: making equality a reality, RCPsychiatrists

same-sex staff member to assist in access to the toilet). Very importantly many older residents had a range of mental health problems, ranging from depression and anxiety through to dementia and other serious medical conditions. The Royal College expressed particular concern at the poor access to mental health services for older people (access to IAPT services currently ceasing at age 65) and the importance of adopting a holistic approach towards the health and well-being of older people whether in hospital or care homes, where life changing decisions may need to be made about their future care and possible loss of independence. As one carer told us:

*'My mother was a highly intelligent woman, a successful journalist, always interested in everybody. Then she developed MS, a lot of pain, variable mobility. She just couldn't get on with life as she knew it and she got depressed. But nobody took us seriously. We felt she was dismissed because 'old people get depressed don't they'. We were told she was too old for some good local mental health services. In the end we were able to pay. She had cognitive therapy – at 83! – plus some anti-depressants short term and she is her own self again. She says that she needed help to adjust to her new identity as a person with mobility and other problems, having to accept help, acknowledging that she really should move house, it was all loss she said – but she feels she can cope with it. I think it is a kind of disrespect that we withhold treatments from older people which we would prioritise if they were a few years younger. You don't become a different person when you are over 65'.*

We warmly endorse the proposal that:

*'Helping staff to talk with older people and listen to them is perhaps where dignity in care begins. Once that support develops, the care professional will begin to see the whole person and the keystone of dignified care is in place.'*

Some staff may find it difficult to conceptualise *how* they might talk to and with older people who may have cognitive impairments, dementia etc. But tools are available, for example the Alzheimer's Society's *This is Me*<sup>11</sup>, a leaflet which patients and carers will if possible complete before a hospital admission (or at an early stage in an emergency admission). The aim is to provide a snapshot of the person, who she or he was; what their usual life would be like; what interests them and who are their family and friends. Simple and practical, it will set out any special communication issues (eg whether the patient needs hearing aids, glasses or has any particular communication problems, how they like to be addressed etc). As one carer said:

*'We used the 'This is Me' leaflet and it was great. We could explain that my father has always had a hearing impairment but lip-reads very well and prefers that to his hearing aid – but nurses*

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<sup>11</sup> Alzheimer's Society (2010) and Royal College of Nursing, This is Me

*and other people need to stand in the right place so that he can see them! Also he needs his spectacles and in the past we so often found them tucked neatly in their case in the locker so that he wouldn't break them. In the other hospital we were told he was difficult, wouldn't eat his food, and wouldn't cooperate. Really he was just alarmed and upset at things being done to him rather than doing things with the nurses.'*

Another carer, visiting his wife in intensive care, was alarmed at automatic assumptions about DNRs and brought in a photograph of her receiving her doctorate as a reminder of '*the real person in the ventilator*'.

Therefore we welcome the proposal for staff development programmes to enable and encourage staff to talk and listen to older people and their families. We note in particular that carers and friends have important information to share not only about the interests and history of the older person but also about how they choose to communicate. We also note that carers and older people themselves can have a powerful and influential role in staff training.

### **Partnership with carers**

Family carers are crucial to good recovery and for support in enabling an older person to remain in the family home for as long as possible. However, families and other carers also have a critical role when their relative moves into a care home or is in NHS care. Many families feel confused and sometimes disregarded without proactive policies in place to value their contribution and include them as equal care partners. Many carer support networks and resource centres provide support and guidance to families of older people, but participation and engagement are not necessarily built into the system. Carers frequently speak of challenges in communicating with key professionals in NHS settings or feeling disregarded when their relative has moved into a care home or other residential setting.

We note two successful schemes to ensure that families can play a key role alongside their relative or friend in maximising outcomes from hospital settings and suggest that they could be more widely developed:

- **Partners in Care:** This programme was developed in the USA by Planetree<sup>12</sup>, a not-for-profit organisation, with the aim of enhancing the role that patients themselves and their relatives play in in-hospital care. Patients (or carers) nominate an individual from within their own social networks as a 'care partner'. The goal is to normalise the hospital environment and to allow the patient and carer or other representative to share as much as both feel appropriate in care and treatment whilst in hospital. A

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<sup>12</sup> Frampton, S et al (2008), Patient Centred Care: Improvement Guide, Planetree/Picker Institute



designated nurse has an initial conversation with patient and nominated relative or friend about their wishes and feelings and within 48 hours there is a multidisciplinary care conference to discuss diagnosis, treatment and post-discharge arrangements. Ward rounds are family centred and carers are encouraged to help with feeding, personal care etc to the extent that they and the patient feel appropriate. Unusually carers are welcomed in ward rounds, their views heard and noted and discharge plans made collectively. The Planetree approach has reduced emergency readmissions and has increased family confidence about the feasibility of care at home. No assumptions are made about the level of care offered by a particular family.

- **Bradford Royal Infirmary:** As soon as a carer is identified following an admission to the stroke wards, representatives from the local Carers Resource Centre offer to meet them, to offer support at meetings, provide information and help identify any issues about discharge home and generally assist the family to ensure that they have all the practical help they need. Carers have praised the service for *'offering a bridge between family and the professionals, hospital and home, explaining, advising, informing and helping to plan for the future.'*

We strongly advocate the development of key worker or navigator and advocacy systems for older people (and their families) who can so easily get 'lost' through multiple admissions; ward changes and rapid discharges and re-admissions if their needs are not fully understood. The Stroke Association's *Life after Stroke Services*<sup>13</sup> model provides stroke survivors, families and carers with information and practical support and assistance. The Co-ordinators can work across service and sector boundaries; focus on the individual's and family's goals and can provide ongoing support at critical periods such as discharge from hospital. They can also :

- Ensure that any concerns are dealt with at an early stage and in many cases thereby avoid the crises in care that frequently lead to emergency NHS admission or family breakdown.
- Support families if and when there are causes for complaint, whether around a particular issue that can hopefully be rapidly resolved or when concerns need to be raised more formally.

We note that many carers are concerned about potential (or actual) safeguarding issues around the care and support of vulnerable adults but many are unsure how to raise issues more

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<sup>13</sup> The Stroke Association (2012), Life After Stroke, [www.stroke.org.uk](http://www.stroke.org.uk)

formally with the Hospital or Care Home (often fearing victimisation of their relative if they take such action) or with the relevant regulatory bodies.

### **Addressing inequalities**

The Standing Commission on Carers recognises that there are significant challenges in meeting the health and social care needs of older people in an increasingly diverse population. However, we share and endorse the ambitions of Delivering Dignity to ensure that older people do indeed experience high standards across all services and that they are respected and valued as citizens in their own right rather than as burdens. To achieve this end, we need a culture change in order to ensure that older people benefit from the same protections in regulation, legislation and in quality controls as younger members of the population. In order to achieve this transition, we need to greatly improve awareness of the expertise and commitment of family carers and to actively seek their views about the quality of support offered to their relatives or friends.

Page | 10

As noted in the Annex to this paper, commissioner and provider attitudes towards carers of older people vary greatly. Carers' commitment to, and unique knowledge about, their relative may too often be disregarded rather than valued as part of a partnership in ensuring high quality care. We were pleased to see the Care Quality Commission, in partnership with the Relatives and Residents Association, actively seeking the views of residents and their carers about the quality of their care home, with a short checklist on key standards and encouragement to report any issues or concerns.<sup>14</sup>

The Equality Act 2010 identifies specific duties for the public sector in terms of placing equality at the heart of health and social care. This general duty requires public authorities to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relationships across all characteristics protected by the Equality Act 2010. These now include protection from discrimination on grounds of age as well as on grounds of race, disability, gender, age, sexual orientation and religion or belief. Additionally, carers are now protected on grounds of *associative discrimination* because of their engagement with a person who is in the six protected categories. The public sector is expected to consider *and analyse* the impact of any services or developments in terms of the equalities agenda.

There is some positive evidence of health and social care working with the relevant groups to ensure that commissioning and provision are appropriate to their needs. However, many people within the protected categories are already disadvantaged in terms of finance, health,

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<sup>14</sup> Care Quality Commission and Relatives and Residents Association (2012), Tell us about your care home: does it meet the government standards you have a right to expect?

housing and potential discrimination in their local communities. Successful delivery of the equalities duty will require an integrated approaches across all sectors and proactive approaches to working with community leaders and others to address gaps. We envisage health and Well-being Boards having an important role in engaging with minority groups in local communities and identifying strategies to engage them in the development and delivery of appropriate services and support.

We also hope that Equality Impact Schemes will be rigorous and identify potential inequalities at an early stage. We are very concerned at suggestions that the requirement to produce Equality Impact Schemes might be weakened and the opportunity both to plan strategically for greater equality and to monitor progress thereby lost.

We note in this context that the majority of older frail and vulnerable people would meet the definition of disability within either equalities or human rights legislation and would benefit from the disability sector's commitment to support independent living (ie maximum independence with the appropriate support to ensure quality of life). As the Equality and Human Rights Commission (2011)<sup>15</sup> noted in its review of human rights and home care,

*'It appears that commissioning [for older people] is not being consistently used across all sectors in order to protect human rights effectively. Indeed some commissioning practices make the bad experience that older people describe more likely to happen. Although practices vary a great deal, very few seem to be consistently underpinned by local authorities' awareness of their duties under the Human Rights Act.....There is a clear need for supportive senior leadership on the central importance of quality, including respect for human rights principles such as dignity and personal autonomy in the services commissioned.'*

### **In conclusion**

As noted earlier, we support the recommendations of *Delivering Dignity*. If implemented, they would transform the lives of older people. Their implementation will be challenging, as commissioners, staff and providers and providers across the public, independent and voluntary sectors will need to accept a new culture of respect and an equalities-based approach to resource allocation and recognition of the right of older people to high quality care and support. As noted above, we feel that a robust approach to prevention is needed, with appropriate early identification and intervention so that as far as possible older people can remain in family and community. We also hope that carers – relatives and friends – are

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<sup>15</sup> Equality and Human Rights Commission (2011), *Close to Home: An Inquiry into Older People and Human Rights in Home Care*, EHRC, London

respected for their unique commitment and advocacy on behalf of the people for whom they care. As one carer told us:

*'We have a unique knowledge of our relative's strengths, his or her weaknesses and any special care needs. We will be at home caring when the hospital or sometimes the care home decides they have had enough. Carers, like the older people they support, are sometimes seen as a nuisance, unreasonable, even greedy. But in the end families matter. We know what dignity looks like and if we can be true partners in care, then we will achieve services and support fit for the future. At least we are now talking about dignity – it's what makes most people's lives feel worth living!'*<sup>16</sup>

A personal perspective from Barbara Pointon, a member of the Standing Commission on Carers and an Ambassador for the Alzheimer's Society is attached as an annex to this submission.

**Note: Further information and references on any of the above points can be obtained from:**

**Dame Philipa Russell,**

**Chair,**

**Standing Commission on Carers,**

**e-mail: [prussell@ncb.org.uk](mailto:prussell@ncb.org.uk)**

## **ANNEX**

### **Carers as Partners in Care in all care settings: a Personal Perspective.**

**Barbara Pointon.**

**Member, Standing Commission on Carers and Ambassador, Alzheimer's Society**

**I have a growing concern that in some nursing homes, family carers are not valued and respected as 'expert partners in care', but are being marginalised and treated as 'interfering relatives'. For all sorts of reasons they have had to stop giving hands-on care, but they still**

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<sup>16</sup> Carers' quotations come from a workshop organised by a local carers' group to ask carers for their views on care and support and, in particular, hospital discharge.

care about their loved one and the quality of care that is on offer. In addition, they are often struggling with a feeling of guilt, but it is in this phase that the emotional support and professional advice they relied on as a carer at home tends to evaporate.

There is also a subsidiary thread emerging that when community nursing specialists are called in to give nursing advice, the manager or members of the staff may choose not to follow it. Particularly in later dementia, it is the carer who has to speak up or act on behalf of the resident and be particularly vigilant of both care and nursing practices. When they ask questions, make comments or complaints, do they get a fair hearing?

Of course there are many care homes who readily embrace the notion of carers as ‘partners in care’ but there are still too many where carers are sidelined.

I can best describe my concern by a few real life examples of poor practice from the experiences of several carers, followed by my questions:

**1. *None of your business***

Carer protests that a consultant’s advice about reduction of medication is not being followed. The manager says, *“You have handed the care over to us now. We make the decisions”*.

- The home is being paid a substantial sum of money to deliver good care – what is the provider/consumer axis in all this?
- Whose responsibility is it to tell the carer about their role of involvement at the time of placing someone in a care home?

**2. *Carer tries to ensure that professional advice is followed***

Carer has raised serious issues with the manager about poor care of her husband who is mute and immobile and has swallowing problems (including lumpy food, unsuitable incontinence products and insufficient changes in position, resulting in open sores). Her phone call to the continence adviser (asking if she could please be present at the adviser’s next assessment - a request readily granted) together with her subsequent complaint that the advice given was not being followed by the staff are interpreted by the manager as *“undermining and harassing the staff”*. Because she was, in their view, *“always complaining”* she was given 28 days’ notice to find another care home for her

husband. She has tried hard, and he is now on two waiting lists. As the notice has now expired, they threaten to send him to a home not of her choice, which Social Services will choose.

Advocacy has not worked because the home is adamant that it's all the carer's fault. The staff are cold-shouldering the carer and she has become physically ill with worry because she knows that there is clear evidence that moving someone in the later stages of Alzheimer's to an unfamiliar place can hasten death. Safeguarding has become involved, but this move is seen as a 'risk', not an abuse, so no action taken. The carer is left with a no-win situation – placing him urgently in an unsuitable home where there is a vacancy, or Social Services placing him in a home she knows nothing of, could be anywhere and without her consent.

- CQC cannot act on an individual complaint – but surely an individual whistleblower who makes several complaints about a care home should be followed through?
- Where is the support for the carer in this kind of battle?
- What has happened to patient choice? Is the solution reasonable?

### 3. *The effect of the above on other relatives*

Several relatives in the same care home also have issues about quality of care and the attitude of the staff. They are now too scared to complain because they have seen what happens if they do. They have effectively been silenced

- How are standards to improve if complaints by the 'consumer' are squashed?
- How can the voice of carers be strengthened in all inspections?
- Should all care homes be required to have an active relatives' group?

### 4. *Attitude of some care workers to relatives*

Carer is pushed out of the room and the door closed when care workers arrive to change her husband's wet clothing because "*We don't want you spying on us*".

Carer sees a significant change in the resident's condition (e.g. a large bruise on her nose or a newly bandaged heel) and asks about it. The standard reply, "I don't know, I wasn't here" is so ubiquitous that one is tempted to believe that they are told to say that to ward off any whiff of liability. Carers say they want to know immediately about falls etc.

- How can the carer be a partner in care in these circumstances?

**5. *Routine is more important than personalisation of nursing care***

Resident with Parkinson's has swallowing problems. Carer notes that his essential medication (in liquid form) is administered after lunch when it is simply pouched and dribbles out during the afternoon. Carer asks if it can be given before lunch so that there is a better chance of it being swallowed. Not possible because "the nurse on duty always does the medication round after lunch". The resident's Parkinson's and dementia accelerated.

- Is it a lack of staff because of owners cutting corners - or nursing ignorance?
- There are 'dementia-registered' homes but I query how many of them have the specialised nursing skills required in advanced dementia – should the GSF *End of Life Care in Care Homes* programme be rolled out more speedily?

**6. *Carer unaware of entitlement to participate in NHS Continuing Healthcare nursing assessments in a care home***

Carer not informed that visiting nursing assessors were coming to assess his wife. He happened to arrive to pay his daily visit at the same time. The nurses asked him for his name and address to put on the form and they said they would get all the other information from the care home's nurse. He had no idea that he should be involved in the assessment and be given an opportunity to see the final document to check for errors or omissions. Nor did he know that he could actively participate in further discussion and offer written submissions when the Decision Support Tool is being completed.

- Whose responsibility should it be to inform carers of their rights under the Mental Capacity Act and the essential role they can play in all assessments, decision-making, care-planning and hospital admission/discharge in all care settings?

**7. *Financial matters which really worry carers , including a care home's potential conflict of financial interests***

- 7.1** Care home senior staff, who participate strongly in NHS CHC assessments, are employees of the owners and in some cases the owners themselves. In many areas, the fees charged to self-funders are much higher than the local PCT's Continuing Healthcare figure, so the care home loses income if the resident qualifies. This has been openly admitted to a carer as a reason why staff tend to underplay the resident's

nursing needs and it could create a disincentive to put eligible residents forward for assessment in the first place.

- 7.2 If the resident is awarded the 100% Continuing Care and it is below the figure that the home is charging for nursing care, the law prevents the family from topping up. In the best interests of the resident (to allow them to remain in a familiar place), a carer may have to refuse the NHS money altogether or else find a cheaper, probably poorer quality care home and put up with the consequent upheaval and often distressing outcome for the resident and therefore the carer.
- 7.3 The Nursing Care Contribution. This was originally intended to be subtracted from the fee for the resident. Several care homes have taken the line of explaining to carers that "Your relative has now qualified for nursing care so the fees have to go up by .....(whatever the current NCC rate was), but don't worry about the extra charge because the PCT pays it".
- 7.4 People with advanced dementia find that the CHC they qualified for when they were in the aggressive or unpredictable phase is taken away when they become mute or immobile. The carer then has to suddenly find care home fees they had not envisaged. The Decision Support Tool is simply not helpful when assessing people in the severe stage of dementia .
- 7.5 The fees for care homes have rocketed sharply in the last couple of years. The latest dementia care home to open in my area is charging £1,100 per week and 'spouse carers' are understandably very concerned about how they will meet those kind of fees without dipping into savings intended for their own future care needs.
- 7.6 No-one, not even CQC, can look at the books to determine whether residents are getting value for money or whether the profit margin is reasonable. In many care homes the care workers are badly paid, many on minimum wage and the figure for expenditure on food I understand in one home to be as little as £1.80 per person per day. In another home, care workers are required to work 12-hour shifts to save on overheads.

*Some final questions:*



- Have a 'longer arm's length' attitude towards regulation and the increasing practice of self-assessment gone too far?
- What does the Law Commission say about several of these points?
- It's a two way traffic. Carers often have skills that could contribute to the quality of life for residents – such as informal singing together, gardening, artwork, or just sitting and talking with someone who has no visitors. How can the barriers which prevent some homes and carers from benefiting from this mutual support be lifted?
- In what ways can good practice around family carers be shared between care homes?

### A concluding thought

Alzheimer's Society's *Home from Home*(2006), based on carers and care home staff surveys, has a very helpful chapter on involvement of friends and family in care homes (Ch 3). The main recommendations are: ensuring good relationships from an early stage; expansion of relatives' groups; effective and timely sharing of information; ongoing involvement in care; the importance of good leadership; an inspection system which supports family involvement; staff training in developing good relationships; the option of both self-funders and those supported by statutory services to take complaints to an independent body.

Barbara Pointon

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