**Inquiry into regulation of care for older people**

**Scotland Patients Association (SPA)**

SPA wish to thank the committee for giving us an opportunity to respond to this excellent report which demonstrates the vast and varied areas which requires to be inspected and regulated to ensure that the care of older people is standardised throughout Scotland maintaining the highest possible standards of care incorporating human rights legislation.

It is essential to have robust regulation and care inspection since on the occasions when and where poor care is delivered it also delivers misery and poor quality of life, or end of life experiences for those who are "cared for"; there is also a financial cost to the NHS or the taxpayer. Poor care leaves an indelible imprint on the minds of the families who witness such and are or have been, ignored in reporting, thus leaving them with a legacy of nagging mental anguish, wishing they had ignored their relatives plea to "do nothing" and made a greater effort to "do more" to improve care. The latter is not so easy to achieve if health professionals do not make communication easy and / or display poor attitudes; most complaints arise out of the latter two and could be avoided by a more professional partnership. Patients and their relatives often say they felt powerless during this time.

It is not uncommon for patients' relatives to be reduced to sending e-mails in an attempt to obtain answers about care and treatment and not uncommon to be told to desist from this habit. Therefore SPA agrees that it is important for the Care Inspectorate(CI) to obtain independent input from patients and their relatives and also health professionals who observe poor practise but are too timid to speak up to management.

It is important for "whistle blowing" to be made easier and perhaps given to an independent body which could be within the **CI or the Health Environmental Inspectorate (HEI)**, rather than to their line management or higher within their organisation as this is often thought to be too difficult. All doctors, nurses and Allied Health professionals are required by their code of practice to inform if they note poor standards or anything which would put patients at risk. Management should accept the essential importance of "whistle blowing" and actively encourage staffs to "feed - back their "concerns", which perhaps is a more user friendly term. Too often people are afraid of repercussions and the GMC and NMC and other professional regulatory bodies should advertise professional requirements to management.

Despite the fact that our population is living longer, leading more fulfilling lives, albeit eventually, as age advances with more complex treatable medical conditions, this is a success story which should not become a burden. SPA is very pleased that the Government and the Committee acknowledge this and wish to positively discourage age discrimination. Many older people feel undervalued and may struggle on their own, afraid to ask for help until it is too late. It is good to emphasise Human Rights along with the Regulation of Care for the Elderly. It is important to look ahead and prepare for the future with the intention of increasing true care in our communities and to diminish

**unnecessary admission or re-admissions** to hospital. We will still need flexibility to be available to admit people who need admission to hospital but while in hospital the emphasis should be on quality care designed to return the older person, from whence they came with the best designed continuity of care.

In time it is anticipated that due to the smoking ban and improved eating and exercise habits that the smoking related diseases will diminish in time but the latter are still with us and have to be dealt with now, in addition to the increasing number of people who will suffer from dementia of different origins, as they live longer. Time spent on treatment and management of long term conditions, in addition to the importance of chronic pain control, will also be essential to maintain quality of life and to enable people to work for as long as possible to maintain physical, mental and independent wellbeing. Sadly abuse of alcohol absorbs great NHS costs which could be spent on research or NHS professionals.

Looking after people better and more appropriately can prevent further deterioration in health. Though this will come at a cost it should have savings in other ways. For example to provide more and more appropriate care within our communities must mean more health professionals which will carry a cost to have them in the most appropriate numbers.

SPA feel that some research should be carried out to compare the model which evolved from the 1990s of private sector care homes compared to a non-profit-making local authority model of care homes supported by primary care health professionals.

Since “lack of loneliness” enhances the wellbeing of older people, SPA would also welcome research to evaluate the impact of the number of carers, provided by private companies, and the little time they have to deliver their services, compared to the older model of home help service, which was abandoned, where “home helps” spent longer time providing their services with extremely valuable company. Ask anyone and they would prefer the latter model.

SPA welcomes the suggested research into nursing skill mix in all forms of care. When patients leave NHS Continuing Care to come under nursing care in the community the proportion of fully trained State Registered Nurses (SRN) reduces greatly in favour of Care Assistants (CA) who is trained to deliver a more task based form of care.

SPA have suggested to the Nursing and Midwifery Council that they should regulate and register CAs who perform nursing duties. This should improve patient safety. It is important that confidence must not outweigh competence in health professionals. Research should also look at the qualifications of staff available to care for elderly people and measure outcomes. It would be good to know to what extent staffs is routinely monitored on the job to improve standards and their personal development.

SPA is concerned that many relatives are worried about the delivery of medication to older people, especially in those who suffer from dementias and Parkinson's disease and the CI should be able to examine this area regarding patient safety. Some research into medication and delivery of medicines should be undertaken along with examination as to how often this is reviewed. Perhaps there is a greater role for pharmacists to be responsible for patient medication reviews in partnership with general practitioners. How many care homes should general practitioners safely cover as well as their NHS practices? We would also include the Liverpool Care Pathway in this research.

The CI may find it difficult to assess monitoring of medications and feedback from patients or their relatives we feel is essential. National standardisation of drug records and food and fluid balance charts should be considered. For the CI to be successful it requires honesty and accuracy in record keeping from all health professionals and personal commitment and accountability. **Therefore SPA believes that it is a waste of time and money for the CI to announce inspections and we would encourage all inspections to be unannounced and would hope standards to rise as a result.**

Due to the reduction of hospital beds, coupled with the lack of beds within communities, this has put a great burden on families who are caring for a loved one. Families need more help on what is available for care and a good idea of what it will cost and how this cost can be paid for and so relieve their present burden of care, wholly provided by them.

SPA agrees that it should be easier for relatives to see what standard of care has been determined by CI inspections. This should be on all front pages of all care home websites and not tucked away, requiring more "mouse clicks". The same should apply on the CI website. CI report information regarding care establishments should be easily found by post code to aid relatives examine past care reports with the most recent assessments. **SPA agree that standardisation of assessments is important.**

We also think that tariffs for various types of care should be visible in premises, on websites and literature. SPA understands that care packages need to be tailored to personal needs and costs determined will be discussed in private. Also visible on care websites and literature should be the number of specialist nurses provided for the care of patients who for example require stoma care, dementia care, or patients with Parkinson's disease who require accuracy in timing of medication in addition to other basic care.

SPA have found that examination of cases, where relatives have shared concerns with us, has exposed more and more problems of which, had these concerns been sympathetically dealt with at the time, could have prevented further concerns or formal complaints. Please see the annex for case examples which illustrate the complexity of problems surrounding care and human anxiety.

**SPA would advise a central point through which all complaints can be dispersed to relevant people and coordinated and checked before**

**replying to the complainant. We would also advise ongoing training to improve communication skills and staff attitudes of all health care professionals in addition to their need to understand what power of attorney means as well as financial and welfare guardianship orders. We would also promote a more-do-as-you-would-be-done-by-culture.**

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**Annex**

**Case 1**

Has been ongoing over many months demonstrating the difficulties of looking after the wellbeing of a mother with increasing dementia. Communication over time has deteriorated and resulted in e-mail communication to confirm that the daughter who had welfare guardianship was fulfilling her role. Many concerns arose around what was appropriate medication and sedation for her mother who, at one time, was asleep for four days but without food or drink yet sleeping tablets were still being given because they were prescribed. Stoma care gave concerns as did labelling her demented mother as a "pilferer". In the end this patient and her daughter were given 28 days notice to find another care home and her welfare guardianship was threatened to be removed.

This patient is now being well looked after in another care establishment yet the pervious care home still has financial guardianship of her money; currently not resolved.

It is stressful to have a relative in care without the added hassles which present. Relatives are frequently there every day and their perceptions are a good source of information to cross check other information gathered by the CI.

**Case 2**

This week SPA was been asked to support a 36 year old woman who is the main carer struggling to place her demented 59 year old mother in the best care for her within the community. By the time the daughter selected sheltered accommodation with the addition of many paid carers going in morning, noon and evening her mother's condition was deteriorating. This daughter is still visiting in addition to paid carers and is on emergency call at all times. It took time to settle with the new regime but was not without difficulties as her mother would not co-operate with some carers compared to others. In addition problems arose with poor timing in giving medication. This lady is very lonely and would wish company all the time and many different carers in and out through the day are not helpful.

Four months into sheltered housing this lady now needs 24 hour care and naturally the daughter would like to explore what care facilities are not only available to give her mother specialist care but near to where she stays and the cost. Information is slow to be offered other than to be told that she will have to accept that cost will be the main decider and that she will not have a great say since it is not within the daughter's power to assess her mother or the finances to pay for care. This young woman feels that she keeps **"hitting a brick wall"** and when she is in meetings with social work and others that the family feel surplus to requirements which is quite hurtful on top of contending with the trauma of her mother's dementia. This is work in progress with her fatigue levels rising to be told she does not qualify for respite care because of her mother's age.

**Case 3**

Last year, while in an acute hospital a 90 year old husband had a dense one sided stroke from which he did not recover but remained mentally fully aware. He wanted out of hospital but more than six weeks passed and no bed could be found in a care home. His wife and daughter felt they were under pressure to take him home or find a suitable place in a care home. They looked at nine possible care homes but since the social work department had been unable to assess this gentleman regarding his funding the question each home asked was "how will you be paying for care" but this question could not be answered and so stress mounted for both patient and his relatives. It took many more weeks to arrange a care home which was not within close visiting.

People such as this gentleman require full nursing care but do not qualify for NHS Continuing Care as the aim is to greatly reduce NHS Continuing Care. Many such people who still need full nursing care with general practitioner intervention, but not regular consultant for specialist input, have to find places in care homes with nursing throughout Scotland. Are all local "care homes with nursing" able to cope with such complex medical and nursing needs? When required can they provide carers trained in the care of stomas, special diets and dementias?

**Case 4**

Most recently a family are concerned that their mother took 10 days to die on the Liverpool Care Pathway. It did not seem to them to provide a good death for their relative over this time, especially going without food or drink.