

Residential Care

My mother went into a care home after her stay in hospital. It just happened, we didn't know a lot about it and we weren't really consulted although at some stage we realised that there was no alternative. It was a big change, maybe if we had been more involved we would have done something differently but in the circumstances there isn't a lot we could have done. Thanks to the NHS, she was no longer capable of looking after herself at home. Our only concern was that the care home required her to be weight bearing and to our knowledge she wasn't. However, we were grateful to the care home as her condition under the care of the NHS had deteriorated significantly.

Important Note! The majority of factual information in this section has been taken from the documentation package I received prior to the IRP; paperwork I was not aware of whilst my mother was alive. Extracts from information that I did receive at the time are coloured orange. This is quite important since it illustrates how much information was available concerning my mother's condition and just how little information I actually received. Consequently, any decisions I was asked to make were based on very limited information, hence I may well have made wrong choices in retrospect.

At the care home, they certainly gave her a lot of attention, they conducted a general review, created a care plan, conducted a manual handling review, an occupational therapy assessment, a risk assessment in October of 1998, and got her off the antipsychotics, far more than the NHS could be bothered with. Some of the comments from these review and assessments are reproduced below as they convey just how the Alzheimer's had progressed in just 4 months in hospital.

...Agnes needs help with all aspects of personal hygiene, she is unable to wash herself. Two carers give her a bed bath every morning. She is doubly incontinent so extra care is given when washing her and Soudocrema often applied to prevent soreness. She needs complete help to dress, usually done on the bed after washing using the 'rolling' method. She can become panicky and distressed when being dressed so carers need to work slowly with a lot of reassurance. She no longer has a bath or shower as this has become too distressing for her. She needs her food cutting up into small pieces and uses a spoon to feed herself. If given a knife and fork she becomes confused. She needs monitoring to ensure she doesn't put too much food in her mouth without swallowing. She is a very friendly lady who talks to everyone but due to the dementia, it can be difficult to understand her. She responds very well to smiles and tactile communication. She is turned during the night by night staff and cream is applied to shoulders and hips after personal care...

The following are the comments made in the manual handling assessment:-

.....She is unable to weight bear but forgets her limitations. She has a history of not being able to sit still in a seat. Her level of personal mobility is wheelchair and hoist with double assistance. Unpredictable movement puts her at risk if left unsupervised in the wheelchair so a lap strap is employed at high risk times.....

It would appear that at some point she fell of her bed hence a risk assessment was carried out:-

.....She sits in a wheelchair during the day but has a tendency to wriggle forward and could fall out. She also leans forward if sitting in a chair. She has a history of restlessness but the GP advises that is due to the dementia (the drugs administered?) and not to a physical cause. She is not aware of the reality of putting herself at risk but is happy to wear a lap strap. There have been a number of near misses without the strap. Initially she was using a reclining chair which did suit her, but as her condition improved after coming to the home, she became more alert and enjoyed company but at the same time became more mentally and physically frail, she did fall from the chair.....

When she left Hartismere, the instructions to the care home were to ensure that bed rails were in place to prevent her falling out of bed because of her fidgety and excessive movements. My mother was quite happy with the care plan and signed it off. A **statement** from the Care Home manager can be found on the History page. In addition to this, ACCESS carried out their own assessment of my mother's care at the end of October, with the following comments:-

COMPLIMENTS:

When Agnes was discharged from Ipswich Hospital following surgery, she was in quite a poor state, frail, immobile, somewhat agitated, confused and rather disassociated from what was going on around her. I feel she has picked up remarkably since

admission to Residential care. She is much more her old self, more alert, interested and more smiles. Her appetite is good. Enjoys her cup of tea. Nights improved - less restless. On Piriton and painkillers - no longer scratching. She was able to express that she liked it in the Home and happy to stay there. Son and daughter-in-law impressed with the care she is receiving.

CONCERNS: Agnes became immobile in Ipswich Hospital and despite staffs best efforts it has not been possible to mobilise her - her arthritis in knees said to be too severe. Still using a lap strap as she kept falling out of wheelchair. Can undo it herself. Also uses hoist which is most painful in the morning.

PROVIDER RESPONSE:

Having taken above action, provider continues to monitor her situation carefully. Agnes is said to be a popular resident with both staff and other residents because of her gentle, pleasant personality. She seems to bring out everyone's protective instincts. It has been noted how much she enjoys company. She enjoys the Thursday Club, especially music and it is anticipated she will participate in future outings. Agnes is confirmed as a long stay resident. I feel credit is due to the Care Home staff for the way Agnes has picked up since becoming a resident.

As you can see, this Residential Care Home took a lot of time and trouble ensuring that my mother was happy and well cared for. This was quite a comfort to us as we lived some distance away. Thus from the information we had, we were quite happy that my mother was being well cared for and so we just made regular visits to Ipswich to visit and attend care reviews. Unfortunately this was thrown back at me at CHC reviews, see later.

At the beginning of December 1998, my mother was seen by Dr Raj, a psychiatrist from Minsmere. The main extracts from his report, written to her GP Dr Watson, are as follows:-

Agnes, I gather, has been in the current residential home since September and was initially fidgety, appearing to be in some discomfort day in and day out. Furthermore she also was reported to have an itchy skin which I was told did not help the situation. Subsequently with her being given Piriton 4 mgs 3 times a day the itchiness of the skin during the day time is reported to be very much less. However, she, I was told, continues to display fidgetiness during the nights with itchy skin around the area of her buttocks/thighs which in turn, I gather, interferes with her sleep. The staff put such itchiness down to her being doubly incontinent for which she, I was told, wears a pad day and night. In addition the staff told me that she has been prescribed Co-codamol to control pain in her legs experienced especially during the nights. I note that her Risperidone has been stopped and hence the same could be ruled out as a cause for her fidgetiness (akathisia). She is at present wheelchair bound and thus needs a hoist to transfer. She, I was told, also requires help with all activities of daily living and is seen to be amenable to the same. Her appetite was reported to be excellent - eats anything that is put in front of her, and since the recent past is seen to eat very rapidly and as a result the staff keep a close eye on her feeding habits to prevent her from choking with food. Furthermore, she, I was told, has no clue what to do with the things that she used to be familiar with previously, for example when given a book or a newspaper she would just crumple the pages and would put it into her mouth or her ears. The latter behaviour has only been noticed during the last one or two months according to the staff, otherwise she is reported to be a nice cheerful lady.

Agnes was seated in her wheelchair at the table eating biscuits and drinking her tea when I went to see her and greeted me back appropriately when I greeted her. She however seemed to be unable to initiate conversation, probably because of her profound word finding difficulties which became quite evident as the interview proceeded. However, she attempted quite hard to answer my questions in monosyllables. She claimed that she is quite happy where she is but gestured that she experienced pain in both her knees, especially when she tried to straighten them. On examination I found the knees to be in fixed flexion and quite tender on my trying to passively/gently extend the same. However, the knees did not appear to be warm or swollen. She scored 10/37 on our formal memory/information test as opposed to the previous score of 19/37 when she was taking Aricept. However, at both times she appears to have scored 0/5 in her short term memory (five minute recall). She denied experiencing anything strange or funny which frightens her and the staff reported no features consistent with perceptual abnormalities. She also seemed to be soft spoken, quite content and euthymic plus calm in her manner.

As she is at present she seems to be free of any psychiatric illness despite her taking no Risperidone. Nevertheless her dementia appears to have progressed to the extent that she has developed word finding difficulties and also has lost the ability to perform some learnt functions. Physically the nocturnal itchy skin seems to be a problem interfering with her sleep, not helped by the painful flexion deformity of her knees. Hence in order to enhance her sleep may I suggest Heminevrin 1 capsule nocte PRN, which the staff agreed to use at their discretion depending whether she is experiencing any day time hangover or not. In addition to this her knee discomfort could be alleviated by a safer but effective NSATD Meloxicam 7.5 mgs nocte. As at present she is free of any mental illness complicating her progressive dementia I have not made further arrangements to see her, but will certainly see her at your request if a psychiatric need arises in the future.

PS: I am sure you would agree with me that a course of physiotherapy to her knees would also help to ease the knee discomfort.

Basically, although this is a careful and comprehensive assessment, there is no evidence that Dr. Watson acted on any of the recommendations. However, it is clear that the removal of Aricept has not helped at all. Aricept does keep a dementia patient level for a lot longer, but when it drops off the decline is rapid such that my mother was now at Stage 7. Aricept would not have prolonged her life but her brain did last longer in its current state when she was taking it.

The Residential Care Home did keep a **daily record** on my mother for the next 2 years and this is summarised elsewhere in terms of her medical condition only, rather than day to day regular events. One thing I have not seen however is any GP or District Nurse (NHS) records of their visits to my mother at the care home. In May 1999, we attended another review. The comments from the review are as follows:-

It was decided that at present that Agnes's needs can be met on the special needs unit. I said that I would be happy for her to say with the staff she knows and has been very happy with the care she has received. Medication was given in the evening to give Agnes a better night. It was explained that the care home may need to look again at her needs in the future but for now all are happy with the arrangements.

Although nothing was done regarding some physiotherapy on my mother's knees, an occupational therapy assessment was done in June 1999, this noted that her medication was Piriton, Fibogel, Senna, CoCodamol and Lactulose, that she needed assistance to sit up in bed and that the bed had cot sides. Another review was held in December 1999 but this was mainly procedural issues and no comments on my mother's dementia. In a review held in April 2000, my mother was present and she talked about the cat she had at home. In another review in August 2000, the comments were:-

Agnes's health had been good, the last GP visit had been in February for a swollen hand but the condition had not re-occurred. Agnes had a constantly cheerful personality but an occasional show of tearfulness which seemed started by a sudden sad recollection. She is stimulated by various social activities such as outings. She was present but unable to provide a signature to the review summary.

In September, a review of her care plan was undertaken, summarised as follows:

Agnes is toileted at regular intervals during the day and carers use the hoist for this as she cannot weight bear. She wears a yellow pad day and night for her own hygiene. She has her hair washed and set every Friday and a bed bath twice a week. Her hands and nails have to be washed every morning. As she gets distressed and unsure of what is happening, she needs very careful handling with all of her personal care. This can be difficult as she bends her knees up and go very stiff...she needs plenty of reassurance. She likes to have conversations with everyone but doesn't always make sense. She has no short term memory. She likes her food but needs supervising as meal times to ensure she doesn't put too much in her mouth. Because of her condition she does sleep a lot.

The next review was in February 2001, basically her health has remained about the same, some days she likes to be in bed for the afternoon. She still goes out with other residents on outings, she did enjoy going to the zoo. No change in medication. There was no further reviews that year but in January 2002, a whole lot of activities kicked off and because of my mother's frail condition, the Care Home Manager requested a review. A STARS assessment (Short-Term Assessment & Re-enablement Service) was carried out, the score was 64/136 which is judged as very high. The review minutes are as follows:-

Background to the review: The dependency levels on the unit have become increasingly high, it is believed by the senior team and higher management that there are issues of health and safety to consider, both for the residents and the staff team on the unit. All the residents needs have been considered and reassessed, and the decision reached that residents with very high levels of dependency can no longer remain at the home where the staffing levels cannot meet there needs. ACCESS had been asked to reassess Agnes which she has done and her report has been made and she felt Agnes had been and was getting the best care at, however she did say she understood that the staffing levels were not enough to continue to meet these increased needs. A STARS assessment has also been completed showing the very high care needs Agnes now requires. Her son while very sorry that this decision has had to be made does understand the reasons. It was agreed that ACCESS will send her son the list of nursing homes in

Ipswich, they will arrange to visit these as soon as they can make the arrangements, living 150 miles away makes the task a little more difficult.

The conclusion from ACCESS regarding the current situation was:-

Conclusion: From a purely needs point of view Agnes should remain where she is. For a confused older person, continuity of care in an enabling environment is crucial and this is what she is provided with. However I recognise that there are problems on the unit arising from external factors viz. the level of dependence of a number of residents on the unit has risen to the point where health and safety standards cannot be maintained with present staffing levels. Four people now require hoist transfers. Agnes requires the help of two staff for 20 minutes each time she has to be changed, for example. I understand there is no likelihood that additional staff/care hours will be forthcoming so management is currently faced with an irreconcilable dilemma. Her family are unhappy with the proposal of a move at this stage in her life, but have agreed to explore alternatives.

- 1. Finding an alternative placement may not be easy. There is a lack of Nursing Home places, and most homes have a number of people waiting. The home will need to be one the family feel confidence in. Agnes does not need psychiatric nursing care but whereas a good general nursing unit would cope well with her physical dependence, her dementing illness would possibly be less well understood and the units tend to be on the whole larger, less domestic and personal.*
- 2. Moving people along the system as a way of dealing with the pressures on resources is arguably neither a humane nor a cost-effective way of addressing present problems. .*
- 3. Ageism. There is a chronic lack of funding/resources for older people, particularly elderly people with dementia, which is fuelling the present crisis, for which short-term, stop-gap solutions provide no real answer.*

The District Nurse was also called in to make an assessment in February as follows:-

Agnes is a lady with dementia but is reported to have no other behavioural problems complicating this. In 1998, she was diagnosed with carcinoma of the sigmoid colon for which she had a left hemi-colectomy in July of that year. There have been no further complications pertaining to this condition, therefore I have assessed her needs under the category of 'Care of Frail Elderly People'. Due to her frailty, she is now in need of a lot of basic nursing care and physical, as well as emotional intervention from her carers. She requires full assistance to wash and dress and regular toileting, although she tends to be incontinent of both urine and faeces. The District Nursing service have assessed her for continence aids which require regular changing and when the pads are changed, she needs attention to her personal hygiene, requiring the assistance of two carers. For any transfers to and from her wheelchair, commode or bed, Agnes requires the use of a hoist, which for health and safety reasons, necessitates the assistance of at least two carers. She has a constant fear of falling exacerbated by any major intervention (and hoisting is a major intervention), so this procedure often requires the services of three carers, one to reassure her and hold her hand. Due to her fear of falling, she has cot sides on her bed, the bars of which are padded to avoid injury should she knock her arms or legs. Her level of immobility requires a change of position every two hours, whether in the bed or on the chair, to avoid any deterioration of her pressure areas. Her skin is currently in very good condition but is constantly at risk. Altering her position needs two people. She is unable to articulate her needs in words but can communicate her fears and her need for frequent reassurance. She requires feeding and full assistance with holding a drink. Due to her dementia, this process can be lengthy and protracted and although the staff are anxious to give this time, they feel that it takes them away from the other residents. It can mean that at times, fulfilling the needs of both Agnes and the other residents can be compromised. It is my opinion that Agnes requires basic nursing care, however, her nursing needs are not so specialised that she would qualify for NHS funded nursing care. Moreover, it is dubious as to whether a move to a nursing home would benefit her when she has been so well cared for in an establishment that she has obviously come to regard as her own home. Agnes is a lady who requires a lot of tender care and reassurance, which she finds partly in the familiarity of her surroundings and her carers. To 'move house' at this stage could prove detrimental to her health and well-being, and traumatic.

So, having read some of the above provided to us, you will see that there are conflicting views and although the Care Home was pushing to evict my mother into a nursing home, others were considering this as a detrimental move in the circumstances. We spoke to a couple of my mother's carers about the request to move my mother to a nursing home and we got a totally different view of the situation. It turned out that the Local Authority were aiming to cut costs and not replacing carers if they left so consequently yes, they were in effect 'short staffed' and increasing the workload on the remaining carers. They did not understand why my mother was on the list as 'she

was a lovely lady and not any trouble' for them. So we basically did nothing, but I did ask for a definition of 'nursing care' and how this would differ from the care my mother was already receiving. I was open to a reasoned argument. We had some difficulty in understanding the official motive for the eviction request since from the **Day Record** she was having regular hairdressing, hair washed and set, manicures and chiropody, being taken for walks in wheelchair, sitting in the garden, coffee in the pub and enjoying activities in the lounge, games, singers, videos, watching TV, BBQ's etc. She was quite happy and generally cheerful from September 2001 onward. From the 'nursing care' point of view my mother was getting sore groins, pressure areas; eye watering and discharging; teeth and gums bleeding and very tired sometimes needing bed rest during day or early night, often sleeping late, some pressure sore areas requiring ointment, sleeping well at night and the monitoring of bowel movements seemed the only issue for months. This did not seem contrary to what a special needs care Home would be expected to cater for.

Now in March of 2001, Mike Bradshaw, the County Manager for Residential services, having received the above assessment, wrote to request full nursing care (no definition) for my mother, [see letter on main page](#). He apparently was turned down because of 'insufficient resources available for community nurses'. At the time we did not know of this letter but you will see that there is not definition of what the nursing requirement content actually is. In April I received a part version of this letter from ACCESS to which I asked the following questions:-

- a) What exactly is your definition of "nursing care" Specifically what I am looking for is an official definition in a recognised publication. It seems to me that you are all using this term with no appreciation of what it actually represents.
- b) Mum has no injuries, medical condition, medication requirement etc., that require the duties of a nurse but you are telling me that she needs nursing care. Does that mean that a nurse in a nursing home will hoist her into bed or change her incontinence pads? I don't think so. So what exactly would the nurse do and what would be the daily nursing element of her care and how would it actually differ from the care she is receiving now?
- c) The section of the Care Home that Mum is in caters for people with special needs. Can you define what the difference is between residential care, special needs and the care my mother is receiving.
- d) If my mother does in fact need "nursing care", you do realise that the District Nurse can be required to visit.....has that been done? In the DOH brochure "NHS Funding of Nursing Care" it is interesting because it clearly states that residents of residential homes are supposed to have access to the full range of NHS support services and NHS community nursing services for FREE.
- f) I am fully aware that under the CSA, the home has to be registered with the Care Standards Commission but I think it is going a bit far to suggest that it is an offence to care for my mother. Nowhere in the Care Homes Regulations or the Care Standards Act is there a definition of "nursing care"
- g) In the last published Inspection Report for the Home dated 8th. August 2001, in relation to the NCSC, it clearly states that "the home is unlikely to have any difficulty in achieving the National Minimum Standards". The report also acknowledges the presence of 12 mentally frail people in the special needs unit. One of the stated objectives in the Report is "to build on the achievement of the special needs unit by continuing to support those individuals with dementia and their families and exploiting the opportunities afforded by the refurbishment facilities"
- h) It is very clear from the above that the Home is not only renegeing on previous commitments but that the forthcoming requirements of the NCSC were well known last August so WHY all of a sudden is there a problem? There was no problem anticipated a year ago and since my mother's care has not changed at all since then there should not be a problem now!
- i) When my wife and I had our meeting in January, we came away with the impression that SCC were reducing or had reduced the number of carers in the unit, so it was a manpower thing. This latest nonsense about "nursing care" and NCSC regulations could well be a smokescreen for the fact that SCC had reduced manning levels PRIOR to 1-4-02 to deliberately put my mother at risk.

I had an agreed reply from Access and the Care Home manager but again, no help with the nursing care definition to help us. The main items are as follows:-

Working within a specialist team whose goal is to achieve a better quality of life for people with dementia and a fairer share of resources, my own view is that, unless the person with dementia is sick or disturbed, requiring medical/psychiatric intervention, their care is best provided in a familiar environment being cared for by people who know them well and understand them. Ideally when individuals are well cared for and live longer, and become more frail, it should be possible for extra care to be brought to them rather than moving the person to a different type of facility, with the attendant risks of adjusting to change. Unfortunately, because of budgetary constraints such flexibility is not built into the system.

In fairness to the Care Home manager, it is not her wish to move anyone but, as she has been told that extra staffing cannot be provided, she has taken the step of keeping beds empty to avoid prejudicing health and safety as far as possible. When we met for your mother's review the issue was not staff reduction - rather that, because of the increased numbers of physically very frail people on the unit, to give all residents care appropriate to their needs staff enhancement would be required and, unfortunately, would not be forthcoming. I honestly believe your mother is still alive and content because of the excellence of care she has received.

For years now, the debate has persisted about what is medical and what is social and, as far as I am aware, has never been satisfactorily resolved. All I can say about your mother's care is that two nurses have made an assessment of her needs and have both categorised her as 'very frail elderly' and defined her nursing needs as 'basic'. I have not myself read the new Care Standards Act and, so far, no guidelines have been made available about its full implications. What I wrote to you in my last letter constituted direct quotes from the County Manager for Residential & Day Care Services for Older People in his reply to the Chief Executive of Age Concern Suffolk who, as you know, with your permission took up your mother's case with Suffolk County Council. I am surprised though that, as the Care Standards Act says it is illegal for residential homes to provide nursing care, it provides no definition of what nursing care constitutes.

The present trend appears to be to define people's needs by functional rather than holistic assessment i.e. looking at what people are able to do, level of functioning, rather than what contributes to their total well being. This approach, it would appear, has now been enshrined in law.

The Special Needs Units differ from mainstream residential care in being generally smaller and specialising in the care of people with more advanced dementias, often associated with agitation and more challenging behaviours, requiring higher staffing levels and a greater depth of knowledge and training in the care of people with dementia. With the right kind of care, challenging behaviour is found to diminish. In an enabling environment, the underlying anxiety and agitation which so often accompany these illnesses subside and residents are able to attain a sense of well being and security. You will recall that when your mother was first admitted she was a more anxious and agitated lady than the one we see today.

As I said in my last letter, Mr Bradshaw undertook to request nursing input from the community for your mother - but I understand that, because of their own strained resources, the community nursing service is unable to provide the level of input that would be required.

This is really the start of a lot of paperwork flying around behind the scenes, meetings, and involvement of a number of bureaucrats which now appears quite over the top. I was not really resisting a move for my mother to a nursing home but the logistics of the whole thing, to view a home and arrange it all basically defeated me for so far away. If the Authority had at any time found a suitable placement for my mother I would have seriously looked at it but no, absolutely no help in that regard was offered and to me it did raise the question as to whether they were really serious. I am of the opinion that if Social Services **seriously** wanted to move my mother they could have found a nursing home place, that's what they do. Certainly the officialdom were serious, as the following County Care Services meeting notes in May 2002 with the County Solicitor apparently disclose:-

*By way of background the Manager said that in November 2001 the Unit was becoming very difficult to manage as the care needs of several residents had increased dramatically, causing stress to staff and resources becoming over stretched in meeting the care needs of residents. Four residents were identified through regular reviews as being beyond the capacity of the level of care hours allocated to the Home. One gentleman from this four was admitted to hospital and **died shortly afterwards**. One lady moved to the Home where she has settled well. A third is currently waiting for a place at a Nursing Home, and has been waiting since January. The fourth of these residents is Agnes. She is unable to express a view herself regarding her care but she seems content. Staff are devoted to her and a huge amount of resources are being tied up in caring for her and the other lady who is awaiting transfer to a Nursing Home. They are both, in effect, occupying two beds and there is not the staff to care safely for any further residents who have a high level of dependency. By way of example the manager explained it takes two carers an hour to get Agnes up in the morning, she uses a wheelchair and all transfers require double handling. (no change there then)*

One of the difficult aspects of this case was that a review was carried out in January 2002 by Agnes's Social Worker, who works for Age Concern/Access. She said that she couldn't say that it was in Agnes's best interest to move because she was getting all the care, love and attention she needed. Her son, has naturally seized upon this and is adamantly opposed to his mother moving. It was felt that his expectations were raised unreasonably concerning what the Care Home could do for his mother. Unfortunately the Social Worker confused her advocacy and social work roles and this has created some management difficulties. Meanwhile, he has not looked at any alternative Homes for his mother and has clearly set his face against the prospect of his mum moving.

In a letter dated 10 May a Dr Chhabra states very clearly that Agnes's needs more care than the present Care Home can provide. All agreed that this was an unequivocal statement that the present care Home was not a suitable placement for Agnes. A question was raised whether there was any point in considering an independent review of Agnes's situation, given the fact that the current review by the Social Worker is unhelpful both to the Department and her son, the former for obvious reasons and the latter because it is not helping him to any acceptance of the difficulties that the Home is having in coping with his mother. There were significant concerns about going down this route, due to wider issues concerning the Department's relationship with Age

Concern/Access. He advised that there are perennial problems with tension between the advocacy and social work roles that Age Concern workers have and he felt that to pursue this route would not be helpful at this stage as the damaging affect it would have to the relationship between Social Care and Age Concern would outweigh any helpful affect it would have in this particular case. Clarifying what the contractual arrangement would be between the resident/family and Social Care, it was advised that there was an in-house agreement, not legally binding, under which the resident was provided with care. Was there any guarantee of "a home for life"? The Home leaflet clearly states that a resident can stay for as long as the Home is able to meet their care needs.

Legal advice was provided on the following issues:-

- Regina -v- North Devon Health Authority Ex-Parte Coughlan. As there has clearly been no "home for life" promise made to Agnes or her son the Department has not created an obligation to maintain her in the for that reason.*
- Article 8 Human Rights Acts. JCA advising that it was necessary, post the Human Rights Act 1998, to have particular regard to Article 8, Agnes's right to a private/family life which included being maintained in her home, in this case the Care Home. In making any decision to move a resident in order to be able to meet their care needs it was necessary to balance the need to move the resident against the presumption that they would have their home life respected. It was also relevant, when balancing this equation, to have regard to the needs of other residents currently in the Home, in this regard concern regarding the risk to other residents when staff are dealing with Agnes's significant care needs, and also the fact that the Care Home is being forced to maintain vacancies when there is a huge demand for the service offered.*
- In assessing the needs of a resident in the context of considering a move to a different establishment, it was particularly relevant to look at whether their "need" included a psychological need to remain in their current placement. Depending on Agnes's level of understanding of this situation this may not be that relevant a consideration in this case.*

It would be sensible to make "bridging" arrangements to provide extra resources, making it very clear that this is being done as a temporary stop gap measure pending resolution of Agnes's situation. It was suggested they meet with her son, sharing with him the GP's letter (subject to the permission of Dr Chhabra) in order to explain fully to him the Department's position. It would be appropriate to provide him with a copy of the "starred" review, if he does not already have access to it, and explaining in detail how the Home is not able to meet his mother's needs any longer due to her increased frailty. They would have to be prepared to meet her son's almost inevitable response that the Department should put in more resources to the Home on a permanent basis in order to maintain his mother in her current placement. Clearly, this would not have been an issue if Agnes had been placed in a privately owned residential home as the proprietors could simply have given notice once they became unable to cope with her care needs.

The above is quite interesting. All this lot had to do was to answer a few questions on nursing care so I could understand the situation quantitatively. I found it very difficult to understand their situation without some detail.....just saying 'she needs nursing care' meant nothing. As a result of the meeting minutes above, I was contacted a few times by Peter Shakespeare, the Assistant County manager for Residential Care Services (who incidentally had never met my mother). I advised Mr. Shakespeare that I visited the Care Home quite regularly on a Saturday morning if he wanted to meet me and discuss the issues but of course it was a Saturday and he wouldn't do that. Sadly this was another bureaucrat who couldn't give me the answers I wanted so that didn't get anywhere. However, in October, he did consider sectioning my mother under the Mental Health Act which did of course mean they could have moved her despite mine or anyone else's wishes. The **first guardianship memo** from the County solicitor is available separately on the main page. On the 19th October I received a telephone call at work from a Dr Goodwyn from the Derby Road practice, who gave me a lecture on skin break outs and bed sores and to reprimand me for my mother occupying a place in the Care Home that someone else could have (charming attitude). He apparently visited my mother on the 17th October but he told me nothing about the state of my mother's health. I found the conversation very weird but on the same day I received a letter from Peter Shakespeare telling me that they were going to apply for guardianship under the Mental Health Act. This was all a bit much so next day I went to see my mother. I was quite shocked at her condition, there was a significant change from when we last saw her, she was very weak and had lost a lot of weight. I was told by the carers, **not** by Care Home management or medical staff, that she was nearing the end of her life. My reply to Peter Shakespeare was:-

Because I had no idea of the poor state of my mother's health last Friday, we may have been at cross purposes. However, given that my mother probably has not much longer to live, I do not want her moved. I'm sure no one would want to see the headlines...'Ipswich Social Services evicts dying pensioner'. My mother is not placing any extra demands on the care staff, in fact she is and has always been a lot less trouble to care for than some DESPITE what you may have been told, and the carers are quite happy to care for her. There is NOTHING whatsoever that a hospital or nursing home could add to her care at this time, all she needs is to be left in peace in familiar surroundings and I will do everything that I can to ensure that she is. It really is not the case that the carers are struggling to cope but I know you must have your procedures so I suggest that if you have problems with this you hire an Agency carer for the short time she has left.

Unknown to me and only recorded in the Care Home record, it would seem that they no longer considered my mother as capable of conveying her wishes to carers as from mid-September and that she was experiencing

difficulties in swallowing....she was taking little by mouth. A STARS assessment on the 17th.October was 53/136. Also, and again unknown to me, on the 18th.October, Social Services were in discussion with the Local authority regarding guardianship. **The second guardianship memo** can be accessed on the main page. In retrospect this is quite a strong memo and quite disturbing in a way; I have never met or have had any contact with any of these people, certainly not the Social worker mentioned. Most of the memo that references myself is untrue. In the end this turned out to be a lot of hot air as nothing was done about forcing guardianship, there was no communication with me about the contents of this memo that, at the time, I was totally unaware of. What I still can't understand to this day is the fact that if Social Services were really convinced that it was in my mother's best interests to be move to a Nursing Home earlier in the year, they surely had enough clout to find a place for my mother instead of waiting for me to do all the searching and arrangements from 150 miles away. I can't say that in retrospect it would have changed the situation but at least it would have been helpful at a challenging time when I was faced with aggressive bureaucracy.

One final item I need to mention. My mother's original ACCESS care worker, Jackie, retired during the middle of the year. She was a kind, caring and patient lady who did look after my mother with regular visits when she was in her own home. Looking back on that period I realise how grateful I am to that lady for keeping an eye on my mother, I didn't understand Alzheimer's at the time but she unquestionably dealt with all the issues raised by me which in retrospect some were really misdirected. She retired because I think she got fed up with the inadequacies of the social care system in treating the elderly as numbers rather than persons and just moving them along in the system. From the documentation package I was later sent, her replacement I presume was Mary Beth, someone I never met, had no contact with and didn't know about until years later.