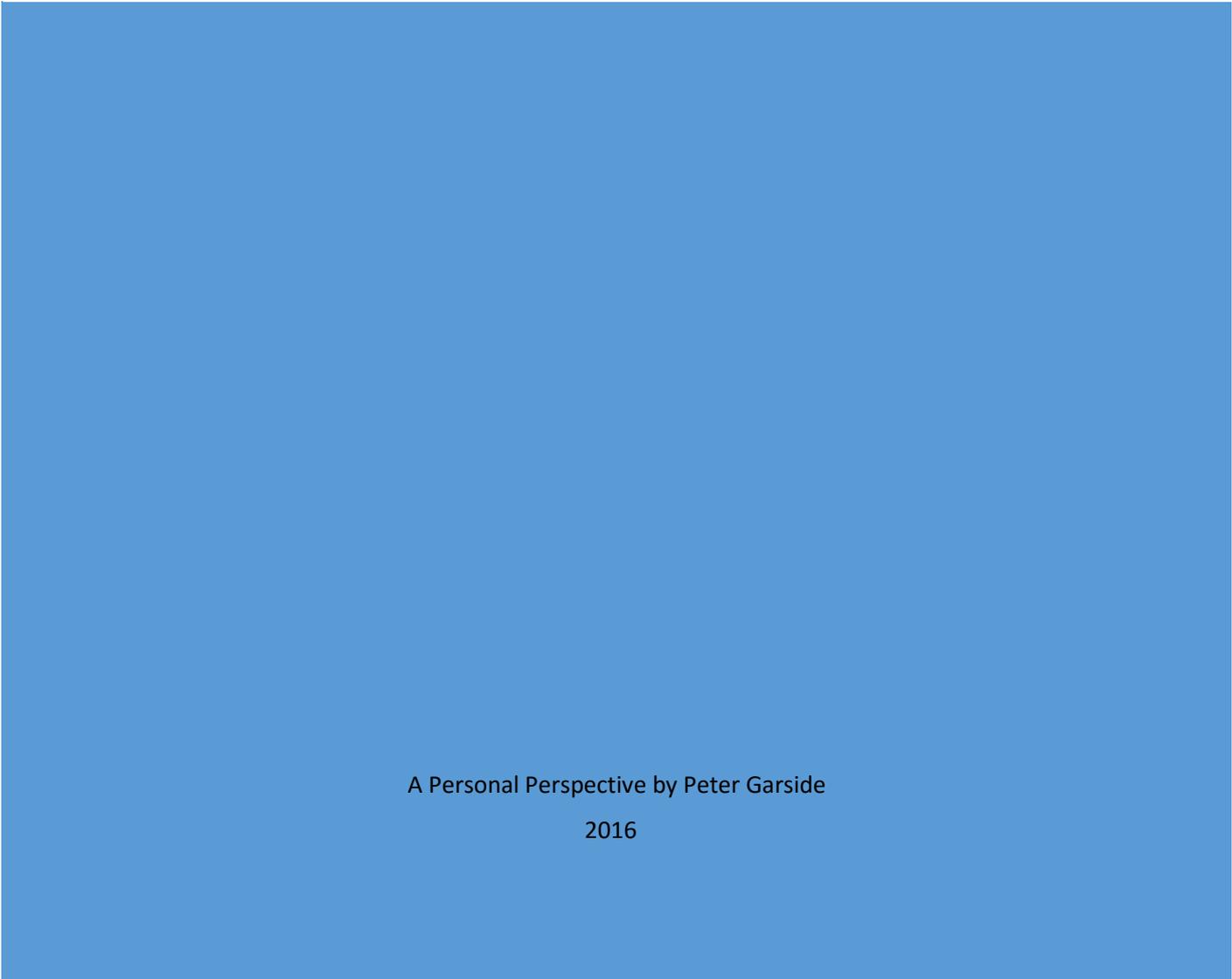




REFLECTIONS ON MAKING AN  
NHS HEALTHCARE APPEAL FOR  
THE CARE OF MRS PAULINE  
GARSIDE

A Personal Perspective by Peter Garside

2016



# Reflections on Making an NHS Healthcare Appeal for the Care of Mrs Pauline Garside

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### Pauline's Story

This reflection is applicable to Pauline Garside's care application made in England. I believe there are more generous arrangements currently available elsewhere in UK.

Due to concerns with Pauline's memory we consulted our GP in late 2012, and he referred us to the Cambridge Older People's Mental Health Services. This was quickly followed by Blood Tests, ECG Scan, and a C/T Scan. The ECG ruled out vascular damage, and the C/T Scan found nothing abnormal, but on 30<sup>th</sup> January 2013 Pauline was diagnosed with Early Onset Alzheimer's Disease. We suspected a problem as Pauline could no longer follow her favourite TV programs, as she could not remember the story line from the previous episode. Pauline used to forget what she was saying mid-sentence on a regular basis, but as I used to often anticipate her thoughts we had managed very well for some time. It was annoying for her when she forgot the need for a loo visit until too late, but again we managed without a fuss with incontinence pants, which we bought privately rather than trouble the NHS. Tablets were prescribed to slow down the effects of Alzheimer's, and existing medication adjusted as required for compatibility.

Pauline's first reaction to the Alzheimer's diagnosis was concern she would be labelled as a Dementia Sufferer, and I should keep the diagnosis confidential. However Pauline admitted to me for the first time that she failed to recognise people she had seen only a few days before, and covered this up by being friendly when people approached her. Pauline also admitted that she would get distressed when I was outside the house, and she had forgotten how the TV Remote worked, as I usually did all the channel changes when we were together in the room. Alzheimer's disease had clearly been developing for some time, but Pauline was able to manage normal living, at least normal for us, before we sought medical advice.

Once diagnosed with Alzheimer's disease NHS were able to advise us to make some changes and get some support organised. Although Pauline had not driven a car for several years we were told to give up her Driving Licence, and get a Lasting Power of Attorney document signed as soon as we could. I would then be entrusted with Pauline's health and welfare needs long term. Community Nurses called at our home and provided helpful advice on how to manage the memory problem, and another nurse called weekly to ensure the new medication (Memantine 20mg) dose could be increased to full strength from the initial 5mg without adverse side effects. I was referred to The Carers Trust to ensure that an Emergency plan was devised so that should I be unable to look after Pauline's needs 24/7 then assistance would be forthcoming. The NHS were very helpful for several weeks but by May 2013 we were on our own, and no further support was forthcoming.

As we were advised on 30.1.2013, Pauline's health would decline steadily over the next couple of years and further details are recorded below, until her eventual death on 9.2.2016, after a short illness unrelated to Alzheimer's disease. To secure our Right to NHS Continuing Healthcare at home, there were 4 separate Assessment Meetings which took place including the formal Appeal Panel as follows:-

14.10.2014 – GP Referral led to an Initial Assessment by a Social Worker visiting our home, and filling out a Questionnaire checklist. It was agreed that our situation merited immediate care solutions, and our application was referred to a senior colleague.

24.10.2014 – The Senior Care Worker made another Assessment, and confirmed our application would again be referred upwards to the Complex Case Unit in Cambridge for a Final Decision on

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the provision of NHS Continuing Healthcare. The Senior Care Worker was very supportive of our case.

12.12.2014 – The “Final Decision” meeting in our home consisted of a detailed Assessment Questionnaire completed by a Complex Case Unit person who seemed to be supportive, & was accompanied by the Senior Care Worker I met on 24.10.2014. Pauline was not seen personally & we had our own privately funded carer with her for company. I had done no preparation for the meeting, and thought our case for NHS help was Routine. This was a mistake as on 7.1.2015 a letter came Refusing NHS Funding because Alzheimer’s disease was not considered to be a “Primary Health Need”, and Pauline “did not meet the criteria for help”!

12.8.2015 – The Appeal Panel Meeting was held, and reversed the previous Decision, Dating our Entitlement to NHS Continuing Healthcare back to the previous meeting on 12.12.2014.

Further details concerning these meetings are noted below in the hope that you will learn from my mistakes, and obtain your Right to NHS Funding of your medical needs in a more timely manner. The key is in the preparation, and understanding of their requirements which is not readily available to the general public, and will take a lot of time discovering on the Internet.

## Care at Home

We were on our own from May 2013. Apart from routine GP consultations there was no input to help us from the NHS. This was brought home to us following an admission to Addenbrooke’s Hospital on 19.6.2014 when Pauline was suffering from headaches and blurred vision. She had been suffering from repeated attacks of Bronchitis and had several courses of antibiotics in the previous months, and our GP requested further investigations to be made. After 6 days of tests and treatment and with the assurance there would be care at home for a much weakened Pauline, she was discharged on 24.6.2014. Although a Community Psychiatric Nurse came to assess Pauline at home there was absolutely no help forthcoming via the hospital to nurse Pauline at home. The Care Network “Welcome Home from Hospital” package we found out is staffed by volunteers not professional carers!

After signing up for this service, and being assured we would be covered at home for the next 3 weeks, the first volunteer to contact us agreed to call round 2 weeks after Pauline’s Discharge from hospital! Then to make matters worse she cancelled 24 hours before the visit as the Tour de France was setting off from Cambridge and she wanted to see the cyclists that day! I was beside myself looking after Pauline 24/7 as she was still unwell, so I told the lady what I thought of her and not to bother calling us again. Fortunately this message got back to the organisers of Care Network as a very nice lady started to visit us daily a week later. This provided me with Respite care for 2 hours daily over the next 6 days, so 12 hours in total so I could do some shopping, as I had not been able to leave Pauline due to her memory problems in the previous 3 weeks.

## Our Introduction to Home Instead Senior Care

The lady who called in, and stayed for 2 hours at a time, recommended me to get in touch with Home Instead Senior Care, who had an Admin Office in St Ives, only a few miles away. They sent out their manager to meet us a few days later, and their company were appointed to provide professional Dementia care at our home for Pauline which started almost immediately. Initially this was for 2 hours each afternoon, 5 days a week, to get Pauline used to this type of care, and allow me to do other things around and outside the house. Coincidentally the young lady who first called on

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us lived with her parents nearby, and had got interested in care Work via her own mother, who visited her Grandmother in a nearby Retirement Apartment. She had learned about personal care and been trained by Home Instead to a high standard. Like Pauline she had a very keen interest in horticulture, so daily Pauline was taken into our Garden, and got very fond of the first carer to visit our home. Anyone suffering from Alzheimer's can find it difficult to adapt to any changes to routine, so this was an excellent start to our life now shared each day with professional care workers.

The other lesson I also discovered, after expending much energy, is if you want a job doing well you need to do it yourself, or get a professional organisation to do it for you and pay them the required fees. NHS were told of our needs very clearly before Pauline's discharge from hospital and I took their word that cover would be forthcoming as described to "Welcome Us Home". Nothing could have been further from the truth! Whether it was bureaucracy or poor systems, or just pressure of work to clear another bed on the ward, once outside the hospital we were on our own, and forced to manage without any care in the community. There are no doubt many individuals working for the NHS who are a credit to the medical profession, but clearly the demands on the NHS by 2014 far exceeded their capacity to cope, and imagine it continues to get worse every day, until there is an effective partnership between the state and private care organisations in UK, in my opinion.

The beauty of the Home Instead Senior Care organisation is that their care services can be updated and increased as required long – term on a personal basis, to fit the precise needs of their clients in their own homes. They take care of all the admin and training of their staff, and payroll which would have to be done personally if employing your own live in carer.

I could not have managed to look after Pauline at home without this company to help me. The daily hours were increased after a few months to include her personal care, washing and Dressing, as this was starting to take longer each morning as Pauline's health gradually declined. The 4 hours increased to 6 hours daily, then to overnight cover in the last weeks of her life. Pauline died on 9.2.2016 from another medical condition as described later in this Reflection Report.

## A Personal Background to Pauline's Story

Anyone reading these Reflections could very likely form the opinion that I spent most of my married life to Pauline caring for her health rather than her personally. We had an excellent loving relationship founded on our committed Christian Faith, and for 30 years were members together of St Andrew's Church in Histon, just north of Cambridge, England. We enjoyed active holidays, a productive garden, and lots of Friends and Family contacts. My two step sons were close, although too old when we married in 1984 to consider Adoption. They both lived or stayed at our home in the early years, until getting established in their own homes.

Pauline used to joke with me that the test of our relationship would be whether I would still love her if she "Had half a head and no legs". I assured her I would love her unreservedly, little thinking that one day this would in reality happen to Pauline! With our strong Christian Faith, and the support of our close Friends, and Medical Practitioners as required, we coped with Pauline's deteriorating health over the last 10 years of our marriage, maintaining good humour & joy in the company of each other. Pauline was my Best Friend as well as my Wife until her death parted us on 9th February 2016.

When we got married in 1984 I was professionally qualified as an Independent Financial Advisor (IFA), who left the Investment Company World to look after individual clients in a more personal way locally from an Office in Cambridge. I worked at what was then called an Insurance Brokerage

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as the Pensions Director for 8 years. After our wedding a few months later the brokerage was sold and we decided to start our own IFA Business in 1985, and enjoyed for over 23 years looking after a large number of loyal clients, until in 2008 we received an offer to buy our Office from a Local and much larger IFA company. The timing of this approach was perfect as Pauline was by now requiring a Wheelchair and assistance with all transfers, due to a long standing Back injury. My Early Retirement, at the age of 58, allowed us time together which was not always possible when running a busy consultancy. We thoroughly enjoyed this special time in our marriage, and made a point of going out somewhere each day to walk our Dogs, with Pauline using a 4 wheel scooter to be independent.

There were medical issues with Pauline for many years like clinical Depression, Diabetes, and sight problems, but we managed these daily. As the Wheelchair started to be required indoors as well as outdoors we fitted Ramps for ease of access to our Garden, which was Pauline's long term favourite place since we moved to Histon in 1985. We enjoyed our life and Pauline rarely complained about her medical issues as she had a high tolerance of pain, and never liked to make a fuss in the normal way.

## Healthcare Funding Via NHS Continuing Care Provisions

Social care via Local Authorities in UK is subject to a financial means test which for most people, with nominal savings, involves a personal financial cost. Care workers, in my opinion, have far too many people to see each day, so visits are made when they can, and not when they are actually required. The times may differ each day so washing, dressing, meals, and bed time, can vary to suite the Worker's timetable. I am sure there are many devoted care Workers but the numbers of patients and time constraints is a daily issue.

NHS Continuing Healthcare is however assessed on a "NEEDS" basis so if the person's needs are high enough they can qualify for a "Personal Health Budget" paid by NHS 4 weekly to a designated Bank Account. There is no means testing whatsoever. The difficulty however is how to qualify via a system of stonewalling, distortion of facts, and an attitude of putting obstacles in the public's way, in the hope that they will give up on their Application and go away, in my opinion. You need therefore to be determined to obtain your rights on behalf of your Dependant Relative, and be prepared to fight all the way up to the NHS Ombudsman, if necessary. The whole process took me approaching 12 months to achieve, but this was because I was unprepared and did not know how the system worked. We had to go to an Appeal Panel eventually, but when our case was won the benefits were backdated to the day the original Decision made refusing care for Pauline at home. The Appeal had to be made within 6 months of the date of the Refusal Letter on 7.1.2015.

When completing an Assessment, Social Workers and NHS use what they call a "Decision Support Tool" (DST) designed to accurately note under each category of "Need" the correct level of intensity that is applicable. These range from "Priority" to "No Need". A "Priority" "Need" in any one of the four Domains that can carry this level of need, or "Severe" in two or more Domains, should lead to a clear recommendation of eligibility for NHS Funding.

A Domain describes each category of need on the DST Form. There is flexibility however so one score of "Severe" together with a number of "High" or "Moderate" levels of need can also qualify for NHS Funding. The separate Domains are further explained below, together with our personal experience of being assessed for eligibility. It may also be apparent to you that there is a lot of scope for personal opinion when using the DST. The aim of this method of Assessment is to obtain consistent results

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throughout UK, and there is Case Law noted below to enable you to read up on the cases concerned to prepare for your own Assessment Meeting.

The medical condition being assessed must qualify as a “Primary Health Need” and will therefore have to be serious and debilitating. With Pauline in mid or even Later Stage Dementia our DST at the Appeal Panel hearing scored only 4 “High” needs and 5 “Moderate” needs, whereas I was sure Pauline had at least 3 “Severe” and 4 “High” needs. However we scored high enough to win the Appeal after 9 months of self-funding Pauline’s care needs at home.

At the initial Assessment Meetings I had no idea what a DST was and how Pauline’s needs had to be described. A professional health Worker can go through these questions rapidly, and however well-intentioned they cannot know exactly how complex life is each day for you coping with the health situation in your home. One slip or downgrade can make the difference between eligibility for care funding or a refusal! It is essential to understand the DST and research case history on a computer before the Assessment Meeting in my opinion. Actual case history where NHS have granted Funding to people with Alzheimer’s I found on the internet, and is further explained in the section dealing with “Launching an Appeal” which covers the implications for other people with Alzheimer’s.

## Care Domains in the Decision Support Tool (DST)

Great care is necessary at the Assessment Meeting to accurately describe and score the “Level of Need” under each of the 12 separate categories of “Need” in the DST Document. This will take some time to complete so your concentration will have to be at its highest level possible in my opinion. You will be dealing with someone with qualifications who has experience in these matters which you will not have personally. You need to prepare as thoroughly as possible, and to help I will include details of Pauline’s personal health facts of daily living for your assistance.

Bear in mind the categories of “Need” range from the highest level called “Priority”, to the lowest level of “No Needs”

### 1. Behaviour

This by definition is difficult to describe and a complex area to adequately cover as a Domain. It ranges from Challenging Behaviour such as Aggression, Severe Disinhibition, Noisiness, Restlessness, Resistance to Care and Treatment, Concordance, Severe Fluctuations in Mental State, Extreme Frustration with Communication Difficulty, Interference with Others, and high Risk of Suicide. The risk to themselves, others and property, Self-Harm and Self Neglect irrespective of living environment, are all Behaviour issues. There may be more, and they need to be discussed and assessed accordingly as per Risk and “Need” for care in an accurate way.

Pauline’s care required all moves to be assisted because of her Disability and need of a Wheelchair at all times. Because of Alzheimer’s disease her reactions and responses could be extreme and unpredictable. She could be short tempered and prone to verbal outbursts. If left alone Pauline would call out and get very distressed if there was no immediate response. Her short Term memory defect meant Pauline had no comprehension how long she had been left alone, and whether I was in the house, or had gone out somewhere.

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Having familiar and secure continuity of carers greatly assisted our situation at home, and no doubt because we were coping with these Behaviour issues and they were predictable the Appeal Panel decided our “Needs” were only “Moderate”. I had ranked the “Needs” as “High” or even “Severe”, certainly closer to the highest category of “Need” in the DST Form. This downgrading could have caused us to lose the Appeal, but fortunately the other categories scored enough for the overall total to be enough to get NHS Funding.

I would urge anyone approaching an Assessment, especially an Appeal, to be careful under this category of “Need” to state their case assertively to reflect their current situation and all of its details, especially if you have found a way of managing every day by the time of the Assessment. The objective is to reveal the true situation and the correct level of “Need”.

### 2. Cognition

This Domain applies to individuals with learning disabilities, and degenerative disorders. Professional judgements are required to determine the level of “Need” and Risk to the person being assessed. There is a National Framework Guidance in force which needs to be applied under the Mental Capacity Act, including the individual’s ability to make decisions and choices.

As Pauline had been diagnosed with Alzheimer’s disease in 2012 she was clearly unable to make decisions about her own care, and required close supervision with all activities of daily living. Pauline was unaware of risks to her personal safety which was made worse by her short term memory loss. Her attention span had steadily worsened, and could no longer watch television programs to the end.

The Regular carers who called at our home, and were recognised and familiar to Pauline were a great help, although she could not always recall their names. We managed this situation by requesting photographs of the carers from Home Instead Senior Care, and I wrote their names on the photographs. By showing Pauline the photograph prior to the carer calling at our home we avoided stress as far as possible.

The Appeal Tribunal readily agreed with my Assessment that a “High” score was appropriate to Pauline’s health “Needs”, although there are higher levels of classification if more appropriate to your circumstances. If achieved then this will be helpful in obtaining the goal of a “Personal Care Budget” to manage your care needs at home long-term.

### 3. Psychological & Emotional Needs

Irrespective of the underlying condition the impact of this category of needs to the Individuals health and wellbeing have to be assessed. This Domain is used to record how they contribute to the overall care needs required. Where the individual is unable to express their needs due to their overall health situation this is the place to record the details, and make a judgement on how important this category is for them personally.

As Pauline had already been Assessed as suffering from Alzheimer’s Disease by a health professional it was quickly agreed that a “High” level of “Need” was appropriate to her situation. Daily close supervision together with assistance and prompting was required with all activities of daily living. Pauline also had a long history of Depression, Manic Disorder and Intentional Self-

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harm, dating back for most of her life. This involved Admission to psychiatric hospitals on several occasions before our marriage in 1984. Although well managed for the previous 30 years by our GP with effective medication, Pauline relied on me absolutely to dispense the tablets daily due to her poor memory. With manic Depression there can be chronic anxiety together with extreme reactions which required constant and careful management daily. Provided Pauline did not get upset her mood was fairly stable, but this meant that she could not be left alone at home just in case something went wrong. Regular visits from Family and Friends, together with Daily visits from Home Instead Senior Care managed these issues very well. People who did not know Pauline well may not have realised these serious health issues existed but the full extent of them had to be noted under this Domain.

Again I would urge anyone facing issues of this type at home to be completely open and truthful, and make your case strenuously to obtain the highest category of "Need" appropriate to your circumstances. There are higher categories than the one we achieved although Pauline's mental health was a huge issue throughout her life. There are categories of "Severe" and "Priority" but neither of these appeared on the Results page leading me to guess that we in fact got the highest level of "Need" possible at the Appeal Tribunal. The "Decision Meeting" held on 12.12.2014 recorded Pauline's "Needs" as only "Moderate" so I was very relieved that the Appeal Panel, after hearing my evidence, and looking at the facts more closely came to an appropriate decision of a "High Need" in this Domain.

### 4. Communication

This Domain deals with the ability to communicate clearly verbally or non-verbally, and having a good understanding of the primary language used at home. Any difficulties with expression and understanding need to be noted, including the use of pictures, sign language, Braille, hearing aids etc.

Pauline had clear speech, but with Alzheimer's disease, and poor memory, the content tended to be repetitive. Her answers had therefore to be pre-empted and anticipated.

Pauline also suffered from the Eye condition Glaucoma and lacked peripheral vision in Both Eyes. This was caused by too much internal eye pressure which was undiagnosed over several years. Once detected it was treated with Eye Drops 3 times daily, and regular 6 monthly check-ups, with laser treatment as required to prevent further deterioration. This Glaucoma condition had to be advised to all visitors to our home to ensure they approached Pauline from her Front as she could not see things from her side.

Even though Pauline had very obvious communication problems the NHS Assessment concluded that only "Moderate" needs existed. The Assessment on 12.12.2014 unbelievably ranked this Domain as "Low" so the Appeal Panel at least understood that both Alzheimer's Disease and Glaucoma greatly affected Pauline's ability to communicate. However I would have rated Pauline's needs as "High", and so would urge vigilance again when facing an Assessment in order to get a correct and fair score in this Domain. NHS appear to take the attitude that the person being Assessed has to be unable to communicate their needs before they award a "High" score in this section, so be warned and prepared to argue your case if necessary.

### 5. Mobility

This section considers individuals with impaired mobility, and includes issues like wandering into account. If you have had an up to date “Moving and Handling & Falls Risk Assessment” this will be helpful evidence to put forward in your Assessment for NHS healthcare.

Pauline had required the use of a Wheelchair, due to a long standing Back injury, for the previous 12 years when Outside our home, and latterly within the house, when a Walker was deemed too dangerous for her to use due to the risk of falls. Pauline had become less safe around the house and I kept a record of her falls so that the details were available on request at our GP Practice. These were mostly at night when I was asleep and Pauline got out of bed for a Toilet visit. I installed pressure pads beside the Bed which are available from NHS on request. Also one was installed under the carpet by the Bedroom Door to wake me should Pauline try to go Downstairs unsupervised on her stair lift.

Pauline also had the condition Bilateral Lymph oedema in both of her Legs. The excessive fluid problem was controlled by special hosiery used daily. Pauline could not turn herself in bed at night and required re-positioning once or twice a night.

The Appeal Panel agreed Pauline’s needs were “High” as physical harm and pain on movement was a constant issue, and she was unable to co-operate effectively. There was a high risk of falls occurring just getting into or out of a chair or wheelchair. Also the toilet and car were risk areas daily.

If you are in a situation where your loved one cannot bear their own weight, or re-position themselves without assistance then you should qualify at the same level as Pauline or possibly at a higher score of “Severe” as that is also available in the DST Questionnaire, I presume for people completely immobile.

### 6. Nutrition – Food & Drink.

If an individual is at risk of malnutrition, dehydration, aspiration issues, or weight loss is significant in recent years, then this category of Domain is important. However to get into the “High” category they will need to be already receiving skilled treatment to ensure adequate nutrition / hydration, and are likely to be on a feeding device. If they need feeding and take a long time to consume a meal, or even liquidised food, then only a “Moderate” score is likely to be achieved. Constant supervision to prevent choking, and prompting to eat, appears to rate a “Low” needs score. If choking is a regular occurrence I advise stressing this assertively to get a “High” score.

Pauline scored “Moderate” needs in this category in spite of being prescribed a saliva spray by our GP for a constantly dry mouth as a side effect of her daily medication. The dry mouth meant each mouthful of food, even liquidised, required a prompt to take a drink, or choking would be a high risk. I would have pushed this Assessment had we been required to Appeal to a higher Authority to secure NHS Continuing Healthcare. I believe Pauline should have scored “High” or even “Severe” needs in this category.

Daily drinks for Pauline required close supervision due to the constant risk of spillage, and consequent need for change of clothing. Straws and beakers were tried but as these required

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suction Pauline often found them difficult to use without encouragement. If I was not so attentive to her needs when Pauline was assessed we would have achieved a higher score in my opinion.

### 7. Continence

As with nutrition I found the Assessment for Continence to be unsympathetic and frankly unrealistic in terms of a home Environment. Unless continence care is problematic and requires timely intervention beyond routine care like a Bladder wash out and manual evacuations then a “High” need Assessment is unlikely to be achieved in my opinion. Even the use of a catheter can be supervised by a District Nurse, so this does not appear to be ranked as a “High” need.

Pauline was incontinent of both urine and occasionally faeces. She had recurrent urinary infections and treatment from antibiotics. Due to the Alzheimer’s disease our daily carer was urged to be observant and if necessary enquire if passing urine was painful or not, if they were quick enough to get to the toilet or commode before an accident occurred. In spite of me suggesting our needs were “High” the level recorded by the Appeal Panel was only “Moderate”.

I would urge the public to be assertive under this Domain to get a fair score appropriate to their “Needs” and realistic for their home environment. Again I would have appealed if necessary under this category as I felt our needs were not accurately assessed at the Appeal.

### 8. Skin Including Tissue Viability

Evidence of wounds and skin condition should be very carefully monitored daily. This is especially relevant where it is known skin rubs on skin daily at say the lower stomach area. Pressure damage can lead to wounds and ulcers which should receive specialist dressing and treatment via say a District Nurse. If this is a long-term issue then a “High” level of need may be achieved, or even a “Severe” score if necessary.

With Pauline’s care it was part of my routine, and later the personal carers, to ensure her skin was not allowed to break down by applying cream twice daily. I helped her re-position in Bed as required at night, and we attended the Lymph oedema and Diabetic clinics regularly. Pauline’s Diabetes caused partial loss of feeling in both of her feet, so we also attended a podiatrist as required to deal with any injury, and a chiropodist every 2 months. Due to the great care we took over Pauline’s skin we only scored a “Moderate” level of need on the DST. It appeared to me that the more you did for yourself the lower the score applied by NHS. This did not seem to be fair or realistic to me when the overall situation should have been relevant. Pauline was a “High” Risk person given her medical history in my opinion.

As before I would urge people to be vigilant and assertive when being assessed to ensure the NHS Continuing Healthcare DST is completed accurately and fairly. All wounds suffered should be carefully recorded over the years so nothing is left to chance in this Domain.

### 9. Breathing

For individuals suffering from Emphysema or recurrent chest infections it is clear what difficulties they are managing under this category of need. If able to breathe through a tracheotomy, or suffering a condition not responding to treatment then perhaps it may be possible to get a “High” score.

Pauline was able to breath for herself and was recorded in the lowest category of “No needs “on the DST.

Although treated for repeated Bronchitis in 2014, 2 years before she died, Pauline was never given a C/T Scan of her Lungs by the hospital until Admitted a few weeks before her Death as described in greater detail below. I do not blame the NHS Appeal Panel on 12.8.2015 for their score as no one had any idea then that Pauline had a Terminal Illness affecting both of her Lungs which would make her breathing extremely difficult in the last weeks of her life. With the benefit of hind sight we left hospital on 24. 6. 2014 with both zero preparation and zero investigation as to her chest problems which had caused the Admission to hospital in the first place! Had this level of incompetence occurred in the private sector of Business or professions then I would expect their Indemnity Insurers would be preparing for a claim in my opinion!

As you can see from the above I am still suffering from the shock of losing Pauline on 9.2.2016. If someone has been suffering from a Chest Infection or Pain and Blurred Vision as Pauline presented on 19.6.2014 and Antibiotics had not been effective then something more should have been done before her Discharge on 24.6.2014. They may just have found what led to her death 18 months later.

Pauline had a mole removed from the back of her neck in December 2014 by our GP as a precaution. We were advised later that a myeloma was detected but of the lowest risk in terms of depth and so not to be concerned. Pauline attended 3 monthly skin check-ups which all proved to be satisfactory. No C/T Scan of her Lungs was advised or even discussed, so we were horrified to be told in January 2016 that Pauline had myeloma cancer in both of her Lungs and there was nothing the hospital could do to save her life! The NHS were however very sympathetic and gave us as much medication as required to relieve all of Pauline’s pain and suffering.

The lesson I would urge from my experience is not to dismiss a Domain like Breathing so quickly. If there is a chest Infection get it investigated and treated thoroughly by NHS or privately if NHS does do not have time due to Bed pressures to do the job properly. In Canada I have discovered routine C/T Scans are done in every case of myeloma! We have a long was to go for our NHS to be as good as healthcare elsewhere in the World in my opinion.

### 10. Drug Therapies & Medication: Symptom Control

As previously mentioned it is important to come to any Assessment Meeting fully prepared.

Details of prescribed medication can be found on the Repeat Forms to the GP, and you should know what each one is prescribed for, and what symptoms are being managed. The intensity if each condition is important to determine the level of “Need”.

In Pauline’s case, as previously mentioned, she had a long history of Depression since childhood and due to the complexity of her medication on top of Alzheimer’s it meant that all tablets had to be administered under supervision. She was not capable of doing this independently, so NHS

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immediately gave a “High” level of “Need” at the Appeal Tribunal. Had Pauline been able to medicate herself then there would have been a lower level agreed. At the meeting on 12.12.2014 unbelievably the Assessment was given as a “Moderate” need! Had I realised there were different levels, by preparing more thoroughly for the meeting, I would have challenged this very obvious understatement! If I had not been at home caring 24/7 for Pauline then a Registered Nurse would have had to call in at least 4 times each day, and monitor her health constantly.

Home Instead Senior Care has a system for their staff to dispense medication and record details on a chart daily. There is also a helpful system via local pharmacies to dispense medication into “Blister Packs” daily. I managed to get signed up for this service in Histon, but had to wait on a list for 6 months until we were included. There are clearly only a limited number of patients per Branch with this service due to the time taken to liaise with GP surgeries and dispense medication accurately for up to 7 days at a time. These “Blister Packs” are necessary if professional carers are calling daily and are required to take responsibility for medication.

If in the Assessment the person is suffering moderate pain on other symptoms having a significant effect on other Domains then a “High” level of “Need” should be awarded. If the medical condition has the potential to fluctuate, or side-effects are an issue, then I would advise pushing for a “Severe” or even a “Priority” Level of “Need” in the case of unremitting pain. A score of this level would I believe immediately qualify you for an NHS Continuing Healthcare Personal Budget to finance adequately the care needs at home, as well as providing for the necessary Respite care of the person providing daily care 24/7, in order to maintain their personal sanity long-term.

### 11. Altered States of Consciousness (ASC)

Anyone suffering from ASC on a frequent basis requiring the supervision of a carer or care Worker, to minimise the risk of harm should qualify for a “High” level of Assessment of “Need”. If ASC occurs on a daily basis with severe risk of harm then a “Priority” need is clear and NHS Continuing Healthcare should be available.

For Pauline she had “No Needs” in this category, which I was pleased to confirm at the Appeal Tribunal.

### 12. Other Care Needs

If there are any circumstances not covered in the other Domains which are relevant to your situation they should be noted under this category on a case by case basis.

Pauline had no other needs under this heading.

## Decision Support Tool (DST) At Our Appeal

The questionnaire used to note all the above categories of Domain is called the DST by Social Workers and NHS Assessment Staff. The initial Assessment Meetings were not as detailed as far as I was aware. Pauline was not given any “Priority” or “Severe” scores at the Appeal Tribunal, but was graded with 4 “High” needs and 5 “Moderate” needs. The other 3 categories were either “Low” or “No Needs”. The overall Result was well above the required score to achieve NHS Continuing Healthcare. Indeed 2 “High” and 3 or more “Moderate” levels of need would have been sufficient to qualify as far as I know.

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The Appeal Panel sat on 12.8.2015 and agreed that Pauline's health needs were such that without my care at home she would have to enter a nursing home immediately. Pauline was therefore properly assessed as being eligible for NHS Continuing Healthcare, and it was confirmed that her Alzheimer's disease was identified as a "Primary Health Need".

The panel also warned me that her health would continue to decline, and so the funding would require monitoring so that the actual costs of the provision of care at home in the future would be fully covered by NHS long-term. A Specialist Continuing Healthcare Nurse (CHC Nurse) was present at the Appeal Tribunal and she took personal charge of our case thereafter. The CHC Nurse dealt with the financial requirements in an exemplary manner via the Clinical Commissioning Group (CCG) local office for Cambridgeshire & Peterborough. The cost of care at home was financed via a Personal Health Budget (PHB).

Although the Appeal Panel warned me that Pauline would not live long, I expected at the time her Alzheimer's disease would require nursing at home for at least 5 – 10 years, and possibly more. Our victory was hugely important as healthcare would be intensive and expensive, and it was easy to estimate a figure in excess of £ ¼ million. Pauline died on 9.2.2016, only some 18 months later from an unrelated, and totally unexpected, medical condition! Perhaps the panel wanted me to be aware and prepared to deal with her Death, which would not be pleasant, whenever it occurred. However I was prepared, at least financially, as soon as the PHB was in force, as it was very easy to get the required healthcare at home increased via Home Instead Senior Care, and NHS adjusted the cash transferred to the PHB 4 weekly on request via the CCG Local Office.

## Personal Health Budget (PHB)

Having won the appeal at the tribunal held on 12.8.2015, I was very relieved to be advised that NHS would assume responsibility for all monies paid out for Pauline's healthcare since the date of the meeting held at our home on 12.12.2014. By the time cash started to flow the PHB was effectively backdated almost 12 months. This replenished our savings to a large extent. Future costs of healthcare at home were covered 100% as required long-term.

The NHS from April 2014 in England gave everyone eligible the option to have Continuing Healthcare at Home via a PHB. This enabled people to manage their care in a way that suits them through individual choice and control. To arrange and pay for your own support in this manner NHS requires a PHB to be set up with a "Support Plan" setting out the Health Needs and Outcomes. This "Plan" details the amount of money available, and how this will be used. The "Support Plan" is checked and agreed by CHC Team who then liaises with the CCG who administer the payments. CCG make these payments 4 weekly to the PHB Account.

In a National Pilot study of the PHB payment system NHS found that some people made different choices and bought services, care and support, that they knew would help them, and which the NHS did not ordinarily provide. This is possible, as long as it can be shown that the choice you wish to make is safe, is of benefit to the health needs, and can be purchased within the limits of the budget available.

An undertaking is required by NHS that the PHB will not be spent on non-Healthcare expenses like Rent, Food, Utility Bills, and definitely not on holidays. All of which could no doubt be of help to overall healthcare, but should be funded entirely separately.

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A separate Bank Account has to be set up to facilitate the PHB finances and make payments out for acceptable healthcare costs only. The Bank Account will be audited by CCG, and a record of income and expenses has to be maintained for this purpose.

### The Support Plan & Agreement

This is provided on paperwork supplied by CCG so that their office knows what the care choices are and how the health needs are to be achieved on a Daily basis. This is therefore a very important and practical Document, so that the “Needs “are accurately recorded and understood by the people responsible for the Healthcare at Home via your PHB. The plan also contains space for personal Details, contact phone numbers, next of Kin, and who the carers are that will be personally involved.

After the Support plan paperwork has been completed CCG will want to establish a “Support Agreement “, and the procedure agreed to administer the PHB in a manner that can be easily audited. For instance if a “Nominee “is to be used they will be noted, or a “Third Party Agreement” arranged if payments are to go direct to a Care Provider Company. If you want the PHB to come to your own Bank Account a “Direct Payment” will need to be selected. You can employ your own Live In carer but will have to be responsible for all the Employment Law compliance. If approved the PHB will have provision for the Extra costs of Employment like Indemnity Insurance, Payroll Services, Protective Equipment, Bank holiday and carer holiday provision etc. We however preferred to leave all of these responsibilities in the capable hands of Home Instead Senior Care as a professional Employer who could keep up to date with and compliance with Employment Law.

As Pauline suffered from Alzheimer’s disease and could not administer a Bank Account alone we established a Joint Account to receive the PHB payments, and I dealt with administration personally. As I was on my own in this regard an Additional signatory was appointed just in case I fell ill, and was unable to deal with the payments. Fortunately Pauline’s sister called in weekly and was happy to be included in these arrangements.

Once the paperwork is completed to the satisfaction of CCG they will make a home Visit in order to make an Assessment of the Budget required using a Nursing Expert together with a Case Manager who will quantify the costs on a weekly basis.

For Pauline’s needs at home for personal care, nursing care, and social care we had to cover the fees required by Home Instead Senior Care. There were different rates charged for Weekday and Weekend cover plus Bank Holidays whenever they occurred. Additional contingencies like extra cover so that I could have Respite care and time off to look after my own health were included, and budgeted accordingly. This was allowed for by costing out provision for carers to do sleepover nights adding in the hourly costs per week. When the total per week was calculated this was then paid across 4 weekly to the Designated PHB Bank Account.

The CCG stressed the need for us to review the PHB on a Quarterly basis to ensure it met the actual requirements long – term. This was particularly important when Pauline’s health deteriorated alarmingly after only 3 months from my meeting with CCG.

### Pauline's Final Weeks

Pauline was admitted to Addenbrooke's Hospital on Boxing Day 2015 suffering from chest pain and was immediately placed on the cardiac ward to be monitored closely. A suspected heart attack had occurred or was still taking place according to the paramedics who I requested to call at our home. In fact neither of these had occurred, but because of Pauline's Diabetes, damage to one of her heart Valves had occurred in the past but the resulting pain had not been felt. One would have thought further Tests should have been made by the hospital but these were not suggested before Discharge.

Due to Pauline's Alzheimer's disease, I still kept on the carers and they called at the hospital to ensure there was adequate personal care in the mornings, and social care in the Afternoons. Pauline was very appreciative at seeing her usual carers as the hospital environment is not pleasant for people with Alzheimer's for a number of reasons. Although the staff were no doubt lovely people there were regular changes of staff as shifts changed 3 times a Day, and meals were particularly difficult as Pauline could either not reach the food provided before it was taken away, or required feeding and the staff were not available or too busy to help her. It's not surprising patients lose weight in hospitals or suffer from malnutrition in my opinion! The hospital were careful to note Pauline's health situation in A & E prior to going on the Ward, but I saw no staff trained in Alzheimer's care actually assisting Pauline in the practical Daily Living issues every day. We were very reliant on our own carers, and myself staying each Day until Visitors' were asked to leave each Evening, so that Pauline was cared for as well as possible until Discharge.

On 7.1.2016 Pauline was discharged to our home with a large Bag of medication, including new Tablets because of what the hospital described as "Heart Failure". We were assured this was a general term meaning there were heart problems, but with the right medication further problems should not occur and several years life expectancy should be enjoyed.

It was pleasing to note that a stay in hospital at the expense of NHS of up to 2 weeks does not have an impact on the PHB administration. Funding continued to be paid by CCG.

Pauline's chest pain was not helped by the new medication, and she was not well enough to attend a Follow up Appointment which was cancelled. I called CCG in the circumstances and explained the new situation. The level of Daily care was increased by 50% and due to her weakness following the stay in hospital double incontinence was also now an issue. We managed not very well at home until we could see our GP again on 11.1.2016, and he arranged for an immediate Re Admission, sending us off with a Letter to hand to the hospital on arrival.

After another 6 hours in A&E in 11.1.2016, Pauline was Admitted onto a General Ward for further tests at Addenbrooke's Hospital. One of these tests was a C/T Scan of Pauline's Lungs as the chest pain was still extreme. We got the Results on 13.1.2016 and Pauline was Discharged 24 hours later after the Consultant in charge of the Ward had an opportunity to meet us. To our shock and horror we were told Pauline had melanoma cancer in Both Lungs, and there was no treatment available as the condition was too advanced. I mentioned under the "Breathing" Domain of the DST that Pauline had a mole removed just over a year before, and understood there were no further complications expected. The consultant, although sympathetic, could do no more for us in hospital and Discharged Pauline immediately with a Large Bag of new medication including morphine for pain relief. They also supplied a comprehensive book called "End of Life: a Guide". The 128 pages guide was for people in the final stages of life, and their carers. It took me 3 days to recover from the shock of Pauline's Discharge and the manner this was conducted. I then started to get very angry with the hospital and their inability to detect such a massive health condition, and treat it months or even Years earlier. Pauline was not a

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smoker so Lung problems never occurred to us, but a patient presenting chest pain to a hospital, who had been an inpatient 2 years earlier should have had a precautionary C/T Scan of their Lungs in my opinion.

The hospital took action to refer Pauline to the Local Palliative Care Team, and I got CCG to further increase our NHS Healthcare at Home so that the carers were calling 3 Times Daily plus Overnight sleepover cover with immediate effect. We then had the equivalent of hospice care at home as it was Pauline's Wish to die at home in familiar peaceful surroundings. CCG to their credit did not complain at the substantial increase in the costs of our PHB. The melanoma Outpatients clinic at Addenbrooke's were consulted on 27.1.2016, and were pleased to authorise an increase in the dose of the morphine pain relief, and confirmed that no further treatment was possible. They advised Pauline could live for a further year, or her Death could occur in a few months. The Palliative Care Team came to visit Pauline immediately the following day, and were very helpful arranging a hospital Bed which arrived 24 hours later. A member of their staff was appointed as the NHS's "Lead Person" via whom all services would be coordinated. The person was charming and well trained, and prepared to go the extra mile to be helpful to us. Our own Church was very supportive as were our Friends and Family. Pauline died on 9.2.2016, less than 2 weeks after our last hospital Appointment. I should mention that her death was very peaceful and her strong Christian Faith was of great comfort to us both.

The PHB set up by CCG was adequate to provide for all the care needs required at home, and in fact there was a surplus of almost £4,000 which I returned to their office before closing down the Designated Bank Account.

### Pauline's Death On 9.2.2016

Although the Diagnosis of melanoma cancer was an enormous shock for us and everyone who knew and loved Pauline, mercifully the end was very quick and peaceful. Most importantly Pauline Died at home where she wanted to beside a Window overlooking her beloved Garden. This would have been very different in a hospital or hospice Bed where strangers may have been present, and pain may have been an issue. Also we have given thanks that Alzheimer's did not develop to an extent that a loss of dignity would have had to be endured. With hindsight we could not have wished for a better death for Pauline and relief from her suffering of the last few weeks.

### Was The Effort To Get NHS Continuing Healthcare Worth It?

The struggle to get the PHB from the initial GP Appointment in October 2014 to the Appeal Tribunal on 12.8.2015 was with hindsight 10 months very well spent. It would however have been far less stressful if NHS had properly Assessed Pauline on 12.12.2014.

The main difficulty was getting NHS to agree that Alzheimer's disease is a "Primary Health Need". The information recorded at the meeting on 12.12.2014 incorrectly noted Pauline's needs so that the team which considered the Results stated that "Pauline does not meet the criteria for NHS Continuing Healthcare". They did not consider that the "nature, complexity, intensity and unpredictability of the totality of her needs warranted this award, and that her needs were predominantly for personal and social care". Had the DST been recorded correctly then the Result would have been entirely different. Our GP considered Pauline's needs were adequate, and so did I after discussing the subject with the Carers Support Team. I concluded therefore that NHS was making claims of this type difficult and as a

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routine were declining Applications in order to save money and keep within NHS spending targets. A fight for our Rights was therefore necessary.

I expected to nurse Pauline at home for many years so it was vital that NHS were made to comply with their obligations to provide healthcare for Pauline's needs long term. It was very unfortunate that Pauline should die from an unrelated and undiagnosed condition only 6 months after winning the Appeal, and getting NHS healthcare provided at home as requested. As the PHB was in force when Pauline got seriously ill from a terminal condition the income was increased very quickly in accordance with the increased needs. This was dealt with very efficiently by the CCG and the Specialist Nurse appointed to supervise our individual needs. They were available via email and telephone to respond efficiently, including home visits, with genuine sympathy for our situation. Had I not fought for Pauline's Rights the last few months would have been a lot worse for her, and for my own health.

## Launching an Appeal

### Implications for Other People with Alzheimer's

To lodge an Appeal if necessary against a NHS Decision to Refuse Continuing Healthcare you need to quote case history and case Law where successful Appeals have been made in the past. These cases created Legal Precedent and a guide for the conduct of Assessments in the future.

The hard work had been done by those involved in these cases. I know this to be factual as I have seen Guidance notes prepared for NHS staff dealing with such Applications noting Legal Precedents of significance affecting Continuing Healthcare claims. However I was totally unprepared in December 2014 when Pauline was Refused NHS care 3 months after lodging our claim for this Benefit.

As previously mentioned an Appeal has to be made within 6 months of the Decision Letter. I had therefore to do Research and find People to help us, plus look after Pauline's needs at home, all before July 2015. I studied cases published online, and obtained guidance from a lady trained as a Legal Executive, but employed by the Carers Support Team appointed to look after my needs as a Full time carer. I discovered several very helpful cases and the best one for people suffering from Alzheimer's disease was coincidentally relevant to a couple living in the same Health District as our own, and therefore presumably well known to the person who refused us any help!

Malcolm Pointon lived just South of Cambridge and was nursed by his Wife Barbara at their home. Barbara fought NHS right through to the NHS Ombudsman in 2003 to achieve her victory and get Alzheimer's recognised as a "Primary Health Need". She achieved funding for a Live in carer having been forced to give up work to care for her husband full time at the age of 51, after a huge battle lasting several years. In the NHS Notes this had the Reference Number PCT.E. 22/02-03.

In addition I discovered there was the Pamela Cuglan case which clarified NHS Continuing Healthcare law in 2007, when a "Primary Health Needs Approach" was adopted and had to apply in all Assessments thereafter. This I expect led to the DST approach to try and get consistency of results throughout out the country. As previously advised you need to understand the Domains covered by the person making the Assessment to hopefully get a fair Result.

In 2005 in another case, Maureen Grogan challenged the NHS in the High Court for Care Funding, and won her case in 2006. She was chronically ill with multiple Sclerosis and Additional Needs with nil

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mobility and was already in a nursing home paying for her own care. Her home had to be sold to pay the care costs. The Judge ruled that NHS should pay for her care!

Now you have the Pauline Garside case as described in these notes. I managed to obtain the Appeal Tribunal hearing by quoting the above cases, and proving that Alzheimer's Disease had been accepted as a "Primary Health Need" in the past, and Pauline should be reviewed again as a dreadful mistake had been made at the Assessment Meeting held at our home on 12.12.2014. This argument was accepted, and the Appeal Date arranged 3 weeks after my letter was received. If you are Applying for NHS Continuing Healthcare I would advise you to quote Pauline Garside, who got a PHB to be nursed at home in 2014 suffering from Alzheimer's.

## The Appeal Procedure and Appeal Submission

To put forward an Appeal to NHS I advise you to obtain professional Assistance. I discovered in an online search Kate Hurley who lives in the North of England. She was trained by NHS, but made redundant in 2011, and is now working to assist clients prepare in a professional format for NHS Healthcare Assessments. Had I looked and found her earlier then perhaps Pauline & I would not have needed to make an Appeal.

Kate provides an initial ½ hour advice free, but thereafter obviously has to charge on a time cost Basis. She was enormously important to me to ensure the Appeal Submission was professionally worded for the Appeal Panel who required a copy of my submission 2 weeks before the Tribunal Meeting sat to hear our case. Kate supplied the necessary paperwork by email in time for me to post off to the local CCG Office who dealt with the Appeal arrangements.

Kate Hurley can be contacted on [Kate@kh-continuing-healthcare.co.uk](mailto:Kate@kh-continuing-healthcare.co.uk), or telephone 01207 583788.

The original Refusal Decision Letter was dated 7.1.2015 after the meeting on 12.12.2014 and gave us the Right to Appeal within 6 months. After conducting the Research and making contact with Kate Hurley my Reply Letter was dated 27.5.2015. The 6 months was nearly over and out of time! The Appeal Tribunal I was informed was not a Legal court so I was not permitted to have a Legal Representative speaking on my behalf. They could be present as moral support but not allowed to speak in the Room. It is my opinion that had I not done the Research, and been prepared by Kate, The Appeal would have been unsuccessful, in spite of our strong case for NHS support.

The Appeal Tribunal hearing met on 12.8.2015, and I recall there were 10 people in the Room facing me and my Legal Executive, who was not permitted to speak. It was therefore me representing my Wife Pauline against 10 people sitting in Judgement of our Appeal. The meeting lasted around 2 hours, and I was completely exhausted afterwards! I had been questioned in great detail under each of the 12 Domains by professionals trained and experienced in their field of expertise. There were Doctors, Mental Health Experts, Nurses, Social Workers, and an Independent Chair Person who I believe was a Retired Health Official, but no doubt had many years' experience in health issues. I felt like it was me against the whole medical Establishment, but the Chair Person did try to keep the procedures friendly and atmosphere comfortable. As promised the Chair Person telephoned me later that Evening to advise that we had won our case and the Formal Letter would be forthcoming in the next 10 Days. It was stressed in the telephone call that Pauline was Eligible because of the Level of care she was receiving, and that her health was deteriorating.

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The Formal Appeal Result Letter dated 25.8.2015 backdated NHS Continuing Healthcare to the Date of the initial Decision Meeting on 12.12.2014 which confirmed to me that at last we had got a fair Result. The support from CCG sprang into action and NHS provided Benefits as requested on a "Needs" Basis and not "Means Tested", as would have been the case via the Local Authority. Everyone has a Right to be nursed at home, but to achieve your Rights with NHS you must be prepared to Fight, and keep fighting until this is obtained, as illustrated by our experience.

## Conclusion

To admit to being an uncaring organisation, at least in part, is unlikely to ever be made by NHS. The reality of being refused NHS healthcare funding is I believe a conscious decision made by NHS in order to control as far as they are able the amount of money given to the public each year. I know they have to be careful not to squander their resources but to achieve our Result took a lot of effort.

Tragically it is those in the greatest need of healthcare and financial assistance in their homes that are least likely to achieve the benefit of a PHB. They are very probably too busy nursing their loved ones, and are not sufficiently computer literate, or legally aware, to find cases on the Internet to support their Application for healthcare funding. I got lucky, and was determined to get Pauline's "Needs" recognised by those in authority. I hope as a result of reading about our experience you can achieve your Rights without too much delay. Especially for people suffering from Alzheimer's the quality of life we experienced with the help of Home Instead Senior Care was vastly better than being left on our own to cope with the illness.

It is my hope and that this personal perspective will be a lasting testimony to Pauline's Life spent caring for her Family and Friends. That it could help others trying to get help at a difficult time in their own lives would I believe be her enduring wish.