

CAMPAIGN FOR JUSTICE



From the distress of caring for someone who's dignity is stripped away by Alzheimer's to the constant anguish of fighting against 'flawed' NHS practices on their behalf!

THE FIGHT GOES ON

PHIL SHAKESPEARE

This has been a rollercoaster of a year, I smile when I think back foolishly to the re-assuring fact of having fought and achieved Continuing Health Care Funding for my Mom 4-5 years ago. Mom was finally getting specialist EMI treatment and full support from the NHS, I could sit back safe in the knowledge of a system that really did help the vulnerable in our society and more importantly for me rebuild and recapture some of the quality time I lost with my immediate family, namely my wife and two small children.

Of course, like Tony Blair's often quoted pre-election speech about old people not having to sell their homes for their health care needs, we live within a NHS that's constantly having to re-evaluate and trim back budgets, unfortunately people with Mental Health needs are often seen as the 'Cash Cow', an easy target for removing responsibility. Families have been steamrollered into making 'on the spot' financial decisions and sadly social worker bullying has become the norm.

After Mom's fall, whilst under her 'one to one' supervision, it became clear this was to be the basis for a now assumed 'restructured', less caring SANDWELL PCT to pull the rug from under both of us. I was forced to act again. I won't go into the 'whys and hows' about the many clashes with the PCT but an under current of re-assessing and under hand deceit on numerous occasions was undertaken and the 'fatally flawed' criteria was now being pushed past the point of reason.

I was so tired of the constant harassment from the PCT and their attempts to off-load to several different boundary local authorities and now even other PCT's, that simultaneously started badgering me too, I finally stepped up a gear from just legal representation to standing up for Mom's rights in a more pro-active way, the hundreds of similar cases bought to my attention who feel bullied and let down by the system compounded my frustrations. I distributed a wealth of information via a 10,000 leaflet drop, A web site and support forum for families, a Petition of some 4,000 signatures and an Awareness Pack complete with medical evidence, damning supportive opinions from leading health professionals and a DVD highlighting my media campaign thus far.

The local press, TV and radio coverage I was generating caught the eye of the BBC. I was then given the platform of millions to highlight my Mom's plight. The BBC's Panorama had previously highlighted this injustice and sought to follow-up with more unjust NHS dementia cases. My pro-active fight back for Mom's rights appealed to them. I was filmed and interviewed intensively for a total of two days, both at work and at Mom's nursing home. They also achieved some fascinating professional insights from leading Dementia expert Professor David Jolley that detailed why my Mom should clearly be in receipt of CHC funding. An unforeseen bonus was the BBC Panorama websites detailing my campaign, together with a direct link from their website to mine, which resulted in a tidal wave of hits with hundreds of letters, messages of support, requests for petition sheets and advice from all over the U.K. Through-out this I've never lost my faith in human nature and people who I shall never meet have helped me in ways I could just not imagine twelve months previous!

What does the future hold?

I have perceived from all the above correspondence that any moral victory against the PCT is a hollow victory and a limited time-scale is always in place. Mom has deteriorated dramatically over the past two years and her intense health needs will always have to be highlighted and addressed by me, not because Mom has lost the ability to communicate, which sadly she has, but the bizarre way the postcode lottery of un-even assessment criteria is being unlawfully interpreted into making even the worst of Primary Health Care cases mere social care! If only this was the case, I would love to see my 64 year old Mother happily having a sing song around the piano with my 90 year old Grand-mother who, by strange parallel, happens to be in a residential home with her SOCIAL CARE needs adequately addressed within a non EMI nursing home environment!

The Circus is still in town . . .

WALL OF HONOUR

Particular thanks need to be acknowledged in print to the following individuals: Professor David Jolley (Dementia Plus) - expertise and dedication to upholding of the true NHS values, Ian Austin (M.P.) - political support, Sally Thomas - (Ex-Sandwell PCT) - a rare commodity, someone who put the care of the individual before the bureaucracy of the NHS framework, James Calnan (Journalist), Adrian Tennant (Central Television), Jules McCarthy (BBC Radio WM Producer), Sue Carpenter - Powell & Co. (Legal expertise and moral support), Stephen Scott - (BBC Panorama producer) - exposé expertise, Professor Susan Benbow (Consultant Psychiatrist in Old Age), Andrew Samuel and Kevin Ellis (On-line technical support for www.fightthebureaucracy.org), David Truman (Printcolouruk.com) - unpresidential access to print media, Stephen Johnson (Common cause), Neil Williams (Supportive Press agent), the hard working staff at Mom's Care-home and not forgetting the thousands of people across England who have actively contributed to the Petition - God bless you all!



Will you still need me, will you still feed me NOW I'm 64? - Mom's Birthday last August

My Mom (Pauline) with her Mom (Lily) and me (her Son).



Luke Clements is a Reader in Law at Cardiff Law School and solicitor with Scott – Moncrieff, Harbour & Sinclair London.

LUKE CLEMENTS on CONTINUING CARE

LUKE CLEMENTS

CONSULTATION DOCUMENT and The NATIONAL FRAMEWORK



"In light of this **Continuing Care** debacle the government has tried to sweep the **Coughlan (Court of Appeal 1999)** decision under the carpet. The government reissued guidance after Coughlan but it never actually mentioned what Coughlan was about. Coughlan said that if you need a lot of low-level nursing you could qualify for continuing care, even if your situation is stable, even if it's predictable. That has never been written into the guidance. It seems to me that the only way you could write guidance would be to repeat what the Court of Appeal said in the Coughlan decision. **It's a succinct statement of continuing care criteria.** But that appears in none of the government statements.

"Coughlan said that if you need a lot of low-level nursing you could qualify for continuing care, even if your situation is stable, even if it's predictable".



Tony Blair said at the Labour Party Conference back in 1997

"It's pretty simple, the type of country I want. It's a country our children are happy to grow up in, feeling good not just about themselves but about the community around them. I don't want them brought up in a country where the only way pensioners can get long term care is by selling their homes".

Since then approximately 700,000 homes have been sold to pay for pensioners care. These poor people who have paid taxes and national insurance all their lives suddenly get taxed again when they become ill. What an absolute disgrace!!!!

WE ARE ALL ENTITLED TO FULLY FUNDED NHS CONTINUING HEALTH CARE UNDER THE NATIONAL HEALTH SERVICE ACT 1946/48 AND UNDER THE COURT OF APPEAL IN COUGHLAN.

Profound Injustice

My practice is in social care law and what is astonishing is the across-the-board breaking of the law in relation to the social care rights of vulnerable people, not just by the NHS but also by social services. Largely that's because this is a group of people that don't complain because they are in such terrible straights. Unfortunately, the Continuing Care troubles are not unique but merely a very bad example of this generalised problem. The consequence of the **Governments defective policy** and its implementation by the **local NHS** is that people's homes and savings are being put at risk and also they're being caused enormous anxiety at an acute period of their lives. The way of describing this would be to say that it's outrageous and it's profound injustice".

Luke Clements

There is no doubt the **Coughlan decision** was very inconvenient to this government. It was a strong decision, it was a clear decision, it is a decision that was unpalatable and therefore the government has to weave a way through it without being totally untruthful but also without actually referring to the case or referring to the case as little as it can.

I'm a well-versed lawyer and I think the criteria that are emerging from **strategic health authorities and continue to emerge, are unlawful.** They are saying things that are clearly not Coughlan compliant and nobody seems to be pulling them up on this.

The issue that comes across to lawyers like myself is that when you take a case and challenge the criteria, the **NHS end up making a deal.** They give in. But how many people have got the energy to find a lawyer, get legal aid, go along and challenge somebody before they die. In the majority of cases, people just give up. Throughout the country Strategic Health Authorities are doing things that fundamentally affect the life of ill people and their carers, which are unlawful.

NHS - THE GREAT DECEIT*

BLEDDYN W HANCOCK
NACODS (WELSH MINERS UNION)

NICOLA MARTIN
HUGH JAMES SOLICITORS

When Labour won a landslide election victory in 1945 there was a National Health Service, free for all at the point of use. The National Assistance Act of 1946 made it clear that health care would be provided by the new NHS and local councils could only provide a very limited amount of health care if it was "incidental and ancillary to" someone's need for accommodation which could be provided by the local council. The 1980s saw an explosion in the number of privately run Nursing Homes. Patients were moved out into private Nursing Homes and into "care in the community".

It was during this process that the **NHS**, slice by slice, attempted to transfer the financial responsibility to local councils. The **NHS** "helpfully" assisted this process by providing criteria for judging who was entitled to **continuing care** that was funded by the **NHS** and who was not. On the whole, local councils tamely went along with this without once ever challenging the criteria that was proposed as being unlawful.

Nursing Care and Social Care

The **NHS**, organised locally, would draw up criteria to see who qualified for **NHS** funding for continuing care. Needless to say, they drew up criteria that were most beneficial, financially at least, to the **NHS** and not to the local councils. The local health authorities' criteria would usually exclude from **NHS** funding anyone who, in their opinion, only qualified for "social care". The **NHS** would only pick up the bill if they decided that the patient qualified for "nursing care".

The 1946 Act of course dealt with health care and made it very clear that anyone whose **primary need was for healthcare** should be the responsibility of the **NHS**. The new criteria being drawn up by health authorities created new divisions that had no foundation in **law** at all. The end result is what we have today. We have a bizarre situation where desperately ill people are deemed to need only a bit of "**social care**" that has nothing to do with the **NHS**.

This abuse of language allows the abuse of the most vulnerable, those who cannot fight for themselves.

CAMPAIGN FOR JUSTICE
PLEASE CHECK-OUT THE NEWLY REVAMPED WEBSITE
FEATURING ALL THE LATEST DEVELOPMENTS
AND CONTRIBUTE TO THE 'ON-LINE' PETITION
fightthebureaucracy.org
NOW INCLUDES
A SUPPORT FORUM
FOR FAMILIES & CARERS
NATIONAL FRAMEWORK ISSUES
AND THE 'AWARENESS' DVD UPLOADS

INJUSTICE FACT
"The law relating to continuing NHS care is misunderstood and inconsistently applied, resulting in the sick and elderly paying for medical services that should be free".
A CALL FOR POLICY CHANGE

* Article in greater details on P7

Stephen Johnson (Brother and attorney) describes his struggle to obtain Continuing Health Care Funding for his Brother

The STORY of ROD JOHNSON MRICS.

STEPHEN JOHNSON

18 months ago my brother Joseph Roderick Johnson, MRICS aged 53 suffered a massive Intracerebral Haemorrhage. He was taken to the Intensive Care Unit in Warrington. The prognosis was not good and we were told he would probably die. He did not, and eventually he was moved to the high dependency unit and then to a side room. He could not communicate, eat or drink and after approx 4 months he was moved to Northwich Infirmary to get him nearer home. On arrival he was still in a bad way. After a lot of pushing and shoving by hospital staff to get him out before Christmas because supposedly he didn't need any more hospital treatment, he had a 9 1/2 minute epileptic fit on Christmas Eve! After 5 months in Northwich we eventually managed to secure a self-funding placement at a Private Nursing Home, as **Central Cheshire Primary Care Trust** would not pay because he did not meet their **unlawful** criteria.



Rod has been in the nursing home for eight months now and is paralysed on his left side. He has since had 4 or 5 infections including **MRSA** twice, doubly incontinent, constant pain in his lower back, left eye, left arm, left leg and left testicle (Thalamic Pain Syndrome). He has headaches, constant skin irritation, spasms, epilepsy, suicidal tendencies, depression, nightmares, panic attacks and history of heart attack. He is fed through his stomach at night but can be fed chopped up food orally. Rod has a hospital bed with cot sides and a special pressure mattress, has to be turned 2 hourly, at risk of bed sores, has to be hoisted out of bed by two people, isolated in his room and cannot do anything for himself. Rod has had his medication regime changed approx 40 times in eight months and he is currently on

approx 19, but this is still under constant review. To treat his Pain we have to get him to the hospital and Rod is stretched on to an ambulance accompanied by a carer, which causes a lot of discomfort for him. Two of the possible side effects of Rod's latest painkiller are **PERMANENT DISABILITY** or **DEATH**, basically the next step is deep brain stimulation. According to the NHS this man is stable, predictable and his main need is not a health need but a social need! I have never heard such rubbish in all my life.

I wrote a letter to **Central Cheshire PCT** requesting a review in light of the Grogan judgement. Saying they should be aware the judge confirmed that the criteria used by SE London Strategic Health Authority were **fatally flawed** because they did not set out the Coughlan 'primary need' test in full (see below) and also linked eligibility to the RNCC bands. I asked for details of the action the Trust had taken to ensure that guidance being used in the area by both the **PCT** and **Social Services** was not similarly flawed and that decisions were being properly made so that they were legal. If they considered that this was not flawed to send me a copy of the relevant guidance that was being used with details of why they thought it was in line with the judgements. The question was never answered even after contacting **Mike Hall M.P.** (Labour)

I had discovered that the Law had not changed since the **NHS Act 1946/1948** and that criteria were

unlawful. On top of that there was a landmark case in the Court of Appeal (1999) known as the '**Coughlan Case**'. This set a precedent in law in one of the highest courts in the land. Referring back to the National Health Service Act **Ms. Coughlan** won her case against the NHS. After this the Dept. of Health told all PCT's that their criteria should be '**Coughlan Compliant**' but of course they ignored the ruling and continued to act unlawfully. The NHS continues to flout the law of the land with stalling tactics, endless and deliberate delay, procrastination, prevarication, sheer bloody-minded intransigence and non-information, hoping you will just go away.

According to Rod's **RNCC** report his mental health issues "require careful management". No help was offered by **Central Cheshire PCT**. Eight months later we said in a letter that it would be of use for Rod to have a full mental health assessment. Still nothing. I phoned the Continuing Health Care manager. He suggested I go to the GP. I did and the GP agreed that an assessment should take place. Unfortunately he wrote an **URGENT** letter to the very person who suggested I go to the GP in the first place. The round in a circle delaying tactic. We now actually have a date, well over a year since the mental health issue was first mentioned.

The following is from the summary of the Law Society's evidence to the House of Commons Health Committee Enquiry into NHS Continuing Care in 2004

"The judgement in Coughlan clearly establishes that where a person's primary need is for health care, and that is why they are placed in nursing home accommodation, the NHS is responsible for the full cost of the package."

No residential home would take my brother because of his nursing needs.

After an assessment for **Fully Funded NHS Continuing Care** Rod was turned down. I asked for a copy of the assessment, but was told by **Central Cheshire PCT** that I would have to request all his medical records to get this. I complied but the notes took a long time to arrive and I had to pay for them. In a letter from **Central Cheshire Primary Care Trust** I was told that I had been given access to their criteria, which was untrue, I had to get it from another source.

I then stumbled upon a website (WWW.NHSCARE.INFO) - it had all the information I needed to put up a fight.

Rod was subsequently placed in the high band Registered Nursing Care Contribution but evidence submitted by the Ombudsman to the House of Commons Health Committee inquiry stated: **"It seems to us, and is supported by our legal advice, that if a person's needs for registered nursing care are deemed to be at high band RNCC level, it is difficult not to say that that person should also be eligible for NHS continuing care funding, given the similarity of wording...it is difficult to see how a person with health care needs that properly place him or her at high band RNCC would even have reached the stage of an RNCC assessment, had he or she been properly assessed for NHS continuing care. This is because the level of health care needs that warrant high band RNCC would seem to be, at the least, equivalent to those that should qualify a person for continuing care funding, if not higher."**



Stephen with his brother Rod

After many stories in the press we were contacted by age Concern and were the instigators of the Sunday Express Crusade 'Justice For Our Elderly'. We also had our story featured on Granada Television.



Rod being filmed for Granada Reports



(Winner of the landmark case against the NHS in the Court of Appeal 1999).

PAM COUGHLAN Writes . . .

Please expose the unforgivable treatment of the sick, whom the state seems to consider no longer sick if their condition is to be long-term!! This is **UNREASONABLE, IMMORAL and DISCRIMINATORY!** As is the outrageous complaints procedure. As no one so ill or frail can carry it out. We all thought we were paying for a **National Health Service!** *The law says if a person's need for care is primarily a health need then who performs that care whether it be a registered nurse or an auxiliary nurse or a care worker is irrelevant.*

"I think this is the biggest scandal in the whole history of the Welfare State. What we have here is a group of people who 20 years ago would have been cared for in a hospital environment and there would have been absolutely no dispute that their care needs were the financial responsibility of the NHS".

The debacle looks set to continue, as the consultation document offers no new criteria (according to the RCN response). Customers service unit at Her Majesty's Court Service says that the

judicial process is the only way individuals can challenge decisions. (I had asked if there was provision in law for advocacy for those unable to represent their case) he said it is one of the means by which irregularities and the possible need for change be brought to the attention Of those responsible for the policy.

Recently two women have rung asking for contact phone numbers of the solicitors. It is excellent news that you have a number of law firms on board. If their numbers could be available and circulated many more could be helped.

Everyone I talk to says it makes them feel ashamed of our country.

"Asking people to pay for their care and expect them to sell their house! To me it is outrageous not to fund a person who clearly needs care!"

These people are going to be robbed and treated with contempt. People who should be cared for and cherished are being treated as if they don't matter and probably they would rather be dead than treated like that. There must be some reason that Government, or Government Departments, are



Pam Coughlan and her solicitor Nicola Mackintosh celebrate her landmark victory back 1999

Pam has become a great inspiration to all of us unfortunate enough to be caught up in this Continuing Care Nightmare!



IMMUNE TO THE LAW. That is the only thing I can think as the Court of Appeal's judgement laid down the law clearly enough.

The Prime Minister constantly evokes values, fairness and justice as reasons for taking action abroad. He should take action at home on community care funding - Exactly!! Values, fairness, justice!

Frustratingly the NHS is oblivious to the rule of law, so it means, as you perceive, tenacity and a determination that failure to attain one's due under the law is not an option. WWW.NHSCARE.INFO is a great source of advice. If there is anything more I can do, please let me know.

I wish you well in your venture.

Pam Coughlan.



CIVIL RIGHTS ASPECTS OF MENTAL HEALTH LAW AND HUMAN RIGHTS

Peter Edwards runs his own legal practice, Peter Edwards Law, specialising in representing clients at Mental Health Review Tribunals, and litigation in relation to the civil rights aspects of mental health law and human rights. He is the chief Assessor for the Law Society of the Mental Health Review Tribunal Panel.

There may be many people who have either been unlawfully charged or who were unlawfully removed the Mental Health Act 1983. This imposes a statutory duty on local authorities and Trusts to provide 'after care' for patients who have been detained under various sections of the Mental Health Act (section 117).

Peter Edwards Law has recovered over £1 million pounds on behalf of clients who have been wrongfully charged by local authorities for services that the law requires to be provided free of charge.

In July 2003 the Local Authority Ombudsman brought out a special report. 'The Local Government Ombudsmen have received a number of complaints about charging for accommodation provided as part of the aftercare of people leaving hospital. There has been national debate over the validity of charging for such services, and local authorities have adopted differing practices. Recently the law has been clarified and it has been confirmed that charges may not be made. Guidance is necessary to

social services authorities in respect of the points these complaints raise.'

Aftercare services are the services that a person needs for the treatment and care of their mental disorder. Despite this, desperate local authorities have gone to amazing lengths to quietly remove people from aftercare. ***If a person is receiving residential care, having previously been detained under the Mental Health Act on a qualifying section, how could it be argued that 'they were no longer 'in need of' after care?*** The reality is that they are still getting aftercare so surely they still need it.

If a person is unlawfully removed from s. 117 they are still on it. Those services must be provided free of charge. Wrongful charges must be repaid in full with interest (6%). If the person then dies their beneficiaries can claim the sum due as a debt to the estate. The law also requires consultation with families before the

removal of s.117. No consultation could amount to unlawful removal.

I must stress that these provisions only apply where someone has been detained under the Mental Health Act (s.3 or s.37). Check back through their records. If they have been, were they then removed? If so, in what circumstances? Was the person still receiving aftercare? Was the decision to remove them made jointly by health and social services? Was it made after family consultation? If the answer is no consult an experienced mental health solicitor.

One of the great fears that families have is that adequate aftercare will not be provided to their loved ones. There is also anxiety about the use of the Mental Health Act. Being 'sectioned' sounds frightening. However, the irony is that if a person does end up on a qualifying section then they are more likely to get the aftercare that they need and what is more, it will be provided **free of charge!**

THE PROFESSIONAL OPINION

DR DAVID JOLLEY / VIVIAN WHITE

A GROWING SCANDAL: THE NHS CONSULTANT ANSWERS PANORAMA'S QUESTIONS



Older people, particularly older people with mental health problems, are being dealt with in a scandalous way. They are being pushed aside as if they are no longer part of our usual society, that they can no longer expect a fair deal from the, from the health care system.

Dr David Jolley
Psychiatrist of Later Life

Phil Shakespeare's campaign for NHS funded care for his mother is supported by an NHS Consultant, Dr David Jolley who is a psychiatrist of late life. Dr Jolley regularly visited Pauline Shakespeare whilst visiting other patients living in her care home.

Although she was not a patient of his he knew her case well and he has strong views about the way the NHS is withholding fully funded care.

He was interviewed by **Panorama's Vivian White**. (June 2006)

VIVIAN: Why have you taken **Phil Shakespeare's** side in his dispute with the primary care trust over his mother, Pauline Shakespeare?

DR JOLLEY: My position is a professional one, and what I'm wanting to do is give, what I believe to be, an honest, professional opinion about his mother's condition, and her best interests because that's what I have to do as a professional.

VIVIAN: As I understand it, the argument of the primary care trust is that she has dementia before, and she has it now, but since she suffered a fall, she has fewer nursing needs now, than she did. So, from their perspective, whereas she was entitled to fully funded care before, now she's not entitled. I think that's their case. What do you think of their case?

DR JOLLEY: I do find those sort of interpretations very strange. As a clinician I see this lady as having a dementia that was present, is still present, will continue, and she will acquire more impairment between now and when she dies. A passing incident has been the fall. She's recovering from that but the overall requirements remain much the same. So, as a clinician, I stand back and I see someone who needed this form of care, still needs this care, and will need it, frankly, till she dies. And that's what I will wish to provide.

VIVIAN: Have they got a case or not?

DR JOLLEY: It's not a case which I understand, it's a dimension that's not mine. I'm a clinician, I see patients I deal with people. I think most ordinary folk will understand my perspective. It's not clouded by issues of finance, it's what is required by this individual. It might be medicine, it might be nursing care, it may be other sorts of therapy, and that's what I know about.

VIVIAN: Is that logic that the primary care trust have applied in this case an unusual one, or is their logic one that you've come across before?

DR JOLLEY: It's one that people are being encouraged to use. An approach that is preoccupied with finance, and there's also been educated by an idea that clinicians views should be set aside, or not taken as seriously as they have been in the past. There's a sort of suspicion that clinicians are not responsible. But, at another level, we're utterly responsible. We, we are the professionals involved with the care of patients, along with nursing colleagues and so on. There's a worry about postcode finance. You know, you might get a service

in one place and not in another place.

VIVIAN: Are you suggesting that that reassessment of Pauline Shakespeare, that the new decision that she is no longer entitled, in the primary care trust's views, to full funded care, isn't actually driven by a clinical reassessment of her?

DR JOLLEY: The concern is that the main preoccupation is what is the best use of the money, or what is the best distribution of a limited finance. And my perspective has to be what's best for this individual. But taking into account that there is a limited purse. But once someone has been judged as to having deteriorated into this level of need, because of her progressive dementia, it's very unusual to feel that they can make a recovery sufficient that they should come out of that bracket. I think it's very important to have a longitudinal view.

Many of the people who are asked to make judgements, such as the ones you are describing, don't have any longitudinal knowledge, or any longitudinal commitment to that individual. So that's why I think the views of people like myself are important and worth listening to.

VIVIAN: Is **Pauline Shakespeare** getting worse or getting better?

DR JOLLEY: Over time she's progressively getting more impaired. That's the natural history of her dementia. She has done quite well in the nursing home that she's now living in, because the nursing staff, and the environment, has remained steady, people have responded to her,

she's become known by them, and so, thank goodness, she's got a better quality of life than when she was first admitted, when she was more muddled and frightened, because she's become settled. That doesn't mean to say her underlying condition, her biological status, has changed, but she, she is now in a good



My Children have given me the strength to keep fighting on behalf of their Grand-mother, Pauline Shakespeare.



THE PROFESSIONAL OPINION

DR DAVID JOLLEY / VIVIAN WHITE

► balance. That's fine, and it should be maintained, it needs to be sustained like that.

VIVIAN: Do you think the perspective of the primary care trust, of the NHS in this instance, is unusual in your experience, or represents a more general problem?

DR JOLLEY: It does represent a more general problem, and it represents a setting aside of clinical views, and clinical assessments, in preference for a bureaucratic approach, which is about how to spend money, how to control the spend of money, so it is that people are not looked after as individuals with illnesses that have a long term cause, but just commodities that need to be seen to for a period of time. There's the fragmentation of care, the fragmentation of planning what's to happen, and fragmentation of understanding of what is the natural history, what are the natural needs of individuals. Now, I don't want to be unkind or unsympathetic to the people that find themselves in these positions. There's a major preoccupation with how much money is being spent, and so on. But in the end, I think it's counterproductive, because individuals are suffering, and I'm not at all convinced that we get better for the money out of this system.

People are spending a lot of time doing assessments that are nothing to do with therapy, but simply to do with the allocation the of funds.

VIVIAN: I'm sure that the NHS would say, that in this case, and other cases, the nurse assessors who do the assessment, are carrying out a clinical assessment. You're suggesting that it isn't a clinical process that they're engaged in. What do you think they're doing?

DR JOLLEY: I know many such nurses, and they are, by and large, smashing people. But what they're allowed is a one off picture of somebody at a point in time. What's very difficult for them is to have a

longitudinal view. What people like myself, and the nurses who actually do the ongoing care have, is a better understanding of the long term picture. Who is this person, how did they come to be like this, and what's going to be their future? So I think what we have to say is very important. I mean, occasionally, perhaps we need to be checked, but I mean, we haven't any axe to grind other than wanting the best for our individual patients, and that is a reasonable thing for us to pursue.

VIVIAN: In your opinion, is the reassessment of **Pauline Shakespeare**, the decision that she's no longer entitled to fully funded continuing care, justified, or not?

DR JOLLEY: I'm puzzled by it. I hope that people will see that she requires ongoing care, funded in just the way that it has been. Because she hasn't suddenly got better. She's still got all those disadvantages, arising from the same illnesses. Thankfully she's recovered from the fall and the broken leg. That's the natural history of that pathology. But the other pathologies are still there, pursuing their natural histories, and requiring just as much input and support.

VIVIAN: As you know, the legal test as to whether you're entitled to free fully-funded health care by the NHS is meant to be whether you have a primary health need or not? The actual test in the criteria often goes to these words: unpredictability, intensity, complexity, stability of the condition. What do you think is the purpose of these words in the process?

DR JOLLEY: The words are being used so that it's possible to compare this situation with another situation. That's entirely reasonable. But the difficulty is they appear to be being used to ration situations and, and they describe individuals at points in time, and don't have a longitudinal

perspective. So it is, as in **Mr Shakespeare's** situation, that it's possible for people to need health



care this week and social care next week, and presumably health care again later on. And I don't think that's sensible when you have a continuity of pathology primary healthcare need that's producing the overall pattern of need.

VIVIAN: In your experience, is the **Pauline Shakespeare** case and the decisions that the primary care trust has taken in this case, which you find puzzling, which you disagree with, do you think that's peculiar to her case or do you think the same sort of thing happens in the continuing care system up and down the country?

DR JOLLEY: Up and down the country people are despairing or simply giving up and shrugging their shoulders. Older people, particularly older people with mental health problems are being dealt with in a scandalous way.

They are being pushed aside as if they are no longer part of our usual society, that they can no longer expect a fair deal from the health care system. If they have money then they should pay. But that's not right in my view. What's required is that whether you've got money or whether you haven't got money you get appropriate care for your health problems, whether their acute or long term.

For me it's a great tragedy because I've spent 30 years working with older people with mental health problems, particularly dementia, and in many ways we have made progress to improve matters for them, but this is a bizarre perversion of what we've all been trying to do.

And many ordinary people would say the same as I am now saying, because they've found that their parents, or their brothers or sisters are being dealt with in this way and people don't expect this to happen. It shouldn't be happening and I think all the authorities just need help in calming things down and getting back to proper common sense.



'ON-LINE' NEWSLETTER - A MORE INDEPTH LOOK . . .

(Original featured in a concise print on Page 2)

NHS: THE GREAT DECEIT (Prt.1)

BLEDDYN W HANCOCK / NICOLA MARTIN
NACODS (WELSH MINERS UNION) / HUGH JAMES SOLICITORS

BRAVE NEW WORLD

When Labour won a landslide election victory in 1945 there was a wave of optimism that at last the returning servicemen and women could face a better future than the six years of warfare they had just endured.

This brave new world was to include a National Health Service, free for all at the point of use.

However, there was already a health service industry and it was run by a number of organisations. For example, charities, private foundations and even local councils ran hospitals and clinics. So when the National Assistance Act was passed in 1946, it was quite clearly intended to nationalise the existing health care industry. Because local councils had played a role in providing health care the central Government wanted to set out clear lines of demarcation between the two.

The National Assistance Act of 1946 made it clear that health care would be provided by the new National Health Service (NHS) and local councils could only provide a very limited amount of health care if it was "incidental and ancillary to" someone's need for accommodation which could be provided by the local council.

For the best part of 40 years, this created no problems and everyone knew where they stood but healthcare is an expensive business. With increasing demands on the NHS and a genuine desire to provide better care for the wide category of patients, changes were made. To ease the pressure on the number of beds available it was decided that many could be moved out into local authority or private sector Nursing Homes. It was at this point that the brave new world started to crumble.



Standing up for the rights of people denied PCT Continuing Care funding.

WHO CARES? WHO PAYS?

The 1980s saw an explosion in the number of privately run Nursing Homes. At first it seemed like a licence to print money but reality soon started to bite. During this period, many hospitals started to reduce the number of long-term care beds they had. Very often several old hospitals were closed and demolished and the land sold to property developers whilst the new hospitals to replace them tended to have a fewer total number of beds. Long-stay geriatric wards and psychiatric wards tended to be closed while the patients were moved out into private Nursing Homes and into "care in the community".

It was during this process that the NHS, slice by slice, attempted to transfer the financial responsibility for these patients onto local councils. Central Government's advice and guidance tended towards pushing the cost of providing this care onto local councils. The NHS "helpfully" assisted this process by providing criteria for judging who was entitled to continuing care that was funded by the NHS and who was not.

On the whole, local councils tamely went along with this without once ever challenging the criteria that was proposed as being unlawful. There was no doubt an

element of central Government bullying in that local councils were threatened financially if they did not do their bit to end the problem of "bed-blocking".

Usually, the NHS would decide that patients who needed long-term care should leave hospital and become the responsibility of the local council. It is at this point that the intentions of the founders of the NHS were stood on their head.

NURSING CARE AND SOCIAL CARE

The NHS, organised locally, would draw up criteria to see who qualified for NHS funding for continuing care. Needless to say, they drew up criteria that were most beneficial, financially at least, to the NHS and not to the local councils who were going to have to foot the bill.

The local health authorities' criteria would usually exclude from NHS funding anyone who, in their opinion, only qualified for "social care". The NHS would only pick up the bill if they decided that the patient qualified for "nursing care".

The 1946 Act of course dealt with health care and made it very clear that anyone whose primary need was for healthcare should be the responsibility of the NHS.

'ON-LINE' NEWSLETTER - A MORE INDEPTH LOOK . . .

(Original featured in a concise print on Page 2)

NHS: THE GREAT DECEIT (Prt.2)

BLEDDYN W HANCOCK / NICOLA MARTIN
NACODS (WELSH MINERS UNION) / HUGH JAMES SOLICITORS

► The new criteria being drawn up by health authorities created new divisions that had no foundation in law at all. The end result is what we have today. We have a bizarre situation where desperately ill people are deemed to need only a bit of "social care" that has nothing to do with the NHS. This has even been extended to severely handicapped younger people who have now been reclassified as only having "learning difficulties" and are no longer even referred to as patients but are now classed as "clients" of local authority Social Services departments.

This abuse of language allows the abuse of the most vulnerable, those who cannot fight for themselves.

The continued reference to social care rather than health care is due to the ignorance of the many and deceit by the few. The very lack of clarity in NHS criteria means that the cost for looking after very ill people indeed is being dumped on local councils. Because local councils can charge for their services it is usual to find these desperately ill patients being charged for their health care in much the same way as some people are charged for their meals-on-wheels service. Local councils, themselves under severe financial pressures, go into full financial recovery mode whenever they are presented with a patient who needs long-term care.

A patient, in hospital, will be referred to the local council by the hospital and the first action of the local council will be to meanstest that person to see how much money they can take off them to contribute towards paying for their care.

At this point, Social Services departments should know that their first duty should be to check that the law is being complied with. Usually this is completely ignored.

WHAT SHOULD BE DONE?

Whenever a hospital decides that a patient needs long-term care that could best be provided other than in the hospital then an NHS Continuing Care Assessment should be carried out.

This Assessment should take place before the patient is discharged and should involve the patient as well as his/her family if needed; relevant specialists in the hospital and of course a representative from Social Services department.

If the patient qualifies then there is no problem. They can be transferred elsewhere with the NHS picking up the bill. If the patient does not qualify then the next step should be to carry out a further Assessment. This one is called the Registered Nursing Care Contribution (RNCC) Assessment and this is the see if the patient qualifies for some payment towards their care if a registered nurse is needed.

If the patient does not qualify for continuing care then the patient, or their family if they are responsible for them, has the right to have the decision reviewed. During this period the patient is entitled to stay in hospital with all their care funded by the NHS.

It is not unusual to see this entire procedure ignored by the NHS. Whatever can go wrong in this process usually has at some time or another.

Sometimes the RNCC is done and not the full Continuing Care Assessment. In other cases the

relevant specialists are not used for the Assessment. It is not unusual to see no Assessments carried out at all before the patient is discharged.

What is almost universally true is that the local Social Services departments never challenge the Assessments let alone ensure that they are properly carried out.

When patients are transferred to Care Homes regular re-assessments should be carried out because, of course, some patients will deteriorate so if they did not qualify for continuing care in hospital when the original Assessment was carried out, they may well qualify later.

Patients in hospital, or their families, should always ensure that a Continuing Care Assessment is carried out before that person is discharged from the hospital. However, it is quite understandable that given someone who is very seriously ill this is usually the last thing that is thought of. But even when someone has been discharged to a Care Home a Continuing Care Assessment can still be demanded and the review process can still be used.



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(Original featured in a concise print on Page 2)

NHS: THE GREAT DECEIT (Prt.3)

BLEDDYN W HANCOCK / NICOLA MARTIN
NACODS (WELSH MINERS UNION) / HUGH JAMES SOLICITORS

INDEPENDENT REVIEW

The Department of Health, and the similar bodies in Wales, Scotland and Northern Ireland, have all told local health authorities that they must have "independent" review procedures.

There are already genuinely independent review bodies in other fields. For example, the Appeal Tribunals for Industrial Injuries Benefits and Social Security Benefits as well as the independent Tribunals for employment matters.

The NHS however has ignored this and set up bodies that are, by no stretch of the imagination, truly independent.

The review panels they have set up are strictly limited by the terms of reference drawn up by the Local Health Authority. They also make it clear that claimants may not be represented directly by a lawyer at these Hearings. Indeed the Courts have ruled that these review panels are nothing more than the internal decision-making process of the NHS.

It would be interesting to see the response of Local Health Authorities if they were asked what steps they have taken to comply with the requirement to set up truly independent panels.

However, patients, or their families, must go through this process before they can take their cases to Court in the event of a dispute.

Originally the Minister in England said that these reviews should take place within two weeks but practical experience indicates that they can take up to two years, if not longer, before they are held.

THE OMBUDSMAN

The Ombudsman's offices in England and Wales have both issued damning indictments of the NHS on the question of long-term Continuing Care payments.

Unfortunately, all the recommendations made by the Ombudsman seem to have been largely ignored. The main recommendation that has been ignored is to go back to 1996, when Health Authorities first had to have written criteria, to review all the cases that may have been unjustly dealt with. It does not appear that a single case has been voluntarily investigated anywhere.

The Ombudsman is also limited into looking at matters of maladministration only. If it is a question of the local Health

Authority complying with the law itself then that is not a matter for the Ombudsman. It is important that this distinction is made clear because local Health Authorities expect individuals to take the matter to the Ombudsman, possibly for referral back yet again to the local Health Board, before proceeding to Court. Anyone wishing to avoid this should make it clear to the Ombudsman that their complaint is about the content of the local criteria and its unlawfulness and not its application. The Ombudsman should then agree that it is not a matter for him to consider so allowing the claimant to proceed to Court if necessary.

"MY DAY IN COURT"

After having exhausted the local review procedures many people feel so incensed that they want their day in Court to prove that they have been treated badly. However, before you do this you will have to prepare to go to Court properly. Some people may well be competent to do this themselves but for the vast majority this requires a competent Solicitor, with experience in this field, to act on their behalf.

Usually all the medical records will have to be collected and paid for. They will have to be looked at by a Specialist Medical Practitioner and probably a medical report from a Consultant obtained. In addition, the necessary Court papers will need to be drafted by a Barrister and then the Solicitor should serve Notice on the local Health Authority that Court proceedings will be carried out unless reimbursement is received.

It is at this point that many Health Authorities will once again review the case and on this occasion find that because of the "new evidence" that they can find in favour of the applicant and they can receive on-going funding in full or reimbursement of past fees or both.



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NHS: THE GREAT DECEIT (Prt.4)

BLEDDYN W HANCOCK / NICOLA MARTIN
NACODS (WELSH MINERS UNION) / HUGH JAMES SOLICITORS

▶ However, because proceedings were not actually gone ahead with, the costs incurred are not recoverable.

So the claimant may well have to pay their own costs because the NHS has given in just early enough to avoid them having to pay them.

However, such a victory can bring substantial benefit to the claimant or their family. In many cases people's life-savings, pensions and even their homes have been taken off them to pay for their care and a massive bill run up. In these cases the expenditure of a few thousand pounds in legal and other costs can be seen as money well spent if a much larger sum can be recovered and no further payments having to be made.



TELLING THE DIFFERENCE

Many people are quite understandably totally confused in telling the difference between "nursing care" and "social care". Of course the real issue is whether someone qualifies for continuing "health care".

So far, only one case has gone to Court that gives us any idea of the difference between healthcare and social care. This was the case of Pamela Coughlan against the North Devon Health Authority which went to the Court of Appeal in 1999.

The Judgement in this case made it much clearer that if a patient's primary need was for health care then the NHS should pay for it. The Judgement went further to say that it did not matter in what setting the patient was receiving that care, it could be a hospital, Care Home or even the patient's own home, the NHS would have to pay for it.

It is abundantly clear, and many people have made the point, that Ms Coughlan's condition would not have qualified under the various Health Authority's criteria for continuing care. Clearly, there was a need

after this case to review all the criteria with a view to making them compliant with the Court of Appeal ruling. However, even though this was allegedly done, the end result is very little different from the criteria that existed previously. Even more glaringly not a single example was provided to guide hard-pressed discharge nurses in reaching a decision.

The criteria of each local Health Authority usually runs to 30-40 pages on average but with no worked examples as a guide. The references in the revised criteria to the Court of Appeal ruling in Coughlan do not usually give a full explanation of what is meant. In some areas the situation may be marginally better but overall it must be said that the revised criteria is even more confused than the old ones and probably deliberately so.

However, it suits the Government to perpetuate the "confusion" over this issue. The question of proper Assessments on discharge continues to be a complete shambles with vastly different outcomes in the application of the procedure throughout Great Britain.

WHAT SHOULD BE DONE?

It is quite clear that what needs to be done is relatively simple and straightforward and these steps are:-

- (1) As recommended by the Ombudsman all cases since 1996 should be reviewed whether the family ask for the review or not.
- (2) New simplified criteria should be drawn up with clear worked examples and also central monitoring to ensure that Health Authorities comply.
- (3) Local Councils should immediately review their arrangements with Local Health Authorities to ensure that they are not taking on the financial responsibility for patients that they cannot lawfully accept.
- (4) Truly independent review bodies should be set up throughout Britain to properly resolve disputes without having to go to Court
- (5) A major advertising campaign should be run by central Government to ensure that all individuals are aware of their rights and to reclaim any monies to which they are entitled going back to 1996.

WHAT CAN BE DONE?

It is highly unlikely that central Government will carry out any of the above demands and therefore we should concentrate instead on what can be done rather than what should be done.

'ON-LINE' NEWSLETTER - A MORE IN DEPTH LOOK . . .

(Original featured in a concise print on Page 2)

NHS: THE GREAT DECEIT (Prt.5)

BLEDDYN W HANCOCK / NICOLA MARTIN
NACODS (WELSH MINERS UNION) / HUGH JAMES SOLICITORS

► In any case where the amount of money paid has been £5,000 or more then claimants should consider approaching competent and experienced Solicitors to act for them. Under this amount they can take their case to the Small Claims Court themselves when it would not be economical to use the services of a lawyer.

We should all demand of our Local Councils that they stop spending money when they are not lawfully entitled to do so. The threat of reporting the matter to the District Auditor should be sufficient. Where Councils refuse then we should report cases to the District Auditor with a view to having Local Councillors surcharged for acting unlawfully and spending our money on something they are not entitled to do.

We can all write to our Local Council to ask how much they are spending on looking after individuals in Care Homes. This should include not only the very sick and elderly but also those people classed as having "learning difficulties" who need 24-hour care.

A letter-writing campaign to local newspapers should also help. Publicising successful claims is very newsworthy and this should lead to much greater awareness.

Every family that has won a case should write to their Local Council and ask what steps the Council are taking to recover their contribution as well.

Where Health Authorities have been told to set up "independent" review panels and have not done so then they should be reported to the Ombudsman for maladministration.

It is possible that a charitable grant, possibly from the lottery fund, could be obtained to set up a proper information centre with adequate funds for publicity.

We will win

Across Britain hundred of families have been fighting back against this desperate injustice. A Trade Union, NACODS South Wales Area, has taken up the matter on behalf of its members and has had considerable success through using their Lawyers, Hugh James Solicitors in Merthyr Tydfil.

Many cases have been won and are an inspiration to others. Especially those cases that have been publicised on the couple of websites that have been devoted to this topic.

It would be naive to expect any assistance from this Government or possibly any other Government either. The very elderly and the sick, even the young mentally infirm, the most vulnerable in our society, have been swindled out of their savings, hounded out of their homes and conned out of the care they deserve.

The hundreds of cases that have been won show that this is not a lost cause. Over the last few years we have all been learning our way forward. Wading through bureaucracy and evasion but even so, successes have been achieved.

Thanks to the dedicated efforts of those few people who have committed themselves to publicising this issue there are now thousands more people who realise that they have been badly treated. We now need to double-up our efforts to ensure that we win for everyone the right to be treated with the quality and decency at the most vulnerable times of our lives.

BLEDDYN W HANCOCK

For further information contact:
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(Tel. No. **01685 371122**)

MAN OF THE PEOPLE



BLEDDYN W HANCOCK

He started the Miners chest disease claims when he became secretary of **NACODS** South Wales Area in 1988. It was a fight they fought on their own as none of the other Mining Unions would join in. The Government fought the issue to the bitter end in January 1998. So it was a 10 year battle. The Trial started in the High Court in Cardiff in 1996 and ended in the Royal Courts of Justice in London in 1998. It was the longest trial of a personal injury case in history, a full year in court. The Government was ordered to bring in a scheme of compensation. so far about **£3.5 billion** has been paid out and there are about **580,000** claimants through the UK.

The Union played a leading role in the Vibration White finger Claims and again were the only Union involved with some other participants.

They are currently starting another huge class action for miners who suffered from crippling knee injury from arthritis and cartilage damage. He is also fighting the continuing care battle for his members and making a lot of progress.

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(Original featured in a concise print on Page 2)

THE 'GROGAN' JUDGEMENT

MS sufferer wins landmark case

A multiple-sclerosis sufferer has won a High Court ruling over who should pay for her nursing home care.

Wheelchair user Maureen Grogan, who is in a home in Thamesmead, south-east London, has had to sell her home to meet **£100,000** in medical costs.

The 65-year-old was challenging a decision by Bexley NHS Trust that she was **not entitled to full NHS funding**.

The judge agreed with Mrs Grogan saying the trust had used **"flawed criteria"** and the case should be reconsidered.

'CONFUSING CRITERIA'

Mr Justice Charles, sitting in London, said guidance from the department of health was **"far from being as clear as it might have been"**.

He said the case had wider implications for the sick and disabled and health authorities across the country.

The court heard Mrs Grogan has "deteriorating" multiple sclerosis, double incontinence, no mobility and some cognitive impairment.

Her health deteriorated after her husband's death. She had a number of falls and was admitted to hospital in November 2002.

She was transferred to the £600-a-week Gallions View nursing home, in Thamesmead, in February 2003.

She was assessed in 2004/05 and the trust ruled she was not entitled to fully-funded NHS care.

PCT NURSING CARE CRITERIA 'FLAWED IN LAW'

A High Court judge has ruled that the criteria used by many primary care trusts to assess whether someone should have to pay for their nursing care are **'fatally flawed' in law**.

The ruling has 'wide implications for a number of individuals, strategic health authorities and the NHS', Tim Ward, a barrister for the Department of Health, said after the judgment.

The family of Maureen Grogan brought the case against Bexley Care Trust after it refused to pay for the cost of her substantial health needs on the basis that **she failed** to meet the **criteria laid out in its 'continuing NHS care' assessment**.

Grogan did, however, meet the criteria for the trust's separate 'registered nursing care contribution', and thus had part of her clinical nursing care funded.

But Justice Charles ruled that the two **categories were indistinguishable**: if Grogan qualified for high-band nursing care, her health care needs should be **deemed her 'primary' need**. Therefore she should automatically **qualify by law for free 'continuing NHS care'**.

The judge said that while the case had been brought and found against Bexley, the trust itself had been 'led astray' by the DoH. He endorsed recent calls from the Commons health select committee and the health ombudsman for the DoH to issue a single, nationwide set of guidance.

'It seems to me important that the department do this, rather than leaving matters in the hands of care trusts and local authorities, not least to promote a consistency of approach,' he said.

The case, he added, raised 'important and widespread issues of public importance and interest' which 'can have a profound effect on the individual concerned'.

Liberal Democrat MP Paul Burstow, who sits on the health committee, told Public Finance: 'The judgment demonstrates that this government has connived and been part of a process over successive

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THE 'GROGAN' JUDGEMENT

governments of redrawing the boundaries by stealth between what people have to pay for themselves in terms of care and what is free.

'What the court has done is say that it's not sufficient for the secretary of state to say **it's just the PCT's fault**, it's actually down to the underlying guidance that the department has been giving.'

HIGH COURT QUASHES HEALTH AUTHORITY DECISION NOT TO FUND CONTINUING CARE

Last week the High Court added its voice to calls for reform of the system for deciding who should pay for ongoing nursing home care, and quashed the decision of one health authority not to fund continuing care in the case of a sick elderly woman. Doughty Street Chambers practitioner Stephen Cragg acted on behalf of the claimant in the case.

Maureen Grogan a 65 year old woman who has "deteriorating" multiple sclerosis, double incontinence. Maureen is also a wheelchair user requiring two people to transfer her and has cognitive impairment. In 2004 and 2005 she was **assessed as not requiring fully funded NHS care by the Bexley NHS Care Trust**. This was done using criteria drawn up by the South East London Strategic Health Authority. As a result, Greenwich local council placed her in a BUPA run nursing home. But Mrs

Grogan was forced to sell her home to pay the fees - so far almost £100,000.

Mrs Grogan challenged the decision of the Trust not to fund all her care and accommodation. Her case was based on a 1999 decision in the Court of Appeal (in the case of **Pamela Coughlan**) that if a person's primary need is for health care (rather than social care), then the NHS should pick up the whole bill.

The court found that the criteria drawn up by the SHA and adopted by the Trust were **fatally flawed** as they did not reflect the fact that those with a primary health need should be NHS funded. The judge quashed the decision not to fund Mrs Grogan's care and ordered the Trust to reconsider her case again in line with revised guidance.

The Trust claimed its decision was in line with Department of Health guidance and its criteria for deciding who to fund were therefore lawful.

However, Mr Justice Charles called on the Department to revisit it **"not least to promote a consistency of approach to the relevant issues which concern important and widespread issues of public importance and ...which can have a profound effect on the individuals concerned"**. **He found that the lack of clarity in the guidance by the Department meant that local NHS bodies had difficulty in turn in developing criteria which lawfully described the all important divide between health and social care. The Department's attempt to introduce a nursing care contribution for those in**

local authority care led to a two tier system described by the Select Committee (in a passage set out and endorsed by the judge) as a "nonsense", and by the ombudsman as leading to confusion and injustices for old and vulnerable people.

All health authorities rely on the Department's guidance to draw up their **continuing care criteria**. The judgment is likely to mean an anxious scrutiny of all such criteria to see if the mistakes made by Bexley have been replicated elsewhere.

If you have a story to tell good or bad against the injustice of fighting for Continuing Health Care funding drop us a line and we will feature it in any future volumes of this newsletter. Likewise your thoughts or opinions are always welcome. You can contact us via the web-sites:

www.fightthebureaucracy.org

www.continuingcarecampaign.info

www.nhscare.info

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