

P-04-456 Dementia – This Could Happen to you – Email exchange between Tony Alexander, Member of the Alzheimer's Society's Volunteer CHC Support Group and Lynda Chandler, Welsh Government Official, 09.05.14

Dear Lynda

My sincere apologies for being unable to attend the meeting on Friday with Helen. I have volunteered as an “engineer” with REMAP which carries out bespoke alterations for appliances for handicapped people. I have an appointment at the home a handicapped lady and the occupational therapist on Friday.

I am a retired solicitor and a member of the Alzheimer's Society's Volunteer CHC Support Group which advises people who have been refused CHC. Only people who have successfully appealed a refusal are considered for the Group and in my case it was my father in law who had been refused and the decision reversed at the Local Appeal Panel.

I have been a member of the Group for two years and dealt with about 94 cases of which only 4 or 5 have been Welsh. Those have been similar to the English cases in that:-

(a) Assessments which the Framework require to be comprehensive, detailed and holistic are rarely, if ever, anything of the kind. Typically the assessments rely on Care Home notes (the majority of the cases have patients in care homes, unlike Helen's case) and those notes are at best superficial, as to be fair to the carers, they simply do not have the time to make detailed notes; frequently however, they are inaccurate and omit essential details as the carers are so used to such things as challenging behaviour so that unless it is exceptional, it is not mentioned. The extent to which the opinions of psychiatrists and GP s are sought or taken into account varies. Frequently it is a phone call and no written report is obtained. As far as I am aware (it was certainly the case in my father in law's case) the GP s know of the existence of a system for assessing for CHC but do not know the details.

(b) Although the Framework requires the family to be fully informed of the process so that they can play a meaningful role in the assessment process, this has not happened in any of the cases that I have dealt with. Sometimes they are provided with an explanatory leaflet, but no one has been handed the Framework or the DST and had those documents explained to them. The whole process is exceedingly complicated and no leaflet could do it justice. The majority of the families that I speak to say that they are daunted by the system and do not understand how it is supposed to operate.

(c) The assessors have a superficial knowledge of the Framework/DST, but are adept at interpreting the descriptors for the 12 domains in a prescriptive manner notwithstanding the guidance given in the Framework to the contrary.

The Welsh Audit Office report on CHC published in June 2013 sets out the many shortcomings in its implementation. In my opinion it did not pay sufficient attention to the problem of quality control of decision making and ensuring uniformity. A number of respected commentators have criticised the system including Luke Clements (Professor of Law at Cardiff University), the Law Society, the RCN, and the Alzheimer's Society. I believe that the problem of uniformity/consistency of decision making is not being addressed and will not be resolved until there is publication of anonymised case studies. If the Welsh Government adopt the whole of the English Framework (2012 edition) this will further hamper any drive towards consistency. Para 90 of the 2012 English Framework with superb civil service double speak states :-

“CCGs should be aware of cases that have indicated circumstances in which eligibility for NHS continuing healthcare should have been determined, and where such an outcome would be expected if the same facts were considered in an assessment for NHS continuing healthcare under the National Framework (e.g. Coughlan or those cases in the Health Service Ombudsman’s report on NHS funding for the long-term care of older and disabled people). However, they should be wary of trying to draw generalisations about eligibility for NHS continuing healthcare from the limited information they may have about those cases. There is no substitute for a careful and detailed assessment of the needs of the individual whose eligibility is in question.”

In other words CCGs can ignore Coughlan etc but at the same time should be aware of those decisions. Both the Westminster Government and the English Ombudsman found that using cases decided by the Ombudsman as comparators was useful. In 1994, Virginia Bottomley, then Health Secretary, referred to the care needs of the patient involved in the Leeds case (Ombudsman Report Case No E.62/93-94, January 1994) as a benchmark for funding, and the Ombudsman also compared the care needs of Pamela Coughlan in the Wigan and Bolton Case (E420/00-01 2002-03). However as can be seen from Para 90 of the English Framework, the DoH are steering assessors away from using comparators.

It is my submission that in the absence of case studies/comparators, it is impossible to tell if assessments across the Boards in Wales and CCGs in England are consistent, in fact I would argue that in the absence of case studies it would be miraculous if they were.

I compare the situation to various legal principles. For example, the law of negligence. That has been developed over several centuries, but the modern law is based on the 1932 case of *Donoghue v Stevenson* which laid down four criteria which needed to be applied for a claimant to succeed. Those criteria have been analysed, dissected and subjected to minute scrutiny by the Courts ever since and everyone has access to those decisions to see how the criteria are applied in various circumstances and how the principles of the decision have been developed over the 82 years since 1932. The availability of this body of case law means that as far as humanly possible a court in Newcastle faced with the same facts as a court with a case in Wrexham or Swansea will arrive at the same conclusion. However in the case of CHC no one knows if the assessments are consistent. The fact that the number of cases being awarded CHC is declining when the numbers diagnosed with dementia are increasing would suggest that if there is any consistency it is as a result of the bar being unlawfully raised as a means of cost saving. Furthermore, it is difficult to challenge decisions and have them tested forensically in Court because of the decision in the case of *Provincial Pictue Houses Ltd v Wednesbury Corporation*, which means in practice that unless the decision to refuse CHC is perverse/manifestly wrong, then the Courts will not interfere with the decision.

Once again my sincere apologies for not being able to attend the meeting. If you feel that it would be of any benefit to discuss the matter further, please let me know.

Regards

Tony Alexander

Dear Tony

Many thanks for taking the time to compile this e-mail. I'm sorry that we didn't get to meet, but your comments are informative and helpful; I completely understand the need to prioritise your appointment.

Many thanks to Helen also, for taking the time to meet with me this morning. It is impossible not to be deeply moved by your story and the experiences of others that you shared with me.

I sincerely hope that the amendments to the Framework I described will go some way to improving the experience of carers in navigating the CHC process. As we

discussed, and as Tony alludes to below, issuing guidance will only take us so far and Welsh Government is committed to working with the NHS to monitor compliance with the Framework going forward and to address the challenges. This is a longer-term improvement programme rather than a one-off event.

Perhaps it would also be helpful to refer to the specific points you detail below. We have received similar representations from other parties and have sought to address them as follows:

The revised Framework requires that a care co-ordinator is nominated and is responsible for ensuring that the assessment contains all the evidence needed for the MDT to make an informed and rational decision on CHC eligibility. When we publish the Framework at the end of June we will also provide an online Complex Care Information and Support Service, which will be publicly accessible. This will include templates for the submission of specialist clinical opinion. I must admit that we haven't as yet considered specific GP training, but I will take this suggestion back to our training group.

We hope that the role of the Care Co-ordinator (which is explained in detail in the Framework) will improve the experience for families and carers. We have developed three information leaflets: 'Public Information Leaflet on CHC', 'Preparing you for a CHC Eligibility Meeting' and 'What receiving CHC services means for you'. These have been developed with help from the Older People's Commissioner and Age Cymru, and have been tested with over 50's forums - so hopefully will help a little. They inform carers about what information, support and written feedback they should expect. The leaflets, Framework and DST will be publicly available on our website and linked from others. We have also required that families/carers are routinely offered access to advocacy services.

Helen and I discussed the cynicism with which some eligibility decisions appear to be made, and to which you allude in your e-mail. The revised Framework clearly separates the eligibility decision from financial considerations and stresses the importance of professional integrity and judgement (as opposed to rigidly 'ticking the boxes') in the assessment process. This will be re-emphasised in the training programme. Monitoring will include peer review and annual audit. We do also need to consider how we can best capture the experiences of carers, such as those you and Helen have described. Your suggestions would be very welcome.

Ensuring consistency of decision making is, as you rightly point out, an ongoing challenge. A number of mechanisms are proposed in the revised CHC Framework and in the Performance Management Framework. These include peer review and an

annual audit of a sample of cases. The issue of using case studies continues to be debated. As you recognise, there is some sense of caution though we are working with the Ombudsman in the first instance, to hopefully develop a 'Lessons Learnt' section in our online resource.

Helen and I also discussed the importance of values-based training and earlier education e.g. in schools. The importance of wider publicity regarding CHC was acknowledged. Publicity regarding the cut-off date for retrospective claims has been distributed to voluntary sector organisations and GP surgeries etc; there is no reason why we can't repeat the exercise with the general Public Information leaflets.

We are currently amending the draft Framework in response to the feedback received through the consultation exercise. This will then be submitted to the Minister with a briefing which will highlight any stakeholder views that remain unresolved. Whilst I believe we have addressed many of the concerns raised with regard to dementia, we will acknowledge that the issue of the potential removal of CHC eligibility as the disease progresses may not be resolved to everyone's satisfaction. We have however included some flexibility with regard to progressive disease where the assessors believe that the plateau may be short-term and/or require more frequent review.

I will also raise Helen's suggestion of a Dementia Task Group to examine how we can set the standard for a straightforward system for people with dementia and CHC.

I hope this response is helpful, though we do not underestimate the joint effort required to ensure that words are translated into action. I hope that you will both feel able to come back to me with any feedback you may have, or if you would like an update, at any time.

Kind regards

Lynda