

What a year!

2018 proved to be our busiest year yet as our team, and the number of clients we represent continued to grow.

In the current circumstances there have been some hard won successes:

Successful retrospective NHS continuing healthcare funding claims, recovering over

£10,000 per client and in some cases much, much more

Challenging access to NHS continuing healthcare for those who fund their own care in the community – and achieving local change in policy

Successful

DOLS (Deprivation of Liberty) cases that have meant individuals could return to their own home, rather than stay in a care home

Challenging financial assessments for care where one half of a couple would be significantly disadvantaged and successfully avoiding severe financial hardship

Working with

care providers to improve recording keeping which has led to success in continuing healthcare assessments

Representation at best interest meetings to prevent our clients' being moved to a cheaper

care home

56 talks and training sessions for support groups, care providers and advocates

Legal seminars for providers delivered across

5 counties to over **90** support staff

189 tweets which led to **98,881** impressions

Being awarded a

Legal Aid contract for **Care** Community

Thank you so much to all of you who have used our services, referred clients to us and attended our events. Without getting too mushy, we all make a great big team! Here's to an even busier 2019...

Welcome to 2019

Given the continued delays in the publication of the adult social care green paper, the nitty gritty of the new DOLS proposals and the ongoing pain of Brexit, it would be foolish to try and predict what this year holds for health and social care legislation...the only certainty is that budgets continue to be squeezed reducing eligibility and existing care packages. Recent reports from the Local Government and Social Care Ombudsman and Human Rights Watch highlight systemic failures by some local authorities to apply the Care Act due to the relentless pressure to save money. But it is not just social care that is struggling – the budget for NHS continuing healthcare and Funded Nursing Care needs to be reduced by more than £800 million over the coming years – with no change in legislation it is difficult to see how this can be achieved without some 'bending' of the rules.

How can we help?

As this newsletter is now sent out to over 1000 of you we thought we had better check what articles, training and seminars would be most helpful in the coming year. So, over to you! If you:

- are dealing with the same problem issue on behalf of a number of clients,
- need to refresh your knowledge of NHS continuing healthcare,
- think your service users could benefit from a pop up legal clinic,
- are struggling with how risk assessments seem to trump 'best interests'
- want to know more about legal aid and community care

then let us know...all (legal related!) requests considered!

NHS continuing healthcare – Judy's huge success story

This is a success story about joined up thinking, and the importance of seeing clients, patients, people, as unique individuals with unique needs.

As a nurse with over 30 years experience, I am often instructed to represent families in continuing healthcare assessments and appeals. Having worked in continuing healthcare myself, I understand the fundamental importance of clinical judgment when considering an individual's eligibility for this funding. But at a time when the NHS needs to save over £800 million in this area a considered, professional analysis is often abandoned in favour of a line by line application of the National Framework. After all, it's so much easier to decline eligibility when you don't join up the dots.



Mr X's case

Mrs X instructed me in early 2017 to appeal the withdrawal of NHS continuing healthcare funding for her husband who had until this point been funded for a number of years without any problems.

Mr X has advanced Parkinson's disease and Lewy body dementia. As a result he has significant physical and cognitive impairments which are both complex and time consuming to manage.

The first appeal

Following a detailed analysis of his care records, it became apparent that the odds of success at an appeal which adopted the 'line by line' approach to understanding his needs would be doomed to failure. Put bluntly, the notes were wholly inadequate in the way they recorded Mr X's needs, with superficial and even missing entries.

Nonetheless, it was clearly evident to me from a clinical perspective (joining up those dots) that his day to day care needs were overwhelmingly health related.

With evidence from Mrs X and a legal analysis by Debbie Anderson we put together a compelling submission... which was (like so many appeals) rejected by the Clinical Commissioning Group who refused to overturn their original decision.

Despite the fact that I was half expecting their refusal, this decision was hugely disappointing. That Mr X's needs, despite the poor record keeping, 'scored' highly in the twelve domains was not enough (sound familiar?). In a rationale that batted away any idea that Mr X's needs were complex, intense or unpredictable, no one on the appeal panel appeared to be looking holistically at the very nature of his needs.

This appeal was fundamentally a disagreement about what constituted a primary health care need. The rationale used by the Clinical Commissioning Group at the assessment and the appeal reinforced our view that the second part of the DST assessment ('the characteristics of health needs') which considers nature, intensity, complexity and unpredictability is the deal breaker in terms of deciding eligibility in all but the most straightforward cases.

The second appeal

Whilst the appeal process was clearly taking its toll on Mrs X she remained determined to continue to the next stage; independent local resolution. Not only does this involve compiling further evidence based submissions (but really, how many different ways can we say 'primary health need?'), Mrs X and I were invited to attend and contribute to the subsequent panel meeting.

And lo! Real people applying real clinical judgment was the order of the day. Dots were joined and importantly Mrs X (and I) felt listened to. Even though we didn't know that we were successful when we left we felt that Mr X's case had been fairly and comprehensively heard by professionals who were independent of the original assessment and appeal.

The letter I received confirming that we were successful included a rationale from the panel that considered and gave value to the nature of Mr X's needs and the relationship between those needs.

As a result, Mr X is now going to be refunded almost two years of care fees, plus interest. He also remains eligible for NHS continuing healthcare...and we will be ensuring the care records are up to scratch for the next review.

What is a primary health need?

You need to have a primary health need in order to be eligible for NHS continuing healthcare funding.

Whilst there isn't a definition, the National Framework says that "an individual has a primary health need if....it can be said that the main aspects or majority part of the care they require is focused on addressing and/or preventing health needs".

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BBC One's Care programme only speaks to some of the struggles families face

However hard a watch at times (and the word bleak springs to mind), as a drama it inevitably had to choose how it told this story. The ending – where NHS continuing healthcare funding is finally agreed, enabling Mum to move to an appropriate nursing home – may leave the uninitiated viewer with the impression that it all works out fine in the end.

If only.

Those families already entrenched in the care system may be wondering at the speed with which the Independent Review Panel appeal took place, watching with feelings ranging from bemusement to outright rage at a portrayal of how to access NHS continuing healthcare that is completely at odds with their own experiences.

For many clients' that we represent, 'the system' dictates the nature of long-term care rather than an individual's needs. Time pressures relating to hospital discharge, the limited availability of affordable care services and the pressure to make life-changing decisions quickly so as not to cause 'trouble' or, worse still, 'delays' fuels family stress and guilt.

The circumstances facing Jenny and her mum Mary in the programme Care are sadly not unusual. In the past month alone we have represented clients in order to:

- Secure a care home place that doesn't require a 'third party top up'
- Challenge cuts to packages of care
- Ensure that individuals can be discharged to their homes, rather than a care home
- Challenged access to NHS assessments for those in the community
- Negotiate, mediate and complain about services

A lack of joined up information for families and those needing care is a huge stumbling block for those we represent. This has meant that the focus of our pro bono work is delivering training and resources to charities and the third sector to give them the tools to work with and advocate for their clients.

In social care, the Care Act 2014 provides a sound framework for assessing and delivering care and support to those who need it and their carers. However, the financial pressures on local authorities has led to a reactionary focus on basic, urgent needs to the detriment of quality of life, meaningful care planning and flexible care provision. Legal duties to provide information and advice are given a passing thought and minimal resources. After all, people armed with information are more likely to challenge. It is perhaps not surprising that complaints about Adult Social Care services to the Local Government and Social Care Ombudsman are upheld in over 60% of cases, and that the Ombudsman has recently highlighted a worrying trend of systemic breaches of legislation rather than one-off errors.



The Mental Capacity Act 2005 is vitally important in ensuring that adults with cognitive issues affecting their ability to make decisions are supported and represented – but enabling someone takes time and resources. For many families that we represent, the legislation is used more as a sword than a shield; there is an implied threat that health and social care can do what they want lurking behind seemingly innocuous questions such as "...well, do you have power of attorney?"

And lastly, to health. Everyone agrees (more or less) that the NHS provides world class acute and primary health services, but when it comes to arranging and funding longer term care those engaging with many Clinical Commissioning Groups (CCGs - who have responsibility for NHS continuing healthcare funding and Funded Nursing Care contributions) find them inaccessible and dismissive, with their engagement with families that borders on contempt.

The stark difference in attitude between local authorities and CCG's is reflected in their respective Ombudsmen. Local authorities are held to account by the Local Government and Social Care Ombudsman; its work is transparent and it publishes complaint decisions weekly and special reports to provide advice to tackle systemic issues that it finds. You may not agree with the outcome of your complaint, but you will be listened to and reasons for any decision are clear. The Parliamentary and Health Service Ombudsman, is however, opaque. The latest decisions published on their website are those made back in 2015. There are far fewer complaints noted in their annual review – possibly because every effort is made to refer you back to the CCG to resolve. It gives the NHS wide leeway, especially in NHS continuing healthcare, to take its time in dealing with retrospective claims – the fact that people went without vital care funding is not a priority.

All of this is a roundabout way of saying that navigating the care system is a bit like high stakes snakes and ladders: Eligible for CHC funding? Climb the ladder. Funding then withdrawn? Slide down the snake. It's not only families that are feeling the strain, care providers are also being squeezed to do more, with reducing resources. In these Brexit dominated times, the green paper addressing social care is kicked into the long grass, as are people's rights and freedoms.

Jargon Busting

ADULT SOCIAL CARE

The local authority department responsible for social care and safeguarding, also commonly known as social services.

CONTINUING HEALTHCARE (CHC):

Is non-means tested funding from the NHS, available when someone is assessed as having a 'primary health need'.

CLINICAL COMMISSIONING GROUP (CCG):

Clinical Commissioning Groups replaced Primary Care Trusts. One of their responsibilities is assessing and paying for continuing healthcare and funding nursing care contributions, although they often outsource this work to Commissioning Support Units (CSU's).

FUNDED NURSING CARE CONTRIBUTION:

The main legislation for adult social care, supported by a number of Care Act Regulations and the Care and Support Statutory Guidance. It is far reaching, covering (amongst other things) local authority responsibilities in relation to care assessments, eligibility and care planning, paying for care, carers' assessments, adult safeguarding and advocacy.

MENTAL CAPACITY ACT 2005

A comprehensive law that governs (amongst other things) Independent Mental Capacity Advocates (IMCAs) and lasting power of attorneys and established the Court of Protection. It is perhaps most commonly known as providing the framework for those who have to act, or make decisions on behalf of people who lack mental capacity.

OMBUDSMAN

The Ombudsman is independent, impartial and provides a free service that is the final stage for complaints. The Ombudsman can investigate complaints that haven't been resolved internally. The Local Government and Social Care Ombudsman deals with local authority and care providers. The Parliamentary and Health Service Ombudsman deals with health organisations.

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