

Health & Social Care News

National Pensioners Convention

Health & Social Care Working Party

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Introducing the members of the newly formed Health & Social Care Working Party:

Mary Cooke

Clive Evers

Jean Hardiman-Smith (Chair)

Claude James

Shirley Murgraff

Terry Pearce

Pat Prendergast

Pat Roche

Elaine Smith

Dot Gibson (Gen. Sec)

Jan Shortt (Vice President)

We hope you continue to enjoy our newsletter and that you will share your stories with us.

What's coming up?

- 1 October: Older People's Day (see NPC website for details)
- 2 November :Lobby of Parliament Rally in Old Palace Yard at 12 noon, followed by lobby in Committee Room 14 from 1 till 3.
- Pensioners' Parliament report is now available on NPC website, or contact your Regional Secretary.

Care Act : 1 Year On Where Next?

Implementation of the Care Act is far from complete. 69% of carers responding to surveys by the Carers Trust noticed no difference since its introduction and many expressed frustration and anger at the lack of support they received in their caring role.

65% of carers had not received assessments under the new Care Act and too many carers were not aware of their rights. 34% of carers felt that their carer's assessment was not helpful.

The Care Act and its statutory guidance makes it clear that carers' eligibility for support is independent of the person they care for. Evidence suggests that practitioners are not always clear on this point. Not all Local Authorities comply with the law in the way they assess and respond to carers' needs and a further study is needed in relation to this.

Many carers continue to find engagement with health services problematic for them and the person they care for, yet there are many opportunities for the NHS to support carers.

The survey showed little evidence that the Act's 'market-shaping' duty has benefited carers and promoted innovation. Local Authorities could do more to develop their offer to carers.

The Act introduced a transition planning duty for young carers and parent carers. Some Local Authorities have adopted a narrow interpretation of this duty, limiting it to those with care needs, to the exclusion of carers with support needs.

Evidence was found that in regard to assessment, the law is either poorly understood or ignored. Too often it appears that carers are fobbed off with a one-off payment as if that discharges the obligation to promote their wellbeing.

Three key recommendations as a priority:

1. National and Local Government, together with the NHS, urgently invest in the support needed to ensure that the new legal rights for carers are fully introduced in all areas, so that carers receive the assessment, support and breaks they need to be able to choose how and when they care.
2. It is essential that Local Authorities ensure that all social workers and assessors are appropriately trained, and are able to reflect the wellbeing principle in assessment and care and support planning.

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3. Local Authorities, with the Local Government Association (LGA) and the Association of Directors of Adult Social Services (ADASS) should review their systems for monitoring progress implementing the Act.

Other recommendations:

- Public Health England should raise the profile of caring, promoting and developing the evidence base for carer health and wellbeing. It should work with carers towards a commitment consistent with that produced by NHS England.
- Local Authorities should consider implementing the 'no wrong doors' principle between children's and adult services to support young carers and young adult carers. Partnerships between Local Authorities, schools and universities to develop new aspects of transition support for young carers and young adult carers.
- The right to transition planning and support for young carers and parent carers needs to be promoted by Local Authorities amongst young carers, parent carers and those responsible for assessment and support planning.
- Think Local, Act Personal – work with carers to devise and offer training and materials to support practitioners to co-design personalised support with carers.
- The Department of Health should make clear to Local Authorities that the default is that a carer's assessment is automatically offered; that carers are eligible for support in their own right whether or not the person with care and support needs is eligible for support. Practitioners should be trained to explain the purpose of a carer's assessment in a way that does not require the person to take the label 'carer'.
- Local Authorities and local carers services need robust joint strategic needs assessments to fully understand the diversity of their local population and work out how to reach all groups. To ensure that the Care Act is bedding in for all carers, more research is needed about other groups of carers.
- The Short-and-Long-Term (SALT) return should be reviewed, so that it captures all assessment and support activity for carers, including prevention.
- The Equality and Human Rights Commission should ensure that Councils are adopting best practice in fulfilling their Equality Act duties under the Care Act.
- Care provider bodies should work with Local Authority Commissioners to develop appropriate 'aftercare' a carer needs when caring ends or changes.
- The CQC works with carers and carer organisations to ensure that the new programme of monitoring and inspection from April 2017 includes key lines of enquiry concerning carers and that evidence of impact and improvement of care for carers is used in determining whether a provider is found either Good or Outstanding.

Ambitious, much deserved, but is it sustainable in the light of chronic underfunding of the care system?

GP's Feel Impact as CCG Cuts Costs

NHS St. Helens CCG is proposing a complete suspension on all non-urgent referrals to local hospitals. This could see local GPs unable to refer any patients for non-urgent treatment over a winter period of four months maximum.

The CCG – recently rated as 'inadequate' by NHS England – admits it will not be popular, but is facing a £12.5 million funding gap over the next year after a £3 million overspend.

Suspending referrals to hospitals is one of several measures being consulted on. Others are to 'suspend, reduce or withdraw certain services' in order to close the funding gap.

Hospital referrals are one of the biggest areas of financial pressure and currently exceeds the budget received by the CCG.

However, it has been made clear that any decision not to refer will be made in agreement with the patient and GP.

The public consultation is open until 5 October and is through an on-line survey:

<https://www.surveymonkey.co.uk/r/N86SPHJ%20a>

For those of our members continually feeling frustrated by not being able to participate on-line, perhaps you might approach St. Helens CCG and/or your GP and ask them to make provision for you to make your own contribution in another way if you so wish.

Delayed Discharges Rise

Delays in discharging patients from hospital have risen 23% since June last year.

Every day more than 6,000 patients well enough to leave hospital are unable to do so because there is nowhere suitable for them to be discharged to.

NHS England said: 'It's important patients who are well enough to leave hospital can do so at the earliest opportunity. These figures underline the importance of 'joined-up' care and the dependence of hospitals on well functioning social care services – particularly older people living at home'.

Set against closures of A&E services, merging of hospitals in local areas, loss of bed spaces, continued privatisation and underfunding, whole-person care cannot be delivered efficiently and successfully without improving equality of access for everyone.

Medical Examiners in Coroners' Office

Update by Mary Cooke

On the 3 June 2016, the Chief Coroners' office responded to the recently held Consultation with regard to the requirement for Medical Examiner's in Coroners' Offices and in Hospitals, and the Reform of Death Certification. This followed the 2009 Coroners' and Justice Act for the requirement that Medical Examiners scrutinize all deaths that are not investigated by a Coroner.

The Chief Coroner, His Honour Judge Peter Thornton QC, Chief Coroner, set out in his response a number of advantages and a number of concerns, thirty eight points were made in all. He starts his response with the following:-

'That although the advantages of fewer unnecessary referrals to the Coroner, of statutory criteria for reporting deaths and of Medical advice available for Coroners' are to be welcomed, the Chief Coroner has concerns on the likely increase in workload of Coroners' without additional resources.

It is generally believed that there will be an increase in the number of cases referred to the Coroner which will proceed to inquest. It is also expected that many of these cases will be more difficult and more complex medical cases. None of the pilot schemes in place at present have been completed. The Sheffield scheme for example, which has been the most developed pilot has not dealt with community deaths. Never the less the figures from Sheffield are troubling. Sheffield has faced an increase in inquest work of some 35%. This is a very significant increase. It has only been managed in Sheffield thanks to an excellent Coroner, an excellent Medical Examiner and an understanding Local Authority.

The Chief Coroner further points out:- An increase in inquest work of this sort of proportion will not be funded by central Government. There may be insufficient funding from Local government. Coroners' work is stressful work. It is dealing with deaths and grieving families who usually want as little to do with the coroner service as possible. Coroner Officers' have reported significant levels of stress when giving feedback to the Judicial College, the organisation which trains all Coroners' and and Coroners' Officers.

He asks again 'With regard to the costs of the Medical Examiners scheme, Who will pay for the service? How much will they pay? Who will collect payment? What will happen in the event of default of payment? He goes on further:- 'It seems clear that bereaved families will be burdened with this payment even if they have not obviously benefited from the Medical Examiner scheme'.

Another concern is about the independence and quality of Medical Examiners.

With regard to benefits the Chief Coroner suggests the following three ways the service could benefit:-

First, there should be fewer inappropriate referrals to Coroners from Medical Practitioners, both GP and from hospital doctors. The reduction should be achieved by Medical Examiner's being able to advise doctors on the medical cause of death.

In 2015, there were 529,613 deaths in England and Wales; 236,400 of them were referred (reported) to Coroners by doctors, although only 32,857 deaths went to inquest. This figure suggests that too many deaths are reported to coroners unnecessarily.

Secondly, the Medical Examiners scheme is likely to bring with it statutory criteria for doctors on when to report a case to the coroner. This Statutory requirement is now proposed for Death Certification Regulations and this is welcomed. (This Statutory requirement is stated in a number of the points raised by the Chief Coroner).

Thirdly, the presence of local Medical Examiners should make medical advice more freely available to doctors.

Thirty eight points in this response indicates that a lot more work is needed on the role of Medical Examiners - not least on who pays for this service?

And all to be sorted before the changes in Death Certification. I will keep our members updated as to future information as it emerges.

Mary is a member of the H&SC Working Party. She is an active member in the Eastern Region

Inequality in Mental Health Services

By Judith Varley

Mental Health remains the 'Cinderella Service' subjected to cuts in all aspects year after year. There is NO 'parity between mental and physical health' despite repeated promises. When someone is completely irrational/psychotic/wildly caught up in unpredictable and fantastical obsession, they need to be in a safe place for their own and the safety of others. This might be hospital, a crisis house or properly serviced home treatment, but a safe place is essential. Early Interventions, joint work with families/friends/ peers or other support should be available during and after the immediate crisis so recurrences are minimised, perhaps eliminated. To be beneficial, the quality of relationships between service user and support is crucial, so consistency and reliability are equally important.

Psychiatric beds have been cut year after year - a deliberate act of government policy – approximately halved every year. 'Bed-hopping' to wherever a bed is temporarily available is commonplace and maximally disturbing for those already unable to cope with what's going on in their heads. People can be sent hundreds of miles from home, caring relatives/friends/familiarity, wherever an empty bed can be found, an appalling system. Discharge whilst patients are still acutely ill is frequent as a result.

The mantra is that Community Services will pick up the slack. In reality, there has never been surplus capacity in Community Psychiatric Services and these resources too have been slashed, qualified staff replaced by unqualified or less qualified (cheaper) staff – if at all.

This leaves untrained informal carers /families, the involuntary volunteers to cope as best they can. Sometimes, 'the carer' can be a child - in one instance I know, it was a 4 year old looking after his depressed and partially physically disabled single parent Mum. Informal family carers are reckoned to save the Treasury more than £120 billion a year. Not surprisingly, many long term carers become service users themselves, isolated, subject to unpredictable stresses, physical and /or mental breakdowns; some are still first line carers in their 80s and 90s. Carers should have their needs assessed and addressed at least annually (more often at times of repeated acute episodes), with an agreed care plan shared with the GP. Suicides, attempted and actual, and self harm have increased in all age groups, particularly in males.

Child and Adolescents: Mental health problems have doubled in young people since 2010. Tens of thousands self harm, have eating disorders, attempt and may achieve suicide. Self harming 9 year olds have become 'normal'. In the 60s, the age of onset of depression was 45, now it's 14. In some parts of the country, childhood depression, self harm, eating disorders have increased by 600%. Yet the Children & Mental Health Service (CAMHS) budget has been slashed by £58m and many Trusts no longer have CAMHS. Resolving mental health problems early, benefits both the individual and society, and it's infinitely cheaper; not to do so is truly shocking in a supposedly educated advanced country as well as being negligent beyond belief and morally indefensible.

Disability Living Allowance (DLA) is being replaced by Personal Independence Payment (PIP); this is of less value to the individual and will be available to fewer people. It's 'sold' as giving the person autonomy in their life – able to choose how that money's spent, something we'd all agree is good. It is being 'rolled out' gradually across England, and of course it is about 'cuts' in financial support. Between July & Sept 2015, 60% of appeals were won. This suggests PIP is not properly worked out and needs further investigation.

Mental Health Advocacy, Voluntary groups, CAB, Mental Health charities, disability organisations, Inter Personal Support Services, legal aid, welfare officers etc. have either disappeared or have had their funding severely reduced – those remaining are over-stretched and under resourced, although the demand since the advent of austerity has greatly increased. Claimants are left to present their own cases at Tribunals (unless they can fund legal fees themselves). Meanwhile, the Treasury has provided £22 million of public money to hire 'presenting officers' to represent the DWP at Tribunals.

Employment: Government policy is to get unemployed disabled people back in employment. Appropriate fulfilling work, properly paid and supported can help some people with mental health issues without doubt.

Adjustments to help those with physical disabilities have been quite successful, but this rarely extends to those with mental health problems who have been out of work for a long time. People admitting to a history of mental ill-health, to time spent in psychiatric wards, are the least likely EVER to find paid employment, irrespective of their qualifications and capabilities. Frank Field (my MP) told me 'work coaches' are being provided by the government, using money taken from other deserving areas, and these would be useful in his opinion. They are not widely available.

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NICE Guidelines state that anyone on anti-psychotic medication should have physical health checks. This does not seem to be done routinely, and genuine physical symptoms are generally ignored or assumed imaginary.

There is need for a wider involvement of diverse people in developing policy, practice, services and training, real choices and support offered. A one size fits all is totally inadequate.

Ageism – Alive & Well!!

Older women are in danger of receiving worse breast cancer care after NHS guidance dropped an insistence that treatment must never be based on age.

The National Institute for Health & Care Excellence (NICE) decided that the fight against age discrimination was no longer a priority for the treatment of the 54,000 women who develop breast cancer every year. A third of these are over 70.

A range of studies has found that older patients often receive worse care, with doctors failing to refer them for life-saving treatments.

NICE has updated its quality standards on treating breast cancer, emphasising that women suspected of having the disease should get a triple check on a single hospital visit, to speed up diagnosis by avoiding the need to wait for separate examinations, scans and biopsies. It also says that more women should get a genetic test that predicts whether their cancer will spread.

BUT The updated guidelines drops the standard of five years ago which stated: 'people with early invasive breast cancer, *irrespective of age*, are offered surgery, radiotherapy and appropriate systemic therapy, unless significant comorbidity precludes it.'

On being challenged to backtrack on their decision, NICE said: 'that fighting ageism was no longer a national priority, leaving it up to local areas to decide whether to follow the old guidance.'

Older women are less likely to be referred for tests and potential diagnosis. 18% of patients over 85 only find out they have breast cancer after going to A&E, compared with just 2% of patients in their 60s.

Once cancer is confirmed, fewer older patients are offered surgery or radiotherapy. More than 80% of breast cancer patients have major surgery until the age of 65, when rates drop to just 25%.

There is a legal, and moral, duty to treat everyone equally based on their needs and circumstances, not their age. Local areas already strapped for funds will perhaps find it easier to apply the new guidance.

How Sustainable is the NHS England Plan?

In our last newsletter we let you know about the NHS England 'Sustainability Transformation Plan' with 44 'footprints' across the country designed to 'improve' the NHS.

The quest for 'sustainability' is threatening services with the most vulnerable being A&E units and smaller hospitals.

Now we have a new initiative to 'reset' the finances

The tough action by NHS England and NHS Improvement (NHSI), the service's financial regulator, is intended to reduce overspending by trusts from a record £2.45bn last year to nearer £250m by the end of this year.

Trusts will be given money from a £1.8bn "sustainability and transformation fund" to help balance their books only if they agree to make significant savings by the end of March 2017 by signing up to a "control total".

There are 17 trusts in deficit that have so far refused to agree their total with NHSI. Five of these trusts are to be put into financial special measures:

- Barts Health NHS trust in London (which is both the NHS's biggest trust and the one that ran up the biggest deficit last year, at £135m).
- Croydon Health Services £39.8m
- Maidstone and Tunbridge Wells (£22.9m)
- Norfolk and Norwich (£31.1m)
- North Bristol (£48m)

Part 4 of the 'reset' plan argues that hospitals and services which now depend on locums and agency staff need to be closed and centralised in nearby larger units.

Little has emerged from the 44 'footprints' – details having been so far kept firmly under wraps.

However, there are some brave Councils (Hammersmith and Ealing in North West London) who are refusing to sign up for an STP that threatens hospitals in their boroughs.

Whether it is STPs, old-fashioned cuts or the privatisation offensive, every part of the country faces major test as a result of the ruthless spending squeeze.

Data Sharing: Update

Dame Fiona Caldicott (National Data Guardian), along with the CQC conducted a review into the issue of data sharing and its security.

Whilst evidence shows that people are in favour of sharing health information with other health professionals, there were concerns around data security, where data would go and confusion around 'opt out'. Here is a precis of the recommendations made by the report:

1. **Data Security:** The leadership of every organisation should demonstrate clear ownership and responsibility for data security, just as it does for clinical and financial management and accountability. A redesigned toolkit to build professional capability among staff to be available.
 - Trusts and CCGs to identify vulnerabilities such as dormant accounts, default passwords and multiple logins from the same account.
 - All health and social care organisations to provide evidence of action to improve cyber security.
 - NHS England should change its standard financial contracts to require organisations to take account of data security standards. Local Government should also include this requirement in contracts with independent & voluntary sectors. Where a provider does not meet the standards over a reasonable period of time, the contract should not be extended.
 - Internal data security audit and external validation systems should be reviewed and strengthened.
 - CQC should amend its inspection framework for providers of registered health and care services to include assurance that data security standards have been carried out. HSCIC to use the toolkit to inform CQC of 'at risk' organisations and for CQC to prioritise action.
 - HSCIC to work with regulators to ensure a coherent oversight of data security across health and care system.
 - Where malicious or intentional data security breaches occur, the Department of Health should put harsher sanctions in place.
2. **Consent/opt-out:** The case for data sharing still needs to be made to the public, and all health, social care, research and public organisations should share responsibility for making that case.
 - There should be a new consent/opt-out model to allow people to opt out of their personal confidential data being used for purposes beyond their direct care. *(This appears to imply that if there is no opt-out, then your data could well be shared beyond the realms of health-related organisations).*
 - The government should consider introducing stronger sanctions to protect anonymised data. This should include criminal penalties for deliberate and negligent re-identification of individuals.
 - The forthcoming Information Governance Alliance guidance on disseminating health and social care data should explicitly refer to the potential legal, financial and reputational consequences of organisations failing to have regard to the Anonymisation Code of Practice by re-identifying individuals.
 - People should continue to be able to give their explicit consent, for example to be involved in research.
 - The Health Research Authority should provide the public with an easily understood explanation of the projects that use personal confidential data and have been approved following advice from the Confidentiality Advisory Group.
 - HSCIC should develop a tool to help people understand how sharing their data has benefited other people. It should show when personal confidential data collected by HSCIC has been used and for what purposes.
 - The Department of Health should conduct a full and comprehensive formal public consultation on the proposed standards and opt-out model. Alongside this consultation, the opt-out questions should be fully tested with the public and professionals.
 - There should be ongoing work under the National Information Board looking at the outcomes proposed by this consultation, and how to build greater public trust in data sharing for health and social care.

Whilst welcoming this review and its proposed recommendations, there is still uncertainty about the opt-out model. Recently we have seen Google DeepMind involved in collecting all kinds of data because no single database exists for acute kidney injury. There is nothing in the review that says how data that has been captured in this way is to be dealt with. We hope members will get involved with the public consultation.