



Camden Carers' Voice meeting
Minutes – 28 September 2017, 10.30 am – 12.30pm
Argenta House, Aspern Grove, Belsize Park, NW3 2AB

<p>Attendance</p>	<p>26 carers Chair: Jacky Spigel (Steering Group) Vice chair: Kate Harwood Presentation/ Guest Speakers: Martin Emery, Deputy Head of Engagement - Camden Clinical Commissioning Group Nick Ince, Transformation Team Steering Group - Jessica Buck, Sue Parry-Davies, Eamonn Cashin, Costas Louis Allegra Lynch, Chief Executive, Camden Carers Service (CCS) Naomi Feather, Support Worker (CCS) Philippa Russell, Engagement & Outreach, CCS & C404 Apologies: Sally MacKinnon, Janet Cabot (Steering Group), 3 carers</p>
	<p>The chair welcomed everyone to meeting, went through the ground rules. The Steering Group were introduced.</p>
<p>Carer feedback and actions from last meeting</p>	<p>Action and feedback from last meeting</p> <ul style="list-style-type: none"> • Lorraine – will feedback on Day services at the next meeting. Action PR to send minutes in advance / include on CCS website • Lorraine talked about a new panel of champions to represent different groups. They are setting up terms of reference and will have focus groups with carers and voluntary groups to hear issues and input. Lorraine is champion for carers and People with learning disabilities. • PR has details about becoming an appointee and benefit signposting • Steering Group has been in touch with Tulip Siddiq MP around carer rights and representation and will chase meeting after the party conference • Changes in benefits – CCS to have relevant news on website • The minutes of the June 2017 meeting were accepted
<p>Carer experiences</p>	<p>Two carers talked of their experiences of medical care in the NHS, which they had hoped Martin would hear.</p> <p>Eamonn –his 48 year old son has schizophrenia and was diagnosed aged 26 and has been in a secure unit since 2015. He talked of shock followed by guilt and how it has completely changed his families' lives. Level of anxiety around what happens when they are no longer alive to care. State of ward is like a prison. Concerns around the NHS – profit and loss driven and low staff morale. Money was found to engage a political party but is not invested in NHS.</p>

	<p>Jacky – Her daughter has profound multiple learning disabilities and complex health needs. She lives in a supported living flat. She has had severe and unpredictable epilepsy for 16 years. They were offered a trial of new medication 7 months ago with no progress. It is unclear if the responsibility lies with the GP or hospital and whether it is purely a funding issue. In terms of pure finance, it is more costly to call out paramedics on frequent occasions as well as the injuries she incurs when falling during a seizure.</p> <p>Carers asked if the quality of life not more important than funding?</p> <ul style="list-style-type: none"> • Issue of research and drugs – eg sodium valproate and risk of LD <p>Action – Steering Group to form actions to campaign on behalf of carers to pass to Martin Emery. As a commissioner, he has the power to take forward. All agreed that medical staff do dedicated work under difficult conditions and to focus on the political dimension.</p>
<p>Presentation on Local Care Strategy</p>	<p>Martin apologised that Sally MacKinnon was unable to attend. Nick Ince from the transformation team would present details of the local care strategy:</p> <ul style="list-style-type: none"> • The CCG purchases health care services in Camden – they pay towards carer services including Camden Carers’ Service. • Plans to integrate Council and health care for community services eg link rapid response team / district nurses over 3-5 years. • This will be tailored to reflect the diverse population of Camden to be: accessible (see the right person), person centered, coordinated, preventative and effective. • Aim to treat the whole person. If patient notes are shared a fuller picture is given of the person. • National challenges such as funding and quality gap – we live longer which should be seen as a positive but we want to live healthier lives • The Care Strategy board talks to patient representative and carer groups • Outcomes – inequalities in areas of deprivation, prevent early death, Improve access to care, Experience of care, Enhance quality of life • Purpose of strategy - move to neighbourhoods, align services in hospital / community / voluntary sector to offer closer, more joined up care providing specialist care • Delivery and engagement covers: adults, children and mental health <p>Nick was thanked for his presentation and carers were invited to ask questions.</p> <ul style="list-style-type: none"> • Where is funding from? Part of existing funding stream which was previously compartmentalized is now being integrated better to give appropriate care. Action – Martin will send slides about CPPEG and work with Keats Group practice

- A carer had great care when her mother died with bereavement counselling, Camden Carers Service, Adult Social Care and funeral service and medical staff.
Action - bimonthly CCG meetings has an elected patient representative and Martin would like to give this positive story
- A number of carers noted the absence of carers in the local strategy and the role and representation of the carer is not acknowledged. Other boroughs don't have eg Camden Carers Service
Action – Have a carer representative on the CCG? CCG is organising a meeting around neighbourhoods with voluntary groups and will have one with Camden Carers' Service. Importance of carer voice.
Action CPPEG have 6 monthly reporting – to include carer feedback
- Workforce – always need more nurses – look to recruit, train and retain with more skilled people in psychiatry. New model where care is delivered in different ways eg through pharmacy, nurse in GP practice
- A carer sees the GP with the person she cares for with no opportunity to mention her own needs. Could there be carer's evenings with GP
Action – importance of time dedicated to carer – have 20 minute appointment for complex needs maybe could extend for patient and carer?
Action - Activities and support for under 16 carers eg the Hive is often not used during the day. Martin to check about use of space
- Other specialist services may not be available locally or accessible for people.
Meant to enhance but not replace existing services. There will be flexibility of special services according to need.
- A carer is having difficulty in applying for blue badge. Confusion around process. Martin and Nick to speak to carer.
- A carer raised the issue of changing services around epilepsy – This will be part of the integrated service and they are looking for a new provider.
- The issue of consent to share records was raised.
Action – Martin to provide update about Camden integrated records – consent from patient or carer to allow patient records to be visible. How is this consent given?

Martin and Nick were thanked for talking to the group and the Steering Group and the Steering Group and Philippa will follow up with issues raised.

The Mobility forum meets on 29 September. Sue and Jessica will report back.

Next meeting - Mayor's Parlour on Thursday 30 November, 5-7pm