



Camden Carers' Voice meeting
Minutes – 20th April 2021, 11am-12:30pm
Via Zoom

Attendance: (Steering Group) Jacky Spigel (chair), Kate (vice chair), Jessica, Galatea, Costas, Leah, Sue. 21 Carers and Former Carers. Allegra Lynch, Mollie Delaney, Ciare Reynolds (Camden Carers), Bee and Desmond (Camden Carers Trustees)

Apologies: Olivia (Steering Group Candidate)

Speakers: Bob Dowd, Richard Chester (Patient Experience Deputy Director at The Royal Free Hospital), Matthew Parris (Director of Healthwatch Camden)

- Jacky and Kate welcome the speakers and attendees and went through the ground rules.
- Allegra introduces the CCV Steering Group Elections and voting takes place.
- All candidates are elected and their place on the Steering Group is confirmed.
- A couple of Carers raised points regarding how the elections take place, they feel it'd work better if the voting was open to all Carers and not just those who attend the meeting. Kate advised the original invitation went out to all carers on the Camden Carers database via the fortnightly newsletter and on their website. They had to contact Mollie to register their attendance.

Update from Bob Dowd:

- Questions regarding benefits were prepared prior to the meeting for Bob to answer.
- **Q** - Have there been any changes to the benefits system during the pandemic that would affect carers? Could you outline and expand these?
A – There has been changes to Universal Credit. The benefits appointments have been taking place virtually due to the pandemic, either via Zoom or telephone.
- **Q** - How would a carer appeal a benefits decision? What is the success rate of appeals?
A – You'd have to firstly read the letter that was sent to you. If you disagree with the decision, you can request a mandatory reconsideration over the phone, you have a month to do this. This will then be looked over and a decision will be made in 2-4 weeks. 90% of the time, the reconsideration isn't altered. Therefore, you can submit an appeal for tribunal by filling out a form online. If you need benefits support, you can receive this from Citizens Advice Bureau. 20% of people that ask

for a reconsideration then go on to appeal for a tribunal. The success rate of decisions being changed at tribunals is 10%, meaning 90% of the original decisions stay the same.

- **Q** - Is there a confusion between Carers allowance and Carers Credit? Carers Credit seems to be linked to National Insurance contributions and would affect future pensions.

A – There is a difference between Carers allowance and Carers Credit. Carers Allowance is a benefit that will have an effect on other benefits if you claim this. If you claim Carers Allowance, you are automatically given Carer Credit. Please see attached documents for more details on Carers Allowance and Carers Credit.

- **Q** - Is there anything more that carers need to know about any benefits that can be accessed and which ones are means tested?

A – Means tested benefits include Income Related ESA, Job Seekers Allowance, Pension Credit, Tax Credits and Universal Credit.

- **Carer** – When are Carers rights going to be recognized again?

A – Can't answer that right now but happy to look into this and feedback.

Action – Bob to feedback on Carers Rights and Benefits.

- **Carer** - Why is my cared for's benefits being deducted as a result of me claiming Carers Allowance?

A – This shouldn't be the case, it'd be best to get benefits advice regarding this.

- Bob explained that you can find more details in the documents that he'll send to Mollie.

Action – Mollie to circulate documents regarding welfare benefits to Carers.

- **Ciare** – Camden Carers work closely with the Mary Ward Centre, Age UK and Disability Law Service. If Carers are in need of benefits support, we can make a referral to any of the services above. The support can include help with filling out an application form, support with an appeal or checking what benefits you're entitled to.

Update from Richard Chester, Patient Experience Deputy Director at RFH:

- Richard works for the Royal Free London NHS Foundation Trust, which covers the Royal Free Hospital, Barnet Hospital and Chase Farm Hospital. Richard is working on a project to help strengthen what the RFL do for Carers.
- Four different areas are being looked at:
 1. Before yourself and your cared for arrive at the hospital - We're looking at sending information on your rights as a Carer.
 2. Agreement – We'd like to know how you'd like to be involved with the care your loved one receives at the hospital.
 3. Draft Agreement - A document will be written, similar to a Care Plan outlining the agreement.
 4. Discharge – We'd like to include Carers more with the discharge of their loved ones. Sometimes we only give Carers a days notice of when the discharge will be which can cause stress for the Carer as they need to be prepared and know what equipment is required at home.
- This is just the beginning of the project, Richard is hoping to have this completed by June 2021.
- It's important that going forward, Carers are aware of the procedures and given training when visiting the hospital. For example, training on the beds or other equipment that needs to be used.
- If Carers have a question regarding an individual case, they can email Mollie Delaney – mollie@camdencarers.org.uk. This will then be passed on to Richard.
- **Carer** – My cared for was allocated a specific worker at the UCLH which meant that I was able to go home to prepare for his discharge. Is this something that the RFL offer?

A – We only offer this in certain areas, e.g for people with Dementia. However, this is something we want to expand on.
- **Carer** – It'd be useful if there was an additional question on the agreement document where Carers can add any other comments that the staff may find useful or need to be aware of.
- **Carer** – My cared for usually goes to the hospital with her paid Carers, however as they're paid they're seen as staff members and left to their own. Are you talking to supported living providers in Camden about this?

A – Yes, we'll be working very differently now, especially in terms of legality and insurance.
- **Carer** – My cared has Autism, he has previously been seen at the A&E on his own but struggles to take in the information that staff discuss with him. The staff weren't aware that he has Autism. Is there a way to alert staff on the patients record stating whether they have a learning difficulty?

A – My colleague, Sarah is currently looking into strengthening this. We are able to flag up on a patient's record whether the person needs additional support. It will also state whether someone needs a double appointment. Sarah Lalley, Acute Liaison Nurse – Learning Disabilities, RFL email: s.lalley@nhs.net

- Carer mentioned an experience she's had with her cared for. Richard agreed to discuss this further with her via email.

Action – Mollie to forward Carer's email on to Richard.

Update from Matthew Parris, Director of Healthwatch Camden:

- Matthew explains that the aim of Healthwatch Camden is to help strengthen the voices of people in regards to health services. This includes hospitals, GP's care homes and more.
 - Healthwatch was established from the Health and Social Care Act and have statutory authority.
 - Healthwatch Camden are currently working closely with Black and Minority Ethnic Communities regarding the COVID-19 vaccine. They're looking into the view of different faiths regarding the vaccine. A report has been created which provides information that people may be missing about the vaccine.
 - They're also working on promoting more services for young people and children, Kooth is one platform that is used to help support them. Some Carers raised that they don't feel this platform has been useful.
 - Matthew asked Carers – If there is one thing you'd like to change about Health Care Services, what is this?
 - **Carer** – No more privatization of GP Practices.
 - **Carer** – Mental Health is a very important topic. How does Healthwatch work with Mental Health Care Groups? Is Healthwatch involved in the Mental Health Care Act ReWhite Paper Review to be issued next month? This is a vital White Paper to revamp a very arcane Act which works against patients' rights.
 - **A** – Matthew will have to look into this and feedback.
- Action – Matthew to feedback on the work Healthwatch do surrounding Mental Health.**
- **Carer** – There needs to be more Mental Health Services for children.
 - **Carer** – It'd be useful for Healthwatch to look into the Mental Health problems that specifically black men face.
 - **Carer** – I believe there have been Social Care changes between government and councils and/or GP's and NHS. If so what are the changes and how will they affect councils, carers, NHS and GP's?
- A** - Matthew explained that he is not aware of any changes.

Any other business:

- Carer asked whether there is any update on the Carers Card.
- Allegra** – There isn't any update on this. We've been trying to push for discounts to be added to the Carers card but haven't heard back yet. This is something that Careline offer. This may be something a Councillor can look into.
- Action – Cllr Simon Pearson to discuss further with Allegra.**

-Date of next meeting – Thursday 8th July 2021 at 4pm – 6pm.

