

**Camden Carers' Voice meeting
Minutes – 16th July, 11am-12pm
Via Zoom**

Attendance: (Steering Group) Jacky (Chair), Kate (vice chair), Jessica, Janet, Shahram, Galatea. 11 Carers. Allegra Lynch, Mollie Delaney (Camden Carers), Sheila Porritt, Bee Lee, Desmond Walcott (Camden Carers Trustees), Martha Daniels (On behalf of Cllr Pat Callaghan)

Apologies:, Costas, Sue, Terry

Speakers: Mark Agathangelo, Amanda Tabor, Betty Wynne, Richard, James Townsend

- Jacky introduces herself, Kate and attendees. Briefly went through the minutes of the last CCV meeting.
- **Actions:** Jacky asked Martha Daniels to pass on the actions to Cllr Callaghan: To send to Allegra information on what Camden does regarding domestic violence with adults and children in Camden. Also mental health issues getting worse due to lockdown.
- Cllr Callaghan was going to look into whether we could invite a designated police officer regarding domestic abuse to one of our CCV meetings
- Cllr Callaghan is invited to all our CCV meetings

Update from Mark Agathangelo – Patient Partner, Camden MSK (musculoskeletal service)

- Introduces himself and his job role. Camden MSK is a self-help support group. They offer a patient advisory group. The organization was established around a year ago and has a lot of engagement from Carers.
- Camden Carers previously held a MSK event. This helped make a connection between Carers and Camden MSK.
- The patient advisory group is taking place online at the moment via Zoom which is open to anyone who has or cares for someone with MSK problems, to join and discuss certain topics. Some of the topics include: pain sufferers, self-management, flare ups, sleep, diet and diabetes. A consultant from the UCLH recently did a talk on diabetes.
- Q- What does MSK cover?
- A- It covers any problems with hips, knees, bones and rheumatology
- Q – How do you get referrals?
- A – Yes you can self-referral but it is generally done through your GP.
- **Action – Christina to send update to Allegra**
- Carer – There are usually two meetings that take place through Zoom each week. Anyone can join to discuss and raise an issue. I am concerned about the future for GP practices but I'm pleased that Camden MSK exists as it still allows us to have a voice.
- Q - Does pain management come under MSK?
- A – Yes
- Carer – I'd like to know what will happen to appointments that have been cancelled due to COVID-19. **Action – Allegra/Mollie to send Camden MSK Zoom details to Carer**

Update from Amanda Tabor, Patient Experience Manager, UCLH NHS Foundation and Richard, Family & Carer Liaison, UCLH. Apologies from Betty Wynne (Assistant Chief Nurse UCLH) as she had to join another meeting

- Amanda – Introduces herself and job role which involves getting feedback from patients and Carers both in wards and as outpatients. The feedback is looked into and helps to improve the service.
- There is a patient engagement group which allows people to share their views. However, this has been taking place via Zoom at the moment.
- Restrictions have been made at the UCLH hospital for the safety of everyone. We do not allow visitors at the moment but are looking at how we can start to allow visits again.
- Q - How do you get feedback?
- A – Usually after appointments we will ask patients for feedback, people can also get in contact through the PALS (Patient Advisory Liaison Service) department, through a formal complaint, forums and patient listening events.
- Richard – Introduces himself and job role which involves medicine for the elderly, supporting families and unpaid Carers at the UCLH. They recognize that it is hard for people not to visit their loved ones at the moment.
- Richard focuses on informing patients and Carers on the support that is available to them. Carers are asked about their cared for's needs so that the hospital knows how to best support them.
- Richard also educates staff at the hospital on unpaid Carers so that they receive support with their role. **Action – Camden Carers to send out information about UCLH**

Update about online support for Carers from James Townsend, CEO, Mobilise:

- Introduces himself. Mobilise is an online start up for Carers which is currently at a pilot stage. They provide support for all Carers and are focusing on certain areas including Camden, Hammersmith and Fulham, Shropshire.
- James and Kyro Brooks are both carers and provide support in three key areas – how unpaid carers can get support via 3 key “buckets”: how to navigate the system, how to pass this on and the technology to do this. They start conversations with them.
- They have developed a model for people that don't recognize that they are Carers.
- Mobilise sends out an e-support package everyday which includes practical tips, information from the government and funny GIFS to make people laugh.
- In order to get Young Adult Carers to engage with the service we have created a group for them to write their stories and experiences of being a Carer on a blog. They tend to use the blog posts to share their point on issues rather than their own caring role. The focus is on making a change. This is done on several social media platforms such as Twitter, Facebook and Instagram.
- During the COVID-19 pandemic, they have been holding daily cuppas online for Carers. They found that mutual support is helpful and that it is best to listen to Carers rather than rushing to try to fix the problem. All Carers are welcome to join and share their experience.
- They found that at the start of lockdown, Carers had practical issues such as getting shopping. However, now Mental Health is an issue as the stress is getting to them. A lot of Carers also had problems before lockdown which they put on hold such as operations and appointments but as time has gone on the problems have worsened and it now needs to be sorted out.

Q – How big is the membership and do you make referrals to Camden Carers?

A – We currently have 800 members. Some engage every day and some dip in and out. We focus on finding people hidden Carers that aren't engaged with any Carers support. We have made referrals to Camden Carers and Camden Council.

Allegra – There are 17,500 unpaid Carers in Camden and Camden Carers have approximately 4,000 registered. Mobilise gives Carers a choice and offer different things to us which is why we are working together to reach more Carers.

Q – Is there a distinction between Carers and Cared for that have had COVID-19? How do you support them with this?

A- Our support is mainly for the Carer, however we can help to identify support for the Cared for. We've spoke to a few people that have had it and have found that they find the lockdown situation more challenging than the virus itself. **Action – Allegra to send James' contact details to Sheila Porritt regarding the effects COVID-19 has had on her.**

Carer – I looked up Mobilise and noticed that you provide a lot of support online. However some Carers need support on how to use technology.

Allegra – Camden are trying to make improvements on training people on digital technology. The Irish Centre and Age UK also provide training on this.

- **Any Other Business** – Camden Carers have moved into The Greenwood Centre (37 Greenwood Place, Kentish Town, NW5 1LB) and will be based here again once the Centre opens again. A lot of other organisations are also based here.

- **Date of next meeting – 8th October 2020**