

Camden Carers' Voice meeting
Minutes – 21 June 2018, 10.30 am – 12.30pm
Charlie Ratchford Centre, Belmont Street NW1 8HF

Attendance:

27 carers, Chair: Jacky Spigel (Steering Group) **Steering Group** – Kate Harwood, Jessica Buck, Janet Cabot, Costas Louis, Eamonn Cashin
Allegra Lynch, Philippa Russell, Lorraine Revah, Shanta Joseph

Apologies: Sue Parry-Davies, 2 carers

Presentations: Isky Gordon – My Living Will, Suzanna Baker and Samantha Tayler –
Osbornes Solicitors, Toby Scott - Hospice UK

The chair welcomed everyone to meeting and went through the ground rules.

Actions from last meeting

- Philippa noted that Shaun Flook provided some figures around building for the Community Investment Plan and can pass them onto carers.
 - Issues around housing for adults with learning disabilities will be discussed at the next Family Members Ref group on 3 July at 10.30am, Charlie Ratchford.
 - Allegra gave a brief update about the new carers centre. Charlies will be demolished around Oct 2019 once the new centre is built. It will have extra care shelter, staff and Camden Carers' Centre. Issue around the builders using the dining room for their materials during the building work. This is not appropriate as it is community space.
 - Carers' Card – organisations willing to give discounts are joining the scheme. It will be run by Careline. If you carry the card it will be clear you have caring responsibilities and a plan would be actioned as appropriate, for the person you care for. Allegra urged carers to fill out a questionnaire about services.
 - Allegra noted a breakfast event – only 3 spaces left and carers to contact her to book
 - Jacky noted that she visited the Centre for Independent Living building which gives a much better feel for the space. For those interested, it is well worth visiting.
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- Kate – gave a brief introduction. On her husband's diagnosis of dementia, she arranged the Power of Attorney which made a huge difference. However it is something that remains half done for her!
 - **Isky Gordon from My Living Will** - he was a doctor and now works as a consultant in the Camden Memory Clinic and Advanced Care Plan Hospice. It is a charity that encourages people to talk about end of life. It especially applies to people with dementia and frailty.
 - It deals with statement of wishes and preferences. This helps carers and health care professionals know what is important to you.
 - You may have an advance decision to refuse treatment and this needs to be clear
 - The Living Will is legal if the signature is witnessed. Isky advises you give it to your GP to keep with your notes and to your family.
 - Question - a carer with a disabled daughter who can never make her own decisions, can you do the wishes on her behalf? No, but the carer can work in "the best interest" as a guide but this is not a legal document

- Question – Someone does want to be resuscitated and given treatment yet doctors say it's a medical decision. This would be an issue for the Court of Protection as the patient cannot demand treatment.
- My Living Will is currently £10 to make but will be free after end of July.
- Isky was thanked for the informative discussion.

- **Samantha Tayler from Osbornes - Wills & Trusts**

- If you have no Will, everything will go to your spouse. If you have children, £250K goes to your spouse and half the remainder to your children. If there is no Will, all money goes to the government
- A Will means you can choose where your money goes and where you don't want it to go. You can choose an executor you trust (age 18+). Advise to appoint two. They can be beneficiaries too. You may set up Trusts if best for family members
- A Will relieves family members of stress
- Tax planning measures – advice on how to deal with assets / tax saving / zero rate tax. £250K is zero rated and over that is 40% tax
- If you leave all to spouse, there is zero rate tax
- Can leave a legacy such as specific gifts / cash gifts or to a charity
- Discretionary Trust – up to you who and what is given and can set conditions. There can be adverse tax consequences
- Vulnerable beneficiary Trusts – for someone receiving DLA – its flexible with no adverse tax consequences
- Life Interest Trust for married couple. Money goes to spouse and eventually to children but protects money eg if remaining spouse remarries, and money won't pass to new spouse
- Most common area of difficulty is where a Will has not been correctly drafted. If you don't bequeath residual estate, it comes under testate rules. Get professional advice.
- Question – carer would like to change the executor of her Will. Can it be amended? As tax laws change, Samantha advises reviewing the Will and amending the executor clause
- Question – can a solicitor challenge a Will? It can be challenged if the testator says you didn't have capacity or under Inheritance Tax
- Question – what is the advantage of a Trust over a Will? You can do a Trust as part of a Will eg for Discretionary or vulnerable beneficiary Trust
- Question – how do you help the executor? The estate should pay all expenses around probate / tax issues. One person reported they were asked to pay HMRC in advance. You should not pay any expenses ahead of the settlement. All should be paid by estate.
- Question – Trust for child to protect money. Can give a life time gift – if you survive 7 years or it goes back to your estate. You can specify age when a child gets money
- Question – a carer noted he was joint executor with his brother who was not cooperative. The carer made a codicil to become the sole executor
- **Suzanna Baker from Osbornes – Lasting Power of Attorney (LPA)**
- There are two types – 1. Property & Finances 2. Health & Welfare - The LPA governs decisions around what happens when you're alive
- Its a legal document to allow someone you trust to make decisions when you are unable. You need requisite mental capacity otherwise you go through the Court of Protection

- You can have up to 4 people acting for you and give instructions to deal with your affairs.
- Certificate provider includes agreement that you have mental capacity to complete it
- The finance one can be used if you're physically unable but the health and welfare starts when you no longer have mental capacity.
- Question – how do you choose a solicitor? Shop around to get what you want.
- There is a company that undertakes a search for a Will if you are unable to find it
- Question – How can you decide someone with mental health issues no longer has capacity? The certificate provider must sign it off. A medical professional may decide but it depends on circumstances. He would have to give permission or if no capacity it is a court of protection application

ACTION – area for a separate section looking at mental health capacity

- LPA – once signed, its registered at the Office of Public Guardian and activated as needed
- Court of Protection is for when there is no capacity
- A carer noted they had downloaded the LPA forms online and found the forms clear and the Helpline very helpful
- Samantha and Suzanna were thanked and kindly agreed to stay and talk to carers

- **Toby Scott from Hospice UK** (hospiceuk.org and dyingmatters.org)
- Toby works on the Dying Matters Campaign around dying, death and bereavement. They counsel 6 key things while you are still alive:
 - Make a Will
 - Plan your funeral
 - Decide about organ donation
 - Decide about your future care
 - Write preferences down and share with family and friends / medical professionals
 - Digital data eg passwords / online accounts
- Hospice care offers end of life care though many people want to die at home.
- They offer bereavement support
- Funerals – shop around to find what you want. You don't even have to have a funeral
- Kate recommends Which Guide to Dying. A carer recommended the Natural Death Centre
- Make plans for a good death and it helps your family with the grieving process
- Issues around death certificate especially where religion determines the funeral is the following day. This will depend on the circumstance of death and whether it is issued by hospital or goes to a coroner
- Toby was thanked for his helpful contribution to the meeting

Any Other Business

- Shanta left copies of plans for the new Carers Centre
- Centre for Independent Living – service users meeting planned in July to discuss plans
- Cllr Lorraine Revah, Carers' Champion will find out which officers are involved in the new CCC building project and who gives permission to contractors to take over dining area. Lorraine will liaise with Allegra.
- Next meeting 20 September at **Charlie Ratchford, Camden Carers' Service**