



Carers And Parents of adults with learning disabilities in Enfield

Community House
311 Fore Street
Edmonton
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Chair: Surojit Walawalkar
Vice-Chair / Secretary: Wendy Berry
Treasurer: John Berry
Administrator: Luan Malley

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Minutes

Meeting: Monday 14th October 2019
Present: Vice Chair – Wendy Berry (WB) Minute Taker: Luan Malley from EDA
Apologies: Surojit Walawalkar, Jane Richards, Bernadette Reigar
Members attended: 10

AGENDA	
1	Welcome & Apologies
	WB welcomed the members, gave apologies. Our guest speaker Fazilla Amide (FA) from Healthwatch / Our voice newsletter was introduced. WB held a raffle to win a Disability Rights Handbook for 19-20 LM won and donated it to Victoria.
2	Guest Speaker Fazilla Amide from Healthwatch / Our Voice newsletter
	Fazilla introduced herself from Healthwatch and Our Voice. Healthwatch <ul style="list-style-type: none"> • The talk today is about Cancer, which is a horrid word. • Healthwatch are working in partnership with LBE Public Health Team. • They want to get information out to everyone, especially to carers, parents of adults with learning disabilities and people who don't find it easy to access information. It's about thinking of yourselves and your loved ones, to gain information and make decisions etc. • Lots of facts and figures were given around cancer for example used to be 1 in 3 people diagnosed now its increased to 1 in 2. • A questionnaire was handed out for members to complete around what they already know. <ul style="list-style-type: none"> ○ FA asked for the group to think of words associated with cancer. ○ Many were given including death, fear, anxiety. • FA went on to explain the following: <ul style="list-style-type: none"> ○ The ways to cut risks (Cancer Research info booklets given out). <ul style="list-style-type: none"> ▪ Think about diet, sunbathing, smoking, and exercising. ▪ Having the correct information to make the right informed chances. ▪ WB explained the challenges around adults with LD / challenging behavior making the wrong choices which is their right to make the choice as they do not understand. ▪ FA explained the way she explains to her son to understand in his own way to make the right decision. ▪ A better chance if we look after yourselves. ○ The different types of cancers (lung, bowel, breast, prostate). There are approximately 242 different cells in our body that could become cancerous. ○ Awareness- what to look out for and how to approach. <ul style="list-style-type: none"> ▪ Encourage health checks / blood tests ○ What screenings programs available for certain cancers and age related. <ul style="list-style-type: none"> ▪ Swabs





	<ul style="list-style-type: none"> <ul style="list-style-type: none"> <ul style="list-style-type: none"> ▪ Mammograms ○ Early Diagnosis <ul style="list-style-type: none"> ▪ The sooner the better ▪ Knowing your own body ▪ Going to GP (there are challenges going to GP/ hospitals) ▪ Plan and follow up ○ Treatment <ul style="list-style-type: none"> ▪ Planning and speak to the disability nurses ▪ Sleeping facilities (FA requested WB to email re information) • What % of people survive bowel cancer with an early diagnosis or late? <ul style="list-style-type: none"> ○ Early 90% ○ Late 10% • It was discussed around care homes with nutrition/meals. Healthwatch are happy to go and do a talk. • Information leaflets were given out and FA going to email the presentation for LM to email to members. • A second questionnaire was handed out to complete to see if there was a difference after the talk. The answers had changed to a degree. (Prevention, positive, control, hope and don't give up. • Both questionnaire given in. <p>Our Voice</p> <ul style="list-style-type: none"> • FA gave out copies of the newsletter and gave a small talk about Our Voice what they do etc. • Membership is 0 to 25. • Meet together for a more strategic meeting. • We have parent carer forums which are recognized across boroughs bubble up to regional London. FA is a London Regional Rep for the National Network of parent/ carer forums then strategical bubble up to a national and FA is on the steering group. Every care and parent forum is having the same conversation that CAPE is having. Comes down to what's in it for me (at that point). They will come and go only a few will stay and make a difference. FA praised CAPE • This newsletter comes out every 6 months. FA can email soft copy to EDA to then mail out to CAPE members. • CAPE would like to be included in the Our Voice newsletter. • WB would submit articles. • WB suggested a CAPE corner.
3	<p>Reports from meetings</p>
	<p>Incontinence pads</p> <ul style="list-style-type: none"> • Still have issues people are being told that's what we give and only give. This is not true, the few of us that understand the various NHS national framework. We quote them a bit and really push it and make a case do get different pads and quantities. Unless you make your case properly you are told you can only have Ontec. FA asked WB to put a script together and make people aware. Yes but we do not want to be demonized, we want people to come along and listen. • FA can put an article n the newsletter no names. Information is shared it's helpful.



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	<ul style="list-style-type: none"> • This can be a false economy. WB explained about DRE as well. • You are entitled to request other brands. <p>Clinical Commission Group</p> <ul style="list-style-type: none"> • FA explained Healthwatch have been working with a number of organisations including CAPE and EDA. The NHS have finally has a section on their strategy for the next 5-10 years. One of the focuses is people with LD, Autism and ADHD. HW wanted to get a sense from families what their experience have been, what it's like being an adult with LD and how they get supported around health. 165 surveys were completed the results showed problems with continuing healthcare. HW saw it through and with EDA got a group together (around 13-14) the feedback was fairly horrendous. HW is going to reinvestigate this area and try and get more numbers. We are working with local authority, healthcare providers, care homes and CCG. Neil had a meeting with the CCG and NHS England who got to hear which was helpful. The local authority and CCG need to work together better. CCG had had the feedback so are having to be more open, share care plans with LA counterparts, have to share paperwork and decision making in the LA. HW is now meeting the CCG to stay ahead of all the analysis coming out because it's not going to be good. If the CCG let us work with them together, it will be a better out come and it will show they are being supportive and open to feedback. They have previously been defensive but are now being open. • There are meetings planned with NHS England (been rescheduled). Going to try and get more info from them and work with us. They want to look at the survey. They will hopefully send it to all recipients. Its work in progress. It will probably get worse before it gets better. Hold them to account. • FA asked CAPE to continue to feedback. • WB thanked FA for coming.
4	AOB
	<ul style="list-style-type: none"> • The problems CAPE are having with getting new members. We need support. We have knowledge which is powerful and spread the knowledge. Having lived it and learned along the way. • Where are all the carers with adults from 21 and above • FA said it about word of mouth. Our Voice members will come to CAPE gradually
5	Date of next meeting
	Next meeting is our party Monday 9 th December 7pm to 9 pm