



Carers And Parents of adults with learning disabilities in Enfield

Community House
311 Fore Street
Edmonton
N9 0PZ

Chair: Surojit Walawalkar
Vice-Chair / Secretary: Wendy Berry
Treasurer: John Berry
Administrator: Luan Malley

Tel: 020 8373 6228
Email: CAPE@e-d-a.org.uk

Minutes

Meeting: Monday 11th October 2021 10am to 12.00pm

Present: Committee members: Wendy Berry (WB) Surojit Walawalkar (SW), Jane Richards (JR), John Berry (JB)

Enfield Carers Centre Learning Disabilities Carers Ambassador: Nuray Kumbarji (NK)

CAPE members: approx. 20 carers

Minute Taker: Luan Malley from EDA

Apologies: Committee member: Bernadette Reigar (BM)

AGENDA	
1	Welcome & Apologies
	<ul style="list-style-type: none"> SW welcomed the members Apologies from BR and other members
2	<ul style="list-style-type: none"> Update
SW & WB	<ul style="list-style-type: none"> Through these unpredicted times and hoping things are now getting better; CAPE committee members have been still attending meetings. These have been via zoom and Teams. LBE have also maintained contact with the committee and continue to include CAPE. Members were reminded of the CAPE website - www.CAPE-LD.org - which includes updates and information. WB has been sending regular newsletters out during the pandemic months, but these will cease now that 'in-person' meetings with minutes, have been resumed. New leaflets have also been produced to circulate. CAPE is looking to promote the organisation to gain a higher profile. We are looking at March 2022 to re-launch. We shall send out invitations to senior officers, including Bindi Nagra, Director of Enfield Adult Social Services. The history of CAPE was explained, how and why it was formed, including the growth of the committee, and its members. The organisation is run by volunteer family carers. CAPE is looking to increase the number of committee members. The current committee members were introduced and their roles explained. The committee consists of: <ul style="list-style-type: none"> SW President WB Vice-President and Secretary JR Transition (replacing her Carer to Carer role) and Liaison BR Research and Development JB Treasurer and Finance Committee members attend meetings regularly, with the Local Authority (LA), Health, Social Services, and other local organisations. They also represent carers on the Learning Disabilities (LD) Partnership committee and its sub groups. They work hard behind the scenes, being the voice of many parents and Carers.



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	<ul style="list-style-type: none"> NK was asked to introduce herself, as the Enfield Carers Centre LD Carers Ambassador, and briefly described her role. She reports into the Carers Partnership Committee. We keep members updated via email and meetings. We continue to encourage members to feedback so we can highlight issues to the appropriate team. We have support from other organisations and have the latest Luke Clements book “Community Care and the Law’ and The Disability Rights Handbook, which are available for members to reference. CAPE is affiliated to Disability Rights UK, and to CASCAIDr. This is the 2nd ‘in-person’ CAPE meeting since lock down. We hope to continue with regular meetings every two months (normally the first Monday of the month). The group was informed that the newsletters would now be replaced by the minutes from our meetings. Sarah Pope was welcomed by SW
3	<p>Guest Speaker Sarah Pope Head of Integrated LD nursing Team</p>
Question	<ul style="list-style-type: none"> Sarah introduced herself and explained she is new into the role, and commenced this in June this year. She informed the group of her previous employment with Barnet and Chase Farm Acute Services and safe guarding at North Middlesex. Her focus is on both Physical and Mental health. Looking at the individual when they are unwell and when they are at their best. She and her team are working with individuals, GP’s, Primary Health Care Trusts, to ensure needs are being met, looking at the issues, and highlighting and trying to fill the gaps. A small project is currently being worked on, with the hospital sensory integrated department. This is to help, train, develop the staff to make adjustments prior to a client’s appointment and to make the process less stressful for client and parent/carer. Gaps are being identified at local level <ul style="list-style-type: none"> There is a lack of time, understanding and equality for clients with LD. These need to be fed back to SP then they can be escalated to the appropriate body. Sarah’s Email address is Sarah.pope@enfield.gov.uk or sarah.pope5@nhs.net There is no longer an Enfield CCG. It’s now comes under North Central London Clinical Commissioning Group (NCL CCG) was formally established in April 2020, bringing together five north London boroughs – Barnet, Camden, Enfield, Haringey and Islington. Incontinence pads. When having an assessment service users are informed you get what you are given - take it or leave it. Everyone has different requirements. Some parents explained the battle they have to get the appropriate pads. You are then passed from one department to another then back to the GP? Assessments need to be carried out; these should be proactive covering variations and costs. You can self-refer beh-tr.ecscontinenceservices@nhs.net If you purchase pads etc. from personal funds these should be offset as DRE, against any financial contribution you may make, towards the cost of your care services. A questionnaire needs to be circulated to get feedback. This will highlight any inequality and enable us to look at the pathways and procedures.





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Action	<ul style="list-style-type: none">• SP will work to produce a questionnaire and circulate to all LD carers. It may be possible for Enfield Carers Centre (ECC) to circulate this more widely, in order to assess the full extent of this issue.
SP NK	
Question	<ul style="list-style-type: none">• Why is an incontinence assessment not carried out every year, is that something that can be done?• The incontinence team only consists of two assessors.• Clients need to be assessed on an individual basis, plus changes of need do happen.• This should be monitored and it could be added to the health check.• Hospital Passports<ul style="list-style-type: none">○ The importance of having one, and more so, keeping it up to date was stressed. The disabled person, or their carer, should have access to these at all times.○ You can complete them via a form on MyLife Enfield Website<ul style="list-style-type: none">▪ https://mylife.enfield.gov.uk/media/24734/hospital-passport.pdf• The systems of the patient's health information at GP'S, hospitals and health were explained. Some systems are not connected so will not have your history or updated info. Some share information, and others operate on an opt in, opt out policy.• Blood tests<ul style="list-style-type: none">○ Discussed clients' aversion to needles/ attending GP's or hospitals.○ Home visits available through GP / liaise with nurse.○ GP have access to LD training programs, this is optional.• Flagging system<ul style="list-style-type: none">○ The system was explained and again is only as good as the information input and being up to date.○ An alert is placed on system to inform professional that a patient has LD.○ If records are incorrect you need to get your doctor to update them.• Health checks should be offered every year from GP.<ul style="list-style-type: none">○ What is covered in a health check e.g. diet, dentist and exercise.○ A copy of the health action plan which is printed by doctor.○ The difficulties parents and Carers are having, getting the person to attend medical appointments.○ The delivery needs to be looked at and identify people's needs to eliminate / lessen anxiety and stress.• Case law was discussed briefly around Covid and flu injections /signing documents under the Mental Capacity Act.• SP encouraged members to email her directly – sarah.pope@enfield.gov.uk – if they have a specific health issue which they would like to raise. She has a team of LD nurses, who will support families.• SP explained that some of her nurses have specific specialist areas of responsibility such



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	<p>as Epilepsy, GP Health Checks, Transition, Positive Behavior Support (PBS), Mental Health, etc.</p> <ul style="list-style-type: none"> • SP updated the group on how LD patients were treated if hospitalized during Covid. • SP mentioned a new initiative from the NHS called 'Coordinate My Care'. There is a section about this in the latest ECC newsletter. Please see the Patient Information - visit : https://www.coordinatemycare.co.uk/ • SW thanked SP for coming and look forward to another visit with an update on up and coming projects.
4	<ul style="list-style-type: none"> • AOB
WB	<ul style="list-style-type: none"> • Charging (assessment for contributions on care charges). LBE booklet on their website: <ul style="list-style-type: none"> ○ https://mylife.enfield.gov.uk/media/25121/living-at-home-charging-booklet.pdf • You should receive a letter every April to inform you of either a nil contribution or the weekly charge due. • A breakdown should also be received (this is a legal requirement). You can reduce your charge by claiming all of your DRE. <ul style="list-style-type: none"> ○ https://mylife.enfield.gov.uk/enfield-home-page/content/financial/community-based-charges/ click on disability related expenditure • LBE are currently acting unlawfully as they are not providing breakdowns for everyone, due to IT issues. If you call Finance (020 8379 8177), they will send you a breakdown of how your charge has been calculated. • CAPE reps continue to participate in the Money Matters Group (MMG), facilitated by EDA's Enfield Advocacy Service, and led by Karen Grimes. • There has been a success with the Under 25's on UC, who will now be allocated a Minimum Income Guarantee (MIG), which is the same as those aged over 25. This should result in a saving of around £20 per week, for those aged under 25. We await the updated policy documents, and letters, which will be sent to those affected by this change.
SW	<ul style="list-style-type: none"> • Many of those in supported living should have seen their charges reduced, from April 2021 and refunded from 20-21, by approximately £29 per week. • Members briefly discussed the L.A's Deputyship and Financial Assessment teams, and the manner in which they operate. There would appear to be a potential conflict of interest, as these teams have the same person in charge of them. A Freedom of Information request had supported these concerns. This is being raised with the MMG. • If you are a carer who looks after your family member at home, you should receive a free service (if you do not, please look at your DRE). • Enfield Carers Centre, Enfield Connections and EDA can help with DRE, contributions / charges.
SW	<ul style="list-style-type: none"> • SW informed members of a new group which has been set up by Enfield L.A. to discuss 'What Happens when I can No Longer Care'. This is something that concerns us all, and some important work is being taken on by Enfield to address these concerns. SW and



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	<p>WB, as well as reps from ECC, EDA, Brokerage, Deputyship, Commissioning, ILDS Care Management and a major service provider, are involved in these meetings. We shall update members more fully at a future meeting, but this is progressing well.</p> <ul style="list-style-type: none">• SW Informed the group that a lot of work is being done on this subject nationally at The Foundation for People with Learning Disabilities and a publication called “Thinking Ahead - planning guide for families” has been published. You can download this guide from the website www.learningdisabilities.org.uk/thinking ahead. This covers many important subjects including Finance e.g. Trusts, Wills, and legal information, Housing and support, plan for emergencies etc. There is a useful video on this via the website called “Family Carer Support/What happens when I’m no longer...-Hut” and members were urged to familiarize themselves more with this subject which is so vital for all of us.
5	Date of next meeting Monday 6th December 2021
	<p>The group voted that they would like a talk around Lasting Power of Attorney, Trusts, Wills, funeral costs, assets etc. We shall try to organise this, and members will be notified nearer the time of the meeting.</p>