

CNWL Carers' Council

Friday 19th July 2019, 11:30 – 13:30

Bevan 2 Meeting Room, 350 Euston Road, London, NW1 3AX

Attendees	Title/Area Represented
Abigail AGYEMANG	Carer Governor, Harrow
Robyn DORAN	Chief Operating Officer, Executive Lead for Carers, CNWL
Anita DOSHI	Service Manager, Carers Network
Kathleen FRASER	Carer Rep, Brent
J'nelle JAMES	Equality Diversity and Inclusion Manager, CNWL
Veronica KAMERLING	Carer, Eating Disorders
Grace LEVY	Project Officer, Patient and Carer Involvement, CNWL
Lucy PALMER	Head of Patient and Carer Involvement, CNWL
Ela PATHAK-SEN	Interim Borough Director, Westminster Mental Health Services, CNWL
Anne POWER	Staff Networks Coordinator, CNWL
Valerie REID	Brent Partnership Board, Carer, Brent
Janet SEALE	Carer, Westminster
Chandu SHAH	Carer Governor, Harrow
Ann SMITH	Carer, Hillingdon (Chair)
Didier TICKELL	Patient and Carer Involvement Consultant, CNWL (Minutes)
Apologies/Absent	
Stephen ARCHIBALD	Chief Executive, Carers Bucks & Carers Milton Keynes
Kurtis DESAI	Clinical Effectiveness Business Administrator, CNWL
U Hla HTAY	Carer, Kensington & Chelsea
JH	Peer Trainer, Carer
Lorraine LUKE	Carer, Kensington & Chelsea

1. Welcome, introductions and apologies

Ann Smith welcomed all and apologies were noted.

2. Accuracy of previous minutes and matters arising (incl. Carers Week Feedback)

The previous meeting's minutes were read and corrections made.

Lucy Palmer said she would extend the invite to attend the council to others in Milton Keynes. Sue Bowering's name was suggested.

Lucy and Ann briefly explained the new informal procedure for inviting people to join the Carers Council and announced the arrival of two new members, Abigail Agyemang and Lorraine Luke.

Members reflected on the events of Carers Week and Anne Power and Grace Levy thanked everyone for their contributions. The various events the CNWL held were considered successful by all. Members appreciated the Triangle of Care Workshop and the Carers Tea Party. Anne Power said the Employers for Carers presentation had also been a success and highlighted a number of useful points including:

- HR policies are relevant both within the CNWL as well as elsewhere
- How many staff are carers of CNWL patients?
- How many staff carers are there within CNWL?
- The Recovery and Wellbeing College audit was highlighted as a source for statistics on CNWL staff carers

Members reflected on other activities which happened locally. Valerie Reid fed back details on events in Brent, including a visit to Stratford-Upon-Avon and a young carers' trip to the theatre to see Wicked. Anita Doshi talked of events in the Tri-Borough area including a trip to the Tower of London, a trip to Chiswick Park and Kew Gardens, and a carer's festival with a focus on creativity and the arts. Chandu Shah spoke of an afternoon of talks in Harrow on key topics for carers.

Ela Pathak-Sen highlighted a poetry writing competition being run by The Advocacy Project called Healing Words (<https://www.advocacyproject.org.uk/poetry/>) which closes on the 8th September 2019. Details have already been shared by email, but if you need these resent, let Grace Levy know. Veronica Kamerling spoke about the positive impact of the mental health and wellbeing publishing company [Chipmunka](#), who published her brother's poetry, and Ann Smith talked about positive uses of creative writing, poems and painting in West London for people with literacy issues.

Members discussed how the experience of being a carer was different across different health conditions. The stigma sometimes associated with mental health was also discussed.

3. Triangle of Care

Members were given a refresher explanation of the national Triangle of Care model of standards of support for carers. Lucy Palmer updated that the team met with colleagues in Harrow and Hillingdon to discuss those boroughs being potential pilot sites for the roll out of the scheme. Harrow have been looking at how their services meet the standards locally. The issue of Carer Awareness Training being disseminated across the Trust was raised, with members noting the potential problems due to the huge geographical area the Trust covers. Members noted the importance of all staff receiving training, from admin staff, to nursing staff and up to psychiatrists. Lucy Palmer suggested that members could co-produce templates of policies and procedures to adapt to local use.

Veronica Kamerling spoke further about the Triangle of Care's strengths, noting the central role 'collaboration' plays when supporting carers and the strength of making evidence a central requirement.

Veronica mentioned the importance of carer champions being implemented in staff teams and how these will benefit the Trust. Robyn Doran noted there are up to 28 staff 'champion roles' currently in the CNWL and it sometimes can lead to a staff member becoming a champion in multiple areas, which may not be helpful. Ann Smith suggested it would be a good target to place carer champions on all mental health wards, including secure units, noting difficulties that may arise around staff shifts and rotas.

Lucy Palmer highlighted that it is a big project which the CNWL needs to get right, but that there is a lot of enthusiasm. Ela Pathak-Sen reported on the situation in Westminster where they have fortnightly Carers Surgeries to enable carers to meet the borough directors if they have any issues. These surgeries also take place monthly in Harrow. Ela noted staff Carer Awareness Training is better when bite-sized and digestible and also that she had encountered local language and cultural barriers to overcome. Robyn Doran raised further questions about how carer champions might be initiated in the new Ealing partnership services CNWL run with West London NHS Trust.

Veronica talked about the importance of sharing ideas, mentioning Surrey and Borders Partnership NHS Foundation Trust and Oxleas NHS Foundation Trust as 'gold star' Triangle of Care members. Veronica advised that the demands of Triangle of Care amount to a challenging programme for any NHS Trust and it was important not to become disillusioned.

Kathleen Fraser highlighted the issue of fragmentation, mentioning difficulties the Carers Partnership Board experienced recruiting new appointees. Ann Smith drew attention to the logistical complexities created by the enormous size of the CNWL compared to most other NHS Trusts. Ela Pathak-Sen noted that the patchwork nature of carer engagement across boroughs highlights how NHS trusts can share information.

Lucy Palmer asserted that Carer Awareness Training should form part of CNWL staff induction training, suggesting starting with an information stall. Members talked about the exciting future of carer and patient involvement. Ela Pathak-Sen described it as a 'wonder intervention of the 21st century' where lower mortality and morbidity rates correlate with increased patient and carer involvement awareness. The example of support for Grenfell was given, where carer partnerships were called 'families' and not defined by illness.

Actions:

- **Lucy Palmer and Grace Levy to attend CNWL meetings (directors, borough meetings etc) to promote involvement**

4. Carers Rights Day

Members discussed Carers Rights Day which will occur on Thursday 21st November 2019.

It was agreed that the event is better facilitated at a local level rather than centrally at HQ because it provides an opportunity to grow local networks and disseminate information to local carers. Members suggested a number of ideas:

- Create an information sheet listing local events which will occur
- Organise an information event on employment and carers – staff carers network
- Create a stall to take to select service venues to reach out to hidden or hard to reach carers

Members spoke about different experiences of contact with the police a carer may encounter and highlighted some of the complex and challenging issues which can arise as well as the stress and anxiety. Ela Pathak-Sen noted difficulties staff also encounter and members shared concerns about offering support to individuals only when they reach the point of serious crisis. It was suggested that the subject could be covered by a future visit by a police representative and also as a subject at the next carers conference.

5. Carers Conference 2020

Lucy Palmer indicated that the Carers' Conference is now bi-annual and the next one will occur in 2020. Lucy asked members to think about topics to bring to the conference.

Members discussed some ideas and indicated:

- Importance of inviting people early
- Need to check for date clashes with other events
- Potential of holding the conference in a less central location
- Secure a new, more cost effective venue – those mentioned:
 - Carers Centre
 - Wembley Stadium venue
 - Stowe Centre, Royal Oak
- Create more relevant and current workshops – those mentioned:
 - How local authorities help carers and why they differ from each other
 - Diversity
 - Hidden disabilities
 - Police. Law and justice system interaction
 - Key governmental law
 - NHS long term plan
 - What to expect if you approach a community mental health team
 - Different kinds of sections
 - Different kind of treatments
 - Recovery Collage carer courses
 - Information leaflets for carers
 - Safeguarding for citizens

J'nelle James said that existing staff mental health law training could be adapted as a carer resource or conference talk. A Carer Awareness Training in West London which covers medication, treatments, carer skills and wellbeing available was highlighted.

Actions:

- **Grace Levy to research details on suggested venues and note suggestions for topics.**

6. Information and education for carers

It was discussed that the information and education provided to carers and family members by CNWL staff could be improved and this will be discussed further in a future meeting.

7. AOB

Veronica Kamerling notified members of her upcoming Co-dependency Workshop occurring on 13th September.

Abigail Agyemang talked about a project she is looking to implement with supporting young adult carers in Harrow.

J'nelle James highlighted the Carers UK / Employers for Carers 'Carer Confident' Benchmark Scheme, a 3-stage set of criteria for organisations to aspire to meet in supporting carers. Valerie Reid and Kathleen Fraser offered their help in reviewing the Trust's evidence for this scheme.

Valarie Reid informed members the Brent CCG has recently funded a young carers' app service for 11-25 year olds, and also mentioned a web resource, Kooth.com, which supports young people and their mental health. Valarie also mentioned the new support service hubs across the borough.

Chandu Shah highlighted the CNWL AGM which will occur at the Wellcome Institute on 17th September. Grace Levy will share details of this in due course.

Didier Tickell updated members on the current data survey of carers support resources across all CNWL boroughs. Didier noted support was relatively strong except in the area of young carers in Westminster.

Kathleen Fraser spoke of a project on loneliness and mental health that she is involved with at UCL. Ann Smith noted that the Carers Trust survey highlighted isolation as the top issue facing carers and mentioned the Age UK study on loneliness in old age.

Actions:

- **Grace Levy to email CNWL AGM Eventbrite link to members**

Date and venue of next meeting:

Friday 20th September, Bevan 2, Trust HQ - 350 Euston Road, London NW1 3AX.