

Cross Party Group on Dementia

Minutes: December 2019



Tuesday 3 December 2019, 12:00pm-1.30pm

Seminar Rooms 1 & 2, Y Pierhead

Chair: George Parish-Wallace (In absence of Lynne Neagle AM)

Present:

Professor Dawn Brooker (University of Worcester), Huw Owen, Sue Phelps, George Parish-Wallace (Alzheimer's Society Cymru), Dr Eleri Cabbage (Welsh Assembly), Rebecca Cicero (Social Care Wales), Helen Cunliffe (NHS), Gwyneth Sweatman (Marie Curie), Karyn Davies (University of South Wales), Dr Rosslyn Offord (British Psychological Society), Dr Natalie Elliot (Cardiff & Vale University Health Board, RCSLT), Amy Kordiak (Life Story Network – Dialed-in), Nigel Hullah (3 Nations Dementia Learning Group), Ceri Higgins, Linda Willis, Chris Roberts, Beti George

George Parish-Wallace (GPW) welcomed everyone to the meeting and asked everybody present to introduce themselves, stating their name and organisation.

AGM

- **Lynne Neagle AM** re-elected as Chair
- **George Parish-Wallace** elected as secretariat (on behalf of Alzheimer's Society Cymru)

Presentation by Professor Dawn Brooker (University of Worcester)

Professor Dawn Brooker (DB) then presented to the CPG.

DB explained that she was a Professor of Dementia Studies at the University of Worcester. DB then explained that she works in a Department that carries out research for Dementia Studies, providing evidence-based, practical care to improve the lives of people living with dementia. The Department combines a multi-disciplinary approach to research.

The work that DB carries out within the Department is inclusive of people living with and affected by dementia. In addition, the work of the centre is integrated with the DEEP Network and TIDE.

As well as research, the Department has 30 projects ongoing from literature reviews to small-scale research groups. There is also a big emphasis on knowledge transfer and knowledge exchange. There are currently a total of 8 PHD students within the Department.

DB then introduced the concept of Meeting Centres, which provide local, community-driven ongoing local, person-centred care for people living with dementia. The Meeting Centres are run by a small group of permanent staff who are very locally driven with a community planning phase.

Meeting Centres originated in the Netherlands as a concept that provides low-key social support for people living with and affected by dementia. DB then introduced the work of the Department in the development of Meeting Centres around the UK.

Between 2014-2017, the Department partnered with JPND funded research to take learning from the Netherlands to implement in the UK, Italy and Poland. It was later discovered through subsequent studies that the Meeting Centre model is transferable and can be implemented in third countries, such as the UK and throughout other countries across Europe.

The research entailed evaluating the impact of the Meeting Centre, and how they improve the quality of life and sense of belonging within communities for people living with and affected by dementia.

In 2017, a total of two research centres were established in the UK. In 2018, further funding was made available for research for a further 3 years. Such research helps to pioneer workshops and secure new Meeting Centres in communities across the UK. As a result, guidebooks on how to setup such centres are being published, with these due to be translated into Welsh in due course.

Throughout the next 3 years, there will be 15-20 Early Adopters across the UK which will benefit the lives of those living with and affected by dementia.

A National Reference Group has also been established and the Group is currently looking for a representative from Wales to push for further regional development. In addition, National Conferences are also being organised as well.

DB then introduced Meeting Centre Support Programmes (MCSP) which is working towards a definition of a Meeting Centre which are established to serve the needs of the local community.

As such, there are 11 separate criteria for a Meeting Centre. In particular, the 'Adjusting to Change' element is particularly important. The criteria also includes knowing what dementia is, knowing when and where to get help and learning to integrate social adjustments to tackle isolation and loneliness within communities.

There is a clear focus on engaging MCSP clubs which run 3 days a week between 10:00-16:30. Such clubs are there primarily for people living with dementia and family carers. There is an emphasis on flexibility for how people use MCSP's.

It was also emphasised that MCSP's are not full respite services. In this sense, it was emphasised that it is also about how both parties cope with dementia together, as well as apart.

Another key criterion is that everybody involved in the dementia journey is 'in this together'. A further key ask is what the individual can bring to the MCSP. In this sense, it is very much centred around the strength of the community of people, as opposed to one top-down model that fits every community and locality uniformly.

In addition, it was emphasised that rural communities are included as well and that over 65's, as well as under 65's are included. In this sense, they are truly age-inclusive.

There are now new centres in Brecon and Llandrindod, amongst other places. Community Engagement Planning is also underway.

A video was then shown entitled 'Magic' which was a poem by a member of the Brecon Meeting Centre.

Discussion

Sue Phelps (SP) then initiated the discussion following DB's presentation. SP said that the Meeting Centres are a great facility. She also remarked that it was very refreshing to see a model, which, whilst achieving the same ethos, can be adopted to a local community. As such, sometimes Service Providers get fixated on a particular model which does not work in all areas.

DB said in response that it is the right way to go about care in the community. Tailored, personal care is possible, and flexibility in the model is key.

Ceri Higgins (CH) then said that she attended one of the Dementia Workshops provided in Brecon. She explained that it is good to make activities possible for local audiences. CH added that it is about trying to tackle narrow mindsets and inflexible approaches when delivering care within community settings.

DB said that a public meeting is held in order to setup a MCSP. At these meetings, it is established if a Meeting Centre is needed. If agreed to, 12 Volunteers are asked to be part of the Planning Committee to address the seven key questions for organising a MCSP.

Such questions cover issues such as funding, people and activities.

CH added that there are some places that MCSP's would work well in. However, the Social Services & Wellbeing Act is always needed to be complied with, which can be a barrier to progress.

Nigel Hullah (NH) said that if people living with dementia are put at the centre of activities, they will flourish as a result. It is very much about the state of mind of the organisation that contributes towards the success of the organisation. As such, stakeholders must be involved in the organisation of Meeting Centres and other initiatives.

DB then re-iterated that people living with dementia and their families are at the heart of MCSP's. This makes them very flexible organisations that can be implemented to suit the specific needs of a particular community.

Linda Willis (LW) then asked how many of the Committee members are living with dementia.

DB said that it varies, but on average their at least 2 Committee members who live with dementia.

LW said that this is not a high number, and that more people living with dementia need to be included as everyone has different needs.

DB agreed.

SP then asked how we can link MCSP's to Dementia Friendly Communities, adding that as we already have Dementia Friendly Groups & Communities. However, could these be used to further the cause of MCSP's.

DB added that MCSP's provide a ready-made group and that they are generally excellent resources for communities.

SP then asked who the Alzheimer's Society representative was on the Dementia Reference Group.

DB confirmed that currently, Colin Capper sits on the Group.

SP said that Alzheimer's Society will find a representative for Wales to sit on the group.

Inquiry into hospital care

Huw Owen (HO) then updated the CPG on the ongoing hospital inquiry and findings to date. At the previous CPG meeting in October, the CPG had carried out a total of 2 of the 10 Hospital Visits throughout October.

HO then stated that, to date there have been a total of 1,268 responses from the Hospital Roadshow visits. Overall, the response rate (including written responses) has been 1,830.

HO said that he will be writing the report in due course. In addition, he reported that there will be a total of 3 more Roadshow visits. The first will take place on Monday, 9 December in Haverfordwest. This will be followed by Nevill Hall on 6 January 2020 and The Princess of Wales in Bridgend on 8 January 2020.

One key observation to date is that more engagement with care homes is needed, especially with care home staff. As a result, a tweaked survey has been distributed to 250 care homes last week.

Rebecca Cicero (RB) offered to help with this aspect of the inquiry.

HO said that the CPG are aiming for 2,500 responses by the deadline for evidence. The launch event will be taking place in the spring of 2020, with a possible timeframe of early April once logistics are complete. In addition, there will be a media push imminently.

SP then discussed the broader context for the extra roadshow events to the three additional hospitals.

Gwyneth Sweatman (GS) asked when the official deadline is for responses to the survey and call for evidence.

HO confirmed that it is 31 December.

RC asked what the reasons were for care homes being included in the survey.

HO said that there have often been poor discharge practices and admissions from care homes to hospitals as a result of a breakdown in communication between different care settings.

NH said that he attended a conference on Friday, 29 November 2019 in which this was discussed. As such, he said that greater communication is needed between care homes and hospitals in terms of information of patients. As such, care home staff often call ambulances for hospital admission as a last resort, out of fear of poor care once in hospital for people living with dementia.

From personal experience, he said that he has had three very different experiences as a result of being admitted to hospital. He added that dementia services are well funded. However, funding should go into prevention services and not treatments.

As such, he emphasised that people living with dementia should be cared for in hospital.

Dr Rosslyn Offord (RO) said that there are examples of systemic issues within the care system. As such, hospital staff have a very risk adverse culture and this needs to be considered going forwards.

Dr Natalie Elliot (NE) said that there is a great deal of bad experiences evidenced throughout the inquiry's research process. However, it is also important to outline areas of good practice as well.

SP said that areas of good practice will be included in the report.

HO emphasised that, following the writing of the report, meetings will be sought with local Health Boards to demand that good practice areas are rolled out across the whole of Wales, as opposed to in specific localities.

NH said that people respond better to positive recommendations.

CH said that the important thing is to ensure that the report is well balanced.

NH said that there needs to be a direction for Welsh Government to provide the same level of care as seen with drugs and alcohol policy.

SP said that this is not just a medical or NHS issue, but encapsulates the failings in integration of care services. This was evidenced with people using hospitals as a means of respite.

NH emphasised that early intervention is needed in the social care system.

SP added that there will be no more than 15 recommendations in the final report made to Welsh Government, all of which will link closely with the Hospital Charter.

AOB

Dates of future meetings

Tuesday 3 March 2020

Tuesday 19 May 2020

All 12 noon – 1.30pm in Y Pierhead