



Bucks Older Peoples Action Group Meeting

September 21st, 2022

Minutes

at Christ the Servant King, Sycamore Road, High Wycombe

Attendees:

Alan Barnard – BOPAG Chairman Marlow bottom Valley Plus (AB)
Paula Watts – BOPAG Administrator (PW)
Stuart Smith (CSPA) BOPAG Treasurer) (SS)
Professor David Croisdale-Appleby – Dementia UK Trustee (DCA)
Jan Sambrook - DAM Dementia Action Marlow (JS)
Bernie Hunter – DAM
Jen Mason – DAM
Richard Livesey – DAM
Dominique Williams- DAM
Jane Osborn - Lane End OPAG
Simon Meredith – Anchor
June Kerr – Alzheimer’s Society
Jane Quince – Social Prescriber
Carol Heap – Bucks Councillor (CH)
Elizabeth Aylward – PROBUS
Sandie Kemp – Bucks Council ASC South (SK)
John Betts – STOPAG Stokenchurch
Frank Carrie – Local resident (FC)
Mrs Carrie – Local resident
Alison Holloway – Healthwatch Bucks (AH)
Joe Boake – Hughenden Gardens Village
Brian Bolton – Local resident (BB)
Patricia Bolton – Local resident

Apologies:

David Whittaker – BOPAG Vice Chairman
Linda Richards – BEFAB Burnham/Marlow Groups
Mike McDonald – Audley Retirement
Janet Kenny – OASIS
Sue Stuart – Memory Partners
Stephanie Moffat – Bucks Council Public Health
Michelle Bewley – Arc Bucks PCN
Phil Folly – COPAG Chesham Over 50’s Positive Action Group
Barbara Richardson – COPAG
Paul Isaac – Age Concern
Marian Mulady- Local resident
Chris Stanners- (Dignity Champion)
Emma Richardson – Hughenden Village
Hannah Munn – The 50+ Group
Natalie Judson – Bucks Council

Apologies continued.

Fay Ewing – Bucks Council

Nicole Palmer – Dementia UK

Makyla Devlin – Bucks Council

Annie Roy Barker – Local resident

Isobel Middleton – Age Concern

1. Alan Barnard welcomed everyone to the meeting and went through the Health and Safety procedures. Alan then introduced our first main Speaker **Jan Sambrook from Dementia Action Marlow**

Jenny, Jen, and Jan started Dementia Action Marlow about 2 and a half years ago. They have now got to know a lot about dementia and the available support for people with dementia. One of the first things they did was to publish their own information guides at the beginning of the Covid pandemic. They soon realised that there was a need for more information. They discovered that there is information online - but everyone's situation is unique and therefore the opportunity for people living with dementia and their support networks to be able to speak to someone in person is invaluable. Those they work with have all said how useful the Admiral nurse's helpline is because they offer qualified nurses who know and understand their situation. Crucially, they advise on clinical needs and measures rather than merely offering non-specialist support – important though that is. DAM would really like to see them commissioned in the Bucks area to provide face to face support to ease the condition.

2. Speakers – Jan outlined the vital services that DAM provide to their members and the support given to those who are carers of people with dementia. She informed us of the social sessions and various outings that they provide and the support their members give to each other. DAM's aims are to raise awareness nationally and locally of the issues that are faced by people living with dementia, and they are campaigning for Admiral Nurses to be available in the Bucks area.

Alan then introduced our next speaker **Professor David Croisdale-Appleby** who is the Chairman of Dementia UK, Chair of the Royal College of Physicians, and a Professor of Medicine.

David has extensive involvement in health and social care policy and has held and holds a number of appointments in government departments. He has chaired many organisations in the public and charity sectors including NHS Trusts, the Science council, and the sector skills council Skills for Care, and the National Skills Academy.

David gave an enlightening talk about the benefits of the Admiral Nurse Services that Dementia UK provide, for people with dementia and their carers.

Please see the attached notes.

3. Questions and Answers;

AB asked why the Admiral Nurses (AN) are not available in Bucks and what the issue is.

DCA- said that a possible explanation may be that Bucks is seen as a high-income area and that in some cases the residents use their own financial means for support. Buckinghamshire is the only county without any AN.

JS – Mentioned that the current waiting list for mental health services for a diagnosis is 5 months.

DCA – NHS system currently in place is that the diagnosis is down to the GP's who are like the gate-keepers and who then refer to a specialist if they decide the patient warrants it.

BB – asked who puts the pressure on to bring change to the way things are currently done.

DAC – Dealing directly with MPS in Westminster is an effective way, otherwise those who commission local services like the local authorities, NHS, mental health services, hospices, etc., might be approached. Anyone who will employ the services of an AN could be an immediate influencer. When writing letters to MPS he suggested you need to ask questions obliging them to answer, thereby starting a dialogue. He offered to help with wording to encourage response from the MPS.

SK – Mentioned that Steve Baker is very responsive to letters.

AB – suggested going to a Public Board Meeting which are held bi-monthly.

FC – Explained his experiences dealing with dementia and finding it almost impossible to speak to someone and get something done.

DAC- suggested phoning the Dementia UK helpline **0800 888 6678** where you are able to speak to an AN who will assess your situation and try to help.

SK – asked for details from FC and offered to try to help. She is currently working more closely with an access team for a slightly more joined up process. New laws are extending care assessments.

JS- A dementia Support Group is needed and currently dementia specialists are lacking.

DCA – Currently people are signposted where to get help and there are multiple routes which tend to rely on good relationships. In his view, support should not rely on relationship building and it should be universal as it is the patient that matters, and the system is underfunded.

JS – mentioned that continuing health care support is almost impossible to achieve, and the criteria are difficult to navigate.

DCA – mentioned that the Dementia Clinics are extremely helpful and constructive; they give you options and advice on how to go forward.

PW – asked that when the clinic takes place in Bucks DAC to advise so that PW can add to the Hoot magazine.

DCA will share his notes to those that would like them. Please ask PW for copies.

4. Notices – Alison Holloway Healthwatch Bucks – AH introduced herself and gave us an insight into the project they are currently running on Young Onset Dementia. They would like to hear from people who have been diagnosed before the age of 65 to find out what support has been offered, what is available and what is needed. She explained that there is a separate set of issues which are more prevalent for those diagnosed earlier and they want to be able to set up the support required to give a good quality of life to those living with dementia. AH explained, as an example, that currently there are books explaining why grandparents have dementia but there is nothing currently to explain to children why their parents may have it.

BB- Mentioned that the Alzheimer's Society Project Manager came to talk to them, but it was depressing as they were told that half of the staff have left, and the budget has been cut, so wanted to know how HW Bucks were going to fund this new project.

DCA – said that HW was a wonderful organisation, and they are committed to what they do. He finds them to be a constructive and key component of the CQC family. They listen and absorb information and are extremely useful and insightful. It is a vital service with limited resource, and they offer an informed voice of the public. He referred to them as a "mirror", reflecting the views and sentiments of service-users.

AH – said that HW Bucks brings about changes, but minor ones and they aim to raise awareness. HW England do have a stronger voice and we need to let them know about the changes that are required.

JS – said that she finds that people who live with dementia, and their carers, don't complain, they just get on with it as they find it too hard to get through to the NHS support systems.

AB thanked the speakers for their insights.

5. Matters arising from last meeting – PW informed the group that BOPAG have now secured funding to help with the printing and production cost of the Hoot Magazine.

6. Treasurers Report – SS informed the group that the BOPAG Accounts were looking much healthier due to the added funding and that we may be receiving more but are waiting for this information to be finalised.

Alan then asked everyone present to introduce themselves to the group and to give any relevant updates.

7. Any Other Business – DAC asked the group to spread the word about booster jabs as this makes dementia symptoms less severe. He said that it was important to be patient with people living with dementia as their world makes sense internally to them and they may find our world on the outside alien and bewildering. Please just go along with them and give them time. Don't try to put them right. Be humble and most of all be patient.

AB – invited the group to network in the foyer and offered more refreshments.

8. 2022 Meeting dates - face to face meeting Wednesday 16th November 10am

The meeting closed at 12.45 hrs