



Notes taken at the meeting for the Trustees and Steering Group held at Dove Cottage on Wednesday 3<sup>rd</sup> July 2013 at 7.30pm.

**Present** – Paddy Fielder (Chairperson), Lynden Jackson, Sue Jackson, Mary Morley, Gillian Shacklock, Roger Cockerton, Joy Walton & Tony, Steve Robbins, Sam Cage, Tim Mason and Gordon Slack

**Apologies** – Apologies were received from Mike Rous, Alison Gravatt and Peter Holme.

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Paddy Fielder opened the meeting and the minutes of the previous Steering Group meeting were approved. He then invited Sam Cage to give her presentation on The Carers' Co-Op and the Debenham on Call Project.

Following the presentation questions were welcomed and Roger asked how carers are paid. – This is done directly from cared-for to carer. Paddy asked why one of the matchings had not worked out and this was explained.

Lynden added that all the people on the carer's register have two references, one from their current employer and one from a previous employer.

Paddy then thanked Sam.

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Tim Mason & Gordon Slack were welcomed by Paddy and then gave their presentation on The Research Project – “Helping Carers & Cared-for to ask for help before the crisis.”

Tim opened and explained that both he and Gordon are independent advocates. Following this Gordon presented various statistics that have already been extracted from their research before Tim spoke again. Questions were then invited:-

Are their plans for the research to be published on completion and sent to our MP Dr. Dan Poulter and others? – Yes.

Have Tim & Gordon looked at other research in the field? – Yes. They carried out a world-wide search at the start and will return to this again. After carrying out a large trawl of data they found nothing else which was as in depth as this project.

From other surveys is a difference between urban and rural areas detectable?

Has a difference in perception between Carers and GPs & other professionals been detectable?

Do people not like the word ‘dementia’ as it comes from the term demented and would prefer an actual diagnosis such as Alzheimer’s disease. This question was followed by a short discussion noting that there is currently a lack of general knowledge about dementia similar to the position with cancer not so many years ago. Frequently the term Alzheimer’s is used, particularly in the media, when it should be the term dementia and other forms of dementia are not discussed, such as those associated with stroke, Parkinson’s disease and Lewy Bodies.

Lynden spoke about the methodology of the research. The questionnaire is user-friendly and open and is a starting point for entering into conversation.

Paddy emphasised the importance of making Dan Poulter aware of the research and getting him to act on the report.

Paddy thanked both Tim & Gordon for their presentations.

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Steve Robbins was welcomed and invited to tell us about his work with Ipswich Town Football Club. This project is in conjunction with the Ipswich Town Football Club Charitable Trust and is currently in the early stages of development. Many football memories have already been shared and meetings held, including a visit to Portman Road.

Paddy thanked Steve for all his work and, there being no other business, the meeting closed at 9.15pm.