



Local Forums for People with Dementia in Wales: an evaluation

Interim Report: February 2007

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This report presents an evaluation of a pilot project designed to establish local forums for people with dementia. The project is supported by funding to the Alzheimer's Society Wales from Age Alliance Wales over a 2 year period, 2005-2007. The evaluation was conducted over a twelve-month period, from November 2005 – December 2006 by the Dementia Services Development Centre, University of Wales Bangor.

Background

People with dementia are now much more likely to receive a diagnosis earlier in their condition than in the past. This means that in the early stages of the dementia they are able, with encouragement and support, to take an active role in their care and to have an input to the services that support them (National Service Framework for Older People, Welsh Assembly Government, 2006; NICE-SCIE Guideline on dementia, 2006). The Alzheimer's Society 'Living with Dementia' programme sought the views of people with dementia who identified influencing services and meeting with other people with dementia as key priorities. In 2006, the Alzheimer's Society launched its new strategic framework 'Our society: rising to the challenge', with the following principle at its core:

'People with dementia will always be at the centre of everything we do: we will work to ensure that their perspectives inform all our activities'.

The current project; establishing local forums for people with dementia, was designed with these key priorities in mind.

Aims and Objectives

The key aims and objectives of the project were:

- To give people with dementia opportunities to influence dementia policy and service delivery in Wales by considering and responding to strategies, policies and consultation documents that have an impact on their lives
- To include an event where the forum will formally present their thoughts and findings to key individuals in Wales
- To provide a framework for further user-led forums
- To challenge widely held misconceptions about people with dementia
- To improve self esteem and well-being of participants with dementia

Method of evaluation

The forums were evaluated in several ways. Detailed notes were taken by the researchers during the meetings. Qualitative data were collected by holding focus groups conducted with people with dementia and by a questionnaire completed by facilitators, carers and professionals who had attended the forums. Members of the DSDC team attended a selection of forum meetings in both North and South Wales and had access to notes and minutes of other forum meetings.

The evaluation focused on the following outcomes:

- Identifying where people with dementia have been involved in local and national decision making and policy development, arising from the project
- The impact on self esteem and well-being of those people with dementia involved in the forums
- Views of family caregivers regarding the involvement of people with dementia
- Guidelines on the establishment and running of such forums based on experiences during the project.

Progress to date

Setting up

Just over a year into the project the forums are now well-established. A series of seven forums have now been held in both North and South Wales respectively. The forums have taken place every six to eight weeks and vary between three to four hours in length. Participants were identified in the first instance through local Alzheimer's branches, memory clinics and through contact with Community Mental Health Teams.

The facilitators pinpointed several problems they had encountered whilst setting up the discussion forums, these included:

- settling on a reliable venue
- problems with communication
- determining role clarity between facilitators and
- putting the project into the correct context.

For example:

“At first we had to convince staff that people with dementia had something to say and there are people out there at early stages who would be interested in attending these kinds of events.” (Facilitator)

The meetings

Attendance at both groups has been encouraging. A total of 16 people with dementia regularly attend the forums in North and South Wales together with 14 carers and an average of 10 professionals. The professionals are in the main Alzheimer's Society staff although some meetings are attended by outside speakers. Most of the people with dementia are supported by a carer although the attendance of those who do not have a carer available is facilitated by befrienders and other members of the local Alzheimer's Branches. At the present time, ongoing recruitment is being addressed by both groups. For example, group one has attracted new members through contact with a recently established local carer group and is about to re-advertise the forums whilst group two is proposing to relaunch their forums in January 2007.

Facilitator's feedback, borne out by general observations, suggests that the people who regularly attend have formed strong bonds with each other and appear to enjoy engaging in discussion.

"I have been impressed by the willingness of the person with dementia to confront difficult issues and to speak in a highly moving way about personal matters." (Facilitator)

"Even when difficult issues are being discussed there is no reluctance to contribute to the discussion and people with dementia have reported that they enjoy coming along." (Facilitator)

One professional added the caveat that,

"It is possible that some people with dementia may find the experience upsetting and it is important to establish that the people with dementia understand the process. They also need to have access to on going support if issues are raised which they find difficult to deal with."

Overall the degree to which people with dementia are willing to be involved is encouraging as care was taken at the first forum to establish a common set of ground rules or guidelines, these are shown below.

Ground rules

- To show respect for each other and for each other's needs
- To give each other time, to ensure that everyone can have their say
- To elect a chairperson to chair the discussion
- To set an agenda before each meeting to allow preparation time
- To maintain confidentiality

It is apparent that these guidelines have been effective in facilitating contributions from people with dementia and have also led to good group cohesion and confidence. Care is always taken to introduce new members to the forum and name badges are always provided. Our observations indicate that new members are quickly assimilated into the groups.

To date a wide range of topics have been discussed including:

- Accessibility
- The NICE guidance on dementia drugs
- The experience of receiving a diagnosis
- Challenging the misconception of dementia
- Dementia Training
- Advocacy
- Free Personal Care

In general the agenda for the meetings is set by the people with dementia and their carers in consultation with their group facilitator. Both groups receive a set of minutes before each meeting with a reminder about the forthcoming topic for discussion. In some instances additional material is provided; for example press cuttings or summaries of policy documents. Carers had mixed opinions about the information they receive about a forthcoming topic for discussion. Whilst most were satisfied, a few found the information rather vague. A carer from one group observed:

“I think the organizers have intended to send out prior information but for various reasons haven’t managed to arrange this since our first meeting.”

There also was a mixed reaction to this issue from people with dementia. Given their memory problems, some did not find it useful to receive information about the topic prior to the meeting; they preferred just to turn up and ‘tackle the topic’ on the day.

Opportunities for people with dementia to meet together separately

At present the format of the meetings differs between the two groups. In group two, the people with dementia initially meet to discuss a topic separate from their carers. Information is gathered from carers and people with dementia in their separate discussion groups by facilitators summarising the main points using flip charts. The whole group then reconvenes for further discussion. The disadvantage of this approach is that two facilitators are needed; on the other hand, people with dementia are given the time and the privacy to discuss their own opinions. In one meeting it was noticeable that when the whole group met to give their feedback the carers were surprised by some of the comments made by the people with

dementia which led to a thoughtful in depth discussion of some of the key issues raised by the people with dementia.

A professional attending the forums observed:

“I feel that this format truly gives the people with dementia the opportunity to give their own views without their carers rushing in to ‘rescue’ them. Both carers and people with dementia have acknowledged this during discussions.”

Group one has been using a whole group format. People with dementia, carers, facilitators and professionals discuss the topic together. The main disadvantage of this method is that carers may ‘take over’ the discussion.

“I feel that carers have other opportunities to discuss matters they are interested in (e.g. in carers groups) and I feel these discussion forums should focus upon the people with dementia.” (Advice worker)

This issue was raised by a person with dementia during one of the meetings. It was taken on board by the whole group who decided to try the alternative format used by group two at their next meeting.

Impact of the forums

Group one has been regularly attended by local assembly members. The AMs have lobbied the National Assembly and the Minister for Health using feedback from the forum members about issues surrounding problems with the process of diagnosis and the NICE guidelines on the future availability of cognitive enhancers (responses to issues raised by members of the group can be found in the appendix). Update on any progress is provided by an AM at the start of every meeting. Recently, group members have been directly involved in the campaign against the NICE guidance by joining local protest marches, lobbying AMs at regional committee meetings and drawing up petitions.

At an individual level, one person with dementia has raised awareness of the experience of dementia with practitioners by publishing an article in Signpost, Journal of Dementia and

Mental Health Care and has also composed a poem reflecting his thoughts on being involved in the forums (see appendix).

Although at present group two has no government representatives at their meetings, they are aware that this would be of value to the group and are currently working on encouraging a range of policy makers to attend. They do however pass on any comments arising from the meetings to the campaign team at the Alzheimer's Society National Office.

Both groups endorsed the need for a nationwide identity card for use by people with dementia. The Alzheimer's Society has now produced these and is piloting them with people with dementia.

There is good evidence that the facilitators are constantly monitoring the progress of the groups. In group two feedback from people with dementia and from carers is encouraged by handing out evaluation sheets after each meeting. Comments are then summarised in the minutes and distributed to people with dementia and carers.

Carer Feedback

The questionnaires distributed to carers contained open-ended questions designed to elicit their thoughts about practical aspects of the forums for example, venue, structure and location. They were also asked to comment on the content of the meetings, topics of relevance and the provision of written information. They were invited to outline any personal benefits of attending the meetings and to consider any benefits from the perspective the person they were caring for. The first part of the questionnaire contained questions about demographic information including age, length of time spent caring etc.

Demographics

10 carers responded to the survey. Nine were female carers caring for their spouse with one male carer caring for his wife. All but one carer (who is in full-time employment) were retired. The average age of carers was 65 (49 to 83 years of age). All the carers were spending over 50 hours per week caring for their spouses. The average age of the people with dementia was 68 (50 to 85 years of age). Nine out of ten were taking cognitive enhancers.

Attending the meetings

Carers had found out about the forum through their local Alzheimer's Society branch, by word of mouth, through attending a carers group or from a Community Mental Health Team. Only one carer stated that sometimes they had difficulty attending due to conflict with work (this was the only carer in employment) the remainder were happy with travelling to the venue. Provision is made for those without their own transport.

“Although the location is a long way away and is difficult to get to we have been offered lifts, so have managed to attend.”

The structure of the meetings

All the carers felt included in the meetings and stated that they were all given the opportunity to speak when they wanted to. When asked if they felt if the person they were caring for was provided with the opportunity to speak when they wanted to one carer commented:

“The group must allow the time for Alzheimer's sufferers to formulate their thoughts and time to express them.”

Carers were encouraged to identify any topics discussed to date that they felt were particularly relevant to themselves and to the person they are caring for. The majority mentioned the NICE guidance, the process of diagnosis and training of health care professionals. None of the carers felt that any of the topics they had discussed so far were not relevant to themselves or to the person they were caring for.

We asked carers if they felt that some meetings were better than others and to identify the reasons for this in terms of the way the meeting was structured, the speaker, the involvement of carers and people with dementia. Overall the responses were very positive for example,

“Both of us have found the forums a source of information, stimulation, greater understanding of the illness, a release for the dementia sufferers to have a voice and to listen to each other and for carers it's the same. Separating us was a great move.”

One carer identified a potential problem with some of the meetings based on the balance of the contributions from carers and people with dementia.

“A good facilitator is essential to keep the meeting flowing as some carers tend to talk at length and need to be kept in check.”

Benefits

Carers mentioned several benefits of attending the meetings both from a personal point of view and for the person they are caring for. Carers felt that they benefited greatly through gaining mutual support through meeting with other carers. They also appreciated the opportunity to discuss problems and solutions with other carers who understand their feelings. A further benefit was of receiving information and being given the chance to evaluate government policies from a personal perspective.

“Meeting others with similar problems to yourself, knowing that others are aware and trying to help. Evaluating government policies, listening to all points of view, gaining information.”

Carers saw a key benefit to the person they are caring for as being given ‘the chance to speak’. Other benefits mentioned included meeting other people with similar problems in a normal situation where they are given the opportunity to have social interaction with people in a relaxed atmosphere. The key benefits are summed up in this comment by a carer:

“Enabling them to have a voice and to participate in discussion from an Alzheimer’s point of view. The people who are affected do need to have an opportunity to shape the future.”

Impact of the meetings

Carers in the group where there was no AM representation generally felt that the meetings were at present having little impact on policy makers and professionals. They felt they could personally influence policy decisions by:

“Inviting policy makers to a social gathering/meeting of sufferers and carers and producing a paper to be sent to all branches of health care, MPs and AMs.”

Carers in the group with AM representation were more positive about the possible impact of the groups on policy making but had some reservations; for example one person commented:

“Not a lot of impact they don’t like spending money.”

All the carers saw it as vitally important that people with dementia are encouraged to take an active involvement in discussion groups with a view to influencing policy making:

“People with dementia should be fully encouraged to talk about their needs and frustrations as they are the only people who can express how they feel.”

Focus groups with people with dementia

Two focus groups with people with dementia were held as part of the discussion forums in North and South Wales. A total of 14 people with dementia took part. The focus groups were guided by a researcher using a set of pre-determined open-ended questions. Particular care was taken to encourage each participant to contribute to the discussion.

Initially the people with dementia were asked why they wanted to become involved in the forums. Three main reasons emerged:

1. To learn and to get more information
2. To meet people with the same problems and the chance to empathise for example:

“Gaining an understanding of our condition is helped through contact with others in same position.”

3. To have the opportunity to talk and to socialize. It was clear that there was a strong feeling that this helped protect their identity:

“When you stop mixing you begin to feel abnormal.”

The discussion then focused on what they had enjoyed about the meetings. The main themes were the chance to converse and to discuss. Another important aspect was the feeling that they were being taken seriously and the comfort they derived from knowing others have the same problems; one person with dementia summed this up as:

“It’s not just me in the boat I have a crew with me.”

In a similar vein, people with dementia also reported not feeling as isolated as they had prior to attending the meetings. Most said they felt more confident because they had been encouraged to talk about their feelings, thoughts and opinions in a ‘safe and supportive’ atmosphere.

“It’s a chance to make my voice heard and be taken seriously and treated with respect.”
(person with dementia)

In the group that held separate discussion sessions for carers and for people with dementia there was a general consensus that this freed them up to really say what was on their mind without fear of hurting their carer. The group that had previously held discussions together with their carers have recently changed the format and separated into two groups. When asked which format they preferred there was a unanimous decision that they benefited more from being separate. One person with dementia expressed the main reason as being:

When I’m in a large group I feel as if I’m half there and half not. All seems to go over your head. This has been a good experience I feel now as if I have more time and I can really make a difference.”

In addition the people with dementia felt that there were also benefits to the carers:

“They can have their say without fear of upsetting us”.

Most of the people with dementia agreed that they were given the opportunity to set the agenda in terms of topics to discuss at the meetings. However those in group one felt that in previous sessions where they met as a whole group with their carers that they had had less of an influence:

I’ve not felt I’ve had enough of a say in previous meetings you tend to make the assumption that your carer is seeing to it.”

When asked if they felt they were having an influence on policy and practice the general response from group one was positive:

“We need this opportunity.”

“They (the government) weren’t listening but now we can say we want something done.”

“I feel I’ve actually told them what we thought of them – I will never forget that.”

Responses from group two (without AM representation) expressed a hope that in the future they would be able to have some impact.

Meeting the key aims and objectives

There were five key aims and objectives for the project. These are discussed below in terms of the degree to which they are being achieved together with recommendations for future forums.

1. To give people with dementia opportunities to influence dementia policy and service delivery in Wales by considering and responding to strategies, policies and consultation documents that have an impact on their lives

There is good evidence to suggest that the wide range of topics discussed have addressed strategies, policies and consultation documents relevant to people with dementia. All the people with dementia have commented that they considered the topics to be highly relevant and have enjoyed the chance to discuss them in an environment where they feel they are being listened to and that their individual contributions have been acknowledged by other members of the group.

2. To include an event where the forum will formally present their thoughts and findings to key individuals in Wales

To date there has been no formal event. However, group one have had the opportunity to directly feedback to the National Assembly through the AM and have received feedback from

the Minister for Health. This ongoing consultation appears to be of benefit to the people with dementia and their carers by demonstrating that they can make a difference. The groups have also been well-attended by professionals involved in the care for people with dementia who have all expressed a benefit from being given the opportunity to hear the opinions of people with dementia which they can assimilate into their professional lives.

3. To provide a framework for further user-led forums.

The progress so far is encouraging and the work of those involved in setting up and running the groups is to be commended. The first year has certainly provided information that will be very useful in terms of providing a framework for future forums. The recommendations arising from a blend of inputs from people with dementia, and their carers, facilitators, professionals, researcher's observations are as follows.

Recommendations

- To improve communication between groups in order to mutually assess what is working and what is not in terms of recruitment, format, topics and outside speakers. This could be achieved in the first instance by fostering regular contact amongst facilitators.
- To encourage a broader representation of people with dementia for example, those who have no carers or are being cared for by someone other than a spouse in order to gain better understanding of their needs in terms of service delivery and to allow them to have an input into shaping policy.
- To adopt the format of holding separate sessions within the forums for people with dementia and carers and in addition, to ensure that they then meet as a whole group to discuss their views.
- To ensure that there is a balance between the contribution from carers and people with dementia in whole group sessions. It is important to understand that people with dementia do need to be given time to assimilate and to both follow and contribute to the discussion.
- To achieve a balance between discussing the topic and providing the opportunity for people with dementia to communicate and socialize with each other.

- To remind attendees of the purpose of the forums e.g. to enable people with dementia to participate as fully as possible.
- To provide on-going support for the person with dementia especially when discussing difficult issues.
- To promote effective communication between the events/meetings by forwarding minutes and sending out invitations in good time.
- To plan effective methods of ongoing recruitment via carer groups, newsletters etc.
- To provide the opportunity for people with dementia and carers to feedback their thoughts on each forum.
- To actively encourage national and local policy makers to attend and contribute to the meetings.

4. To challenge widely held misconceptions about people with dementia

As illustrated by the previous quote from one of the facilitators, this process begins with convincing professionals that people in the early stages of dementia would be interested in engaging in debate and discussion about issues surrounding service delivery and policy. These forums have started on the road to challenging misconceptions about people with dementia through providing them with the opportunity to discuss relevant issues, encouraging a dialogue with local and national policy makers, by supporting people with dementia to publish their thoughts and opinions in publications and by raising their profile by encouraging them to actively participate in campaigning for better service delivery.

5. To improve self esteem and well-being of participants with dementia.

Although based on retrospective accounts from people with dementia and their carers, their comments strongly suggest that self esteem and well-being for people with dementia has improved through participation in the forums. This is particularly noticeable in terms of reported increased confidence. People with dementia personally report they feel more confident and that they have observed that other members of the group with dementia are more confident also. Carer feedback has endorsed these comments.

Acknowledgments

We would like to thank all the people with dementia, carers and professionals for their time and their contributions to this report.