

## **AN INDEPENDENT EVALUATION OF 'DEMENTIA DIARIES'**

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### **Background**

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Dementia Diaries is a project that records people's experiences of living with dementia. Mobile audio handsets are used by the diarists to record their experiences and thoughts on a day-to-day basis. These audio blogs are available on the Dementia Diaries website.



In November 2015, Leeds Beckett University were asked to find out about the impact of Dementia Diaries on the diarists and family members and to see if Dementia Diaries has influenced the way that the media report dementia.

## What we did

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We interviewed 11 people taking part in the Dementia Diaries project and five family members. We also compared the content and comments posted to on-line articles written by the Dementia Diaries team, with similar articles that were not.

## Findings

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Dementia diaries participants and their family members spoke positively about taking part in the project.

### **Support from the Dementia Diaries team**

People found the training about how to use the hand-set very helpful. When some people came across difficulties, the Dementia Diaries team provided solutions. Most diarists said that the hand-set was very easy to use.

Diarists and their families were positive about the Dementia Diaries team and the support they gave to people taking part. They said the team were always on hand to answer questions or to help to solve any problems. Having this level of support was very important for the project's success.

“They are absolutely key to this thing working. Their friendliness, their encouragement, they keep in contact. Just the encouragement and their attitude is absolutely brilliant.” (Family member)

## The impact of Dementia Diaries

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### Personal satisfaction

People told us that recording diary entries gave them something positive to focus upon. Knowing that their recordings were being listened to and helping other people made diarists feel useful and valued:

“There’s a few main points. Again the main one is I quite enjoy the role... it gives me something to do. You know if you have got Alzheimer’s you need to keep busy all the time and keep your brain busy.” (Diarist)

### Challenging stigma and stereotypes

Participants said that Dementia Diaries allowed people with dementia to give their views and helped their voices to be heard. They felt that their diary entries could help to reduce the stigma attached to dementia. Some other positive results from producing the diaries included:

- **Improved confidence**
- **Stronger family relationships**
- **Support from peers**



## **Reaching the public**

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### **Social media campaigns**

The Dementia Diaries team led a number of social media campaigns, including with Comic Relief on Twitter and a Christmas campaign. These reached a very wide public audience. The collaboration with Comic Relief on Twitter resulted in over 1,500 people joining an online conversation. The Christmas campaign resulted in over 160,000 people watching Dementia Diarists' videos, which were released daily on Facebook and Twitter during December. Other on-line articles and newspaper stories also reached wide audiences.

### **The impact of Dementia Diaries on the media**

We found that when articles in the media were based on the voices and experience of people living with dementia, readers' comments generally showed more understanding, were supportive and were more likely to accept messages that challenged stigma about dementia. Some readers also shared their personal experiences of caring for someone with dementia. People commented how useful and informative they found Dementia Diaries articles.

## **Conclusion**

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The Dementia Diaries project has been successful. Dementia Diaries has made a difference to the lives of the people involved. This includes increased confidence. Dementia Diaries

has also influenced how the media report about dementia and has informed a wide public audience about dementia and issue that affect people with the condition.

In the future making sure the project continues to get funding will help to carry on the positive outcomes shown here. The possibility of diarists meeting face to face should be considered.

### **More information**

The Dementia Diaries web-site

<http://www.dementiadiaries.org/>