A Board Game: for generations to learn about Dementia

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Summary:

This paper sets out to introduce the reader to a new concept. The dementia friendly board game is a unique resource that is proving to meet many of the initial learning and educational needs of generations. It has also shown that the game can introduce dementia to lay people and wider communities using a more positive approach, it gently includes a fun element making it an ideal resource to be used in family homes, individual organisations and wider community members can also begin to establish a more positive experience and understanding of dementia by using a fun element when playing the game that removes discrimination and develops empathy in family homes and wider community groups towards people living with dementia.

Background

The challenge of developing and sustaining dementia friendly communities requires a significant adjustment not just from policy makers but society as a whole. Evidence is emerging that although early and appropriately timed diagnosis for people to access is a good thing, it defeats the objective if no active services are available to provide hands on practical support and the communities are top heavy in signposting (DOH 2013). Research led by the Alzheimer's society (2013) shows that nearly 50% of people diagnosed with dementia only go out to do things in their local area once a week or less because people have not felt valued or empowered within their communities following diagnosis. The Prime Minister's Challenge on Dementia (DOH 2013) was developed to focus on three key areas:

- 1. Driving improvements in health and care
- 2. Creating dementia-friendly communities that understand how to help
- 3. Better research

This paper focuses on the 2nd key area, creating dementia friendly communities that know how to help. Within which there is a particular focus on intergenerational work or in other words working closely with school children to improve understanding, raise awareness and influence societal culture to remove stigmatisation and dismissiveness of people living with dementia in their communities. If we can influence a generation to be more tolerant understanding accepting and finally inviting of people living with dementia then we can really make a difference to the quality of the experience of life with dementia for so many people.

This paper sets out to explain how in the Forest of Dean a board game was conceived within a working group of partner agencies, led by the District Council but in partnership with Gloucestershire County Council, 2gether NHS Foundation Trust and voluntary organisations such as the local Alzheimer's Society branch, Crossroads Forest of Dean and Newent Association for the Disabled; to use as a training resource for schools, with organisations (across public sector, voluntary and private companies) and families in understanding dementia. How some funding was sourced to make the initial first set of board games, how we have evaluated to date the resource and the impact of this on community developments.

Introduction

Working for the District Council, my role as a Community Engagement officer has opened up many opportunities for me to work widely within my community which is the Forest of Dean in Gloucestershire. I have embraced the local Dementia Training Pathway provided jointly by the NHS Clinical Commissioning Group and Gloucestershire County Council and completed all relevant training to enhance my role such as the Gloucestershire Dementia Leadership Award and the National Alzheimer's Society Champions Training.

I recognised quite early that communities had very limited resources to access what could positively influence their understanding of dementia as families or as community groups. There was a real need to consider how we could change the thinking about people with dementia in our communities as *living with a dreaded disease* and disappearing into some form of *safe care* but often not truly what the person with dementia wanted or needed but what the community expected. So realisation that in order to influence communities development and understanding about life with dementia it would be beneficial to develop a resource which would appeal to generations and at the same time could influence older people through younger people improving community awareness and understanding surrounding dementia that could cascade into other areas and contribute towards the building of more inclusive communities where everyone can feel safe, welcomed and at home.

Agreeing the learning resource format

The partner representatives met in March 2013 and began pooling knowledge and understanding about how people could learn best about what is often considered to be a complex and large topic. We needed to produce a resource that would cut across generations and remain fun and interactive as a learning tool for all ages. After much discussion we agreed on the concept of a board game that everyone can play and take part in. The initial format followed a snakes and ladders process.

The cards were initially designed using four themes Myths, Science Communication, Dementia Friendly Communities.

Some examples of the initial questions we posed are:

Myths

Question: People with high IQ's are more at risk of Dementia

True or False? Dementia affects everyone equally.

Question: Memory is always the first skill to be affected by dementia?

True or False?

It depends on the type of dementia & the individual. Word finding problems & visual difficulties can be amongst the earliest symptoms.

Science

Question: The word Hippocampus is Greek for what?

- a) Sea Horse
- b) Rocking Horse
- c) Hippopotamus

A summary of what the Hippocampus is and does is on the card to be read out.

Question: Cauliflower cheese on a white plate may cause the person with dementia difficulties

True or False?

People with dementia can find it very difficult to distinguish similar colours.

Communication

Question: If engaging in conversation with someone who has dementia which of the following approaches would you use?

- Be clear Maintain eye contact
- Speak calmly in short, simple sentences.
- Use open, reassuring body language
- Challenge what they are saying, trying to put them right

Dementia Friendly Communities

Question: If you notice someone struggling in a shop what can you do to assist?

- Ask if you can help.
- Listen very carefully & give the person plenty of time to reply.
- Speak clearly & calmly in short, simple sentences.
- Be patient & flexible.

Testing out the board game

Two community dementia awareness focus groups were set up to test the board game.

Each person was given a 'post it' note and invited to write down anything they would like to ask about dementia. An experience, a concern or something they would like to share. These were then placed onto a flip chart ensuring all questions / enquiries were captured. To play the board game people were put into four teams and the rules were explained.



Rules:

Each team takes turns to throw the dice, moving the appointed number of spaces. Each number has a value:

1 = Communication

2 = option to choose a category or "pass the buck" to another team

3 = Myths

4 =Science

5 = Dementia Friendly Communities

6 = equals take another go. The first team to get to the top of the board won.

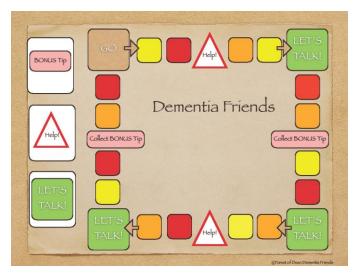
One partner acted as the games master. Four partners joined the teams reading the cards out. Whist the game was playing another partner went through the post it's, putting them in groups ensuring everything was responded to and answered as we played the game.

Feedback from the Focus groups

- During the first session the community members observed that it was difficult for people to remember the value of each card represented so before the second session the card values were manually stuck on the cards with tiny labels.
- The groups told us the board was too busy and the game was too long.
- People also reported to us that the dementia friend communities' card did not fit with the rest of the game.

The evidence we were able to capture guided us towards making some very relevant adjustments.

Redesigning the board game following feedback



Taking into consideration the feedback from the two focus groups this revised draft board design was put together by a partner.

- The Dementia Friendly Communities cards were replaced with two new cards – Bonus tips and a Help card.
- Green squares of Let's Talk were added to facilitate the opportunity for discussion.

After very positive discussions the board game was finally taken to a local designer who was able to work with all the feedback from the focus groups and the initial dementia friend's board (above) to produce the finished version (below)



The board game now incorporates the 'post it' note element from the original design into the *Let's Talk* section. A Top Tips resource was added to the game for people to use to find out additional information if they did not want to write anything down on post its. Our designer incorporated a dementia friend image into the centre of the board.

The questions remained as science, communication or myths depending on where the dice fell.

We also decided to have some blank cards printed in each section so that we could add or amend Q&A's in response to people's experiences, thus continuously evolving and expanding the board game and our knowledge as well as listening to the feedback from the community.

The impact of playing the game

Having successfully sourced funding from a local partnership in December 2013 two prototype sets of the game were ordered. Numerous dementia awareness sessions, using the game, have been delivered across the locality in differing venues and for different audiences. Nearly 300 people have attended – individuals and organisations such as our retained firemen and Police Community Support Officers (PCSO's). At one session issues around ethical lying were highlighted by a volunteer and although this had not been

included initially we have used the blank cards to ensure this is covered in the updated game. The board game has been used within two local secondary schools; both have endorsed the way it adds value to their pupils learning experience and want a copy to support them embed dementia awareness within their schools.

Outcomes

We have been able to evidence that board game is well recognised across the district, and county.

People find it easy, fun and educational in use.

Although two copies of the board game were originally made we have received requests for 23 additional game packs to date.

Successful feedback has secured funding to reproduce six more copies for the Secondary Schools in the Forest of Dean; after further evaluation funding will be sourced to distribute wider.

Local businesses' and shops in particular are more willing to advertise dementia related events

A number of new community developments involving engaging older people and people with dementia in the community have been developed immediately following playing the game.

We learnt that providing information sessions for teachers and creating support networks should be considered an integral option for improving their knowledge of dementia.

We discovered that perhaps an award scheme sponsored by the Prime ministers challenge on dementia should be given to schools who embed dementia training into the curriculum.

Consideration should be given to creating an award scheme which may be sponsored by the Prime Minister's Challenge on Dementia or through the provision of a national incentive to increase the uptake of schools, organisations and community groups embedding dementia within their curriculum or business plan.

People report a better level of awareness and understanding about dementia making them more confident in approaching and supporting a person with dementia.

Use of the board game has enabled conversations which allow people to consider their learning and discuss how they would like to turn their understanding in to action; resulting in people volunteering locally.

Conclusions

In 2014 we were able to take the board game into the local schools and introduced it to over 200 children as a result of playing the game 25 children agreed to a local buddying concept where they would give up some of their free time to visit a person with dementia in a care home or do some shopping as an example. This is a real move in the right direction towards the true essence of dementia friendly communities where people with dementia can feel valued, respected and wanted in their communities often through small and simple gestures like this. The schools in the Forest of Dean continue to value the purpose of the board game and the children are able to introduce their leanings to their families at home.

We set out to bring generations closer together using a family oriented friendly resource and although the board game will need to be updated and will require further financial investment it has shown that is has achieved many of the initial goals.

Word count 2067

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