

Foreword by

DR G. ALLEN POWER



Visiting the

Memory Café

and other

Dementia Care Activities

*Evidence-based Interventions
for Care Homes*

EDITED BY CAROLINE BAKER *and*
JASON CORRIGAN-CHARLESWORTH

Memory Cafés

*Educating and Involving Residents,
Relatives and Friends*

JASON CORRIGAN-CHARLESWORTH



In this chapter I will explore not only the benefits but also areas to consider when looking at developing the role of a Memory Café as part of the care home environment. I will discuss too how this resource can be used to support many people, including both those living within the care home and those living within the local community, and thus challenge the stigma around life in a care home whilst also promoting community relationships. I will also provide advice and guidance on aspects to take into consideration when looking at opening a Memory Café.

Are Memory Cafés beneficial?

In the current decade, Memory Cafés are becoming an ever-popular resource and are opening up both nationally and internationally as a way of providing advice and guidance and supporting relationship building, as well as a way of informally supporting those living with dementia and their carers. I would point out at this stage that Memory Cafés in the United Kingdom are not to be confused with memory

clinics, which are formal assessment services run by the National Health Service.

The very first Memory Café was opened in 1997 in the Netherlands and was the idea of Dr Bère Miesen, a clinical old-age psychologist (Jones and Redwood 2010).

Dr Miesen chose the name 'Alzheimer's Café' rather than 'Dementia' or 'Memory' 'Café', as it was felt that most organisations for people with dementia across the world were referred to as Alzheimer's societies, even though such organisations also provide support and advice for the many other types of dementias and their related impact upon an individual. Alzheimer's disease was, and still is by far, the most common form of dementia, hence the word 'Alzheimer's' was chosen.

In his contacts with people with dementia and their families at the time, Miesen had noticed that talking about the illness, even between partners or within a family, was often taboo. Miesen stated that making dementia 'discussable' and providing information about it and its consequences were very important for the acceptance of the illness, so much so that he thought that it would be good if all those involved could meet each other in a 'relaxed forum' to exchange experiences and to talk about dementia. Dr Miesen was quoted as saying in 1999 that, 'Dementia is a complete catastrophe. Both the person with dementia and their family deserve to be well supported' (cited in Jones and Redwood 2010, p.4). Of course no one would argue with the latter point in this quote; however, the way in which individuals and their carers are supported still remains somewhat of a postcode lottery within the United Kingdom.

Brooker (2007) tells us that dementia is the most feared aspect of ageing. It is misunderstood by many. People with dementia suffer prejudice both because of their age and because of mental decline, and though there have been some improvements in this area, mentioned below, I agree that even today as a society we still come across many

'isms' that mean individuals require support and a voice to continue to fight these.

Various publications, such as the National Dementia Strategy (Department of Health (DOH) 2009), Department of Health policy on dementia (DOH 2015) and the implementation of the Dementia Action Alliance group, to name but a few, have clearly started to steer us in the right direction and have given a voice to those living with dementia and their carers, but there still is a long way to go to ensure that best practice is implemented and shared.

Background research into identifying if Memory Cafés can be beneficial has to date produced differing views due to the variation on how they are organised and run. Toms *et al.* (2015) found that two recent systematic reviews undertaken by the National Institute for Health Research on support groups for people living with dementia concluded that whilst there were subjective benefits, no conclusions could be drawn on whether they promoted positive psychosocial outcomes. This view would appear to be in line with research undertaken by the Alzheimer's Society, released in 2016, showing that 42 per cent of people mistakenly thought that once a person living with dementia stopped recognising loved ones, they didn't benefit a lot from spending time with them (Kemsley 2016). A second survey carried out at the same time found that of 300 people living with dementia, 64 per cent felt isolated from friends and family (Kemsley 2016).

Despite the above findings, research undertaken by Dr Dow (2011) into the benefits of Memory Cafés in Australia found that they promoted social inclusion, prevented isolation and improved the social and emotional well-being of the majority of those who attended. Bryden (2005) tells us that, 'We need all the support we can get, after having what I think is one of the worst diagnoses anyone can get' (p.131). Therefore one could be confused when trying to come to a concrete conclusion as to whether attending a

Memory Café does actually make a difference to those living with dementia and their relatives.

That said, I would state that it would be a fair assumption that Memory Cafés can provide support and benefit to some individuals, as with any support group, regardless of its client group, and it would depend on the exact role and remit of such environments along with the expectations of those attending as to whether they provide an overall benefit.

As mentioned previously, there are many Memory Cafés located within different towns, villages and cities all over the United Kingdom, and that popularity in itself may identify that they do actually provide a benefit. However, these Memory Cafés are predominately accessed by those still living within their own homes, and so access to them for those who live within care homes and their relatives can be very limited, as either travelling to such venues can be an issue. Additionally, as I have experienced from a personal perspective while caring for a relative living with dementia, the number of available places can unintentionally create a selection process or priority may be given to those who are perceived to be at greater risk of isolation.

Implementation and introduction of Memory Cafés within care homes

Before we explore the best ways to implement Memory Cafés within the care home environment, the reader may be wondering why I chose the expression ‘Memory Café’ rather than ‘Alzheimer’s Café’. I personally feel this makes it sound more inclusive, as the word ‘Alzheimer’s’ could indicate that it is purely for those living with a specific form of dementia; also, there are still many individuals who have not received a formal diagnosis and the word ‘Alzheimer’s’ may give the impression that those individuals would be excluded.

One way of enabling the benefits of Memory Cafés to become more accessible to all those living with dementia

and their relatives, regardless of where they live, is for care homes to look at how they can best develop this resource and by so doing also provide a support network for relatives; this is what our organisation has looked at promoting.

It is important to point out at this stage that Memory Cafés are not intended to replace other current practices that are in place, such as residents' or relatives' meetings, or to seek their views of the care provision, as this should be covered elsewhere. The remit of the Memory Café is to build upon ways in which care homes can provide an additional resource not only to further support those they care for but also as a forum for their relatives. This can be achieved by ensuring the environment promotes and supports relationship forming, companionship, inclusiveness, understanding and fun whilst providing guidance and compassion. The Memory Café can also be a good way to explore and identify other ways of meeting current or any future needs in relation to information giving, educating and training delivery in an informal, safe and non-judgemental environment.

Within the organisation, we also believe that there is still a lot of living to do, not only after diagnosis but also after moving into a care home environment, and Memory Cafés can be another method to continue to promote and support this belief.

When I first looked at developing the role of a Memory Café within the care home environment, my first consideration was for it initially to be a resource for those living within the care home as well as their relatives. I also hoped that a Memory Café within a care home could broaden its audience by opening its doors to those living with dementia and their carers in the area. I envisaged the ultimate role of the Memory Café as being beneficial in some way to all those who attended, including relatives and carers. I did not want it to be seen as a place to drop off a loved one, but a way to enjoy activities and spend time together whilst enjoying the company of those with common interests and

common experiences. It was also my intention to provide a resource where information and relevant training could be provided when required to further support all those who attended, and a way of further enhancing community links.

I thought that by developing this opportunity, it could also be a way to promote the positive role of care homes within their localities and to be seen as a hub of support and guidance to all those living with dementia, whilst disproving some of the articles in the press that suggested that care homes are not always a good place to live. For many people living with dementia in the community the reality is that eventually a move into a care home is inevitable and therefore promoting those relationships and showing all the good work care homes actually do could make the eventual transition somewhat less stressful and provide reassurances to all those involved when that time came.

I was very mindful that exploring this overall specific remit of a Memory Café would involve careful consideration as I did not want to cause distress or impede on those who actually live within the care home. Ensuring there was adequate space to run such a resource was crucial whilst respecting that some people may choose not to attend and that these individuals should not be asked to change their routine to accommodate a Memory Café. That said, however, I do believe that care homes have a place in promoting community links and feel this was an excellent method to do so. After all, in 2012 the Prime Minister, in partnership with the Department of Health, published the *Prime Minister's Challenge on Dementia* (DOH 2012), part of which discusses the need for more dementia-friendly communities. Promoting the role of Memory Cafés particularly within care homes can, I believe, be one way of assisting in promoting this value.

Articles written around the roles of Memory Cafés have variations in their remit for such environments; however, I wanted to develop a fluid setting that had variation in what

it provided (as previously mentioned), thus ensuring it was reaching out to everyone who may choose to attend. The first avenue to explore was in relation to the environment (given that care homes vary in size and communal spaces available); this was an area that required careful consideration.

The care home where we initially looked at setting up a Memory Café had the benefit of a separate communal area and therefore could be utilised without impeding on the running of the home or those who lived there who may have chosen not to attend.

Given that we wanted to look at a Memory Café that was going to be accessed by both those living in the home and their relatives, as well as those within the community, the planning and discussion had to consider all of the following areas:

- identifying key people (and their specific roles) who worked in the home who were willing to be involved in facilitating a Memory Café
- the role of relatives and carers when in attendance
- adequate parking facilities
- access by public transportation whenever possible
- accessibility for people who required wheelchairs
- adequate toilet facilities that could also be accessed by people with disabilities
- safe and easily accessible fire escape facilities
- comfortable seating and tables
- provision of a first aid kit
- provision of a selection of drinks and snacks
- a selection of games that could be used for sessions, plus the ability to play music and show films

- developing a resource list and resource library of local and national support services, should those attending require these
- identifying possible professionals/organisations that would be willing to attend to facilitate discussions, should those attending choose to learn more about dementia or specific elements of it
- possibly looking at recruiting volunteers who may wish to assist
- consideration to monitoring the numbers that may wish to attend, and exploring registration of an interest among potential attendees, as over-attendance could be an area of concern
- marketing plans and advertising the Memory Café initially for those living in the care home and then more broadly in the local community.

Once we had explored all of the above, we invited those living at the home and their relatives to a meeting to explore with them what they would like to see from the Memory Café and to share the ideas we had initially come up with. At the meeting, it became apparent that those in attendance were very welcoming and supportive of the idea of a Memory Café being set up at the home. They felt this would be a great opportunity for promoting relationships, sharing experiences and spending fun and quality time together.

What also quickly became apparent was that many relatives in attendance felt they did not know much about their relatives' condition and were unaware of many aspects of best practice in dementia care, for example, that different types of dementia have different traits or how legislation like the Mental Capacity Act supported those living with a dementia. Many relatives also wanted to know how they could further support staff when they visited, in relation to

what to say to their loved one when their reality was different or why areas like life story work were so important.

Following the first meeting, it became clear that my initial thoughts on providing a fluid approach in the role of the Memory Café were accurate. It was clear that the remit of the Café would need to be dual-faceted: some sessions would need to be structured to deliver relevant information and guidance to those who felt they required it, whilst other sessions needed to be more informal and geared around fun and meaningful discussions together as a group.

The meeting also highlighted that all sessions, regardless of their content, would need clear and careful consideration about what information was delivered to those who attended. I am not implying here that those living with dementia should be excluded from potentially sensitive sessions, but that there needed to be recognition that some individuals may not wish to discuss or explore certain topics where others may be willing to; an individualised approach would need to be taken and, where necessary, best-interest decisions made. Also acknowledgement was given that some sessions, depending upon their remit, may not suit all individual needs and therefore individuals needed to be able to choose what sessions to attend or not according to their own beliefs, choices and preferences.

Frequency and times were also discussed and it was agreed by the group initially that the Memory Café should be run every second month, and also run at different times of the day including early evenings, so that it was accessible to all who may want to attend, and also that it would be no longer than two hours in duration.

Finally at this initial meeting I discussed my vision about eventually opening the Café up to members of the local community living with dementia and their carers.

The group felt that such a resource was greatly needed and would have been a great benefit to some of them as

individuals earlier on in their journey, and would have provided a great support network for them.

Concerns were voiced, however, about the numbers of people the Café may attract, so we did discuss a system whereby people would have to contact the home to confirm attendance prior to attending rather than just arriving, as this could have a major impact upon the size of the room and facilities available.

One area that I did not initially envisage any concerns with, however, was that of staff confidence in taking a lead in running such sessions. On discussing the role of the Memory Café with the staff group at the home, although they were all supportive of the idea and felt confident in running various meaningful activities, they felt that facilitating other aspects of the Café would be challenging as this was a completely new concept to them, and for some it took them out of their comfort zone.

Within our organisation, we do have a small dedicated dementia team that supports all of its care homes. However, I did not want the Memory Cafés to be purely run by us as a team but to work in partnership with care homes and support dedicated sessions where more specialist information was to be provided. Realistically, it would be extremely difficult for us to be at each session, particularly if we were going to look at rolling the idea out to more homes across the business. I also wanted to empower the homes to take the lead in running these Cafés as staff would have already built up trusting and empathic relationships with the residents and relatives they already supported. I also felt that those who attended would find this approach less stressful and that they were more likely to attend if there were familiar faces present.

Moving forward

At the time of writing this chapter, the home where we were looking at developing this initial concept has run its very first Memory Café session, which has been successful; both residents and relatives who attended found it beneficial and enjoyable and this resource will continue to be provided so we can ensure we are truly supporting and providing a holistic approach to care for both those who live in the care home and their relatives.

Another home within the organisation has developed a Memory Café, but this is run by a local support group and is open to both the community and residents alike. Though this is excellent, unfortunately not all homes have such groups available to them and therefore we wanted to look at other opportunities to ensure this resource was available to all.

With this vision in mind, as an organisation we are currently working on developing guidelines for all our care homes that provide dementia care for setting up a Memory Café. This will include areas for consideration that both management and staff will need take into account when looking at developing Memory Cafés, including examples of good practice. These will incorporate how to best run/facilitate such groups from their initial setting up, to advertising such a facility, to planning a structured yet flexible programme and also how to work alongside carers and relatives to ensure that it is an inclusive setting.

We are also exploring the introduction of some kind of evaluation format that can be completed periodically for all those who are attending to ensure that current and future needs can be considered, and to allow homes to continue to develop and discuss the contents of the Memory Café format to meet any change in need or expectation of the group who attend.

One way we are also considering to support the development and success of the Memory Cafés is to align the objectives of the Cafés to the seven domains of well-being introduced by Power (2014). Each of these domains could support sessions by ensuring that all those who attend acknowledge the domain, and would give the format some clear aims and objectives. Each of these domains would fit well and, as an example, could look something like this:

- *Identity*: All those who attend each session regardless of its contents are to be included, encouraged and supported in conversations that revolve around them as unique individuals.
- *Connectedness*: Those who facilitate and attend each session ensure they are known by everyone by way of initial informal introductions and sharing similarities, and promote meaningful experiences including joint interactions and discussions.
- *Security*: A safe non-judgemental environment is provided where everyone is respected for who they are and any anxieties are acknowledged and supported. If people have moments of uncertainty then this is recognised and supported, and reassurance provided.
- *Autonomy*: Independence, choice and respect are constantly provided and promoted and any involvement, regardless of what it is, is recognised.
- *Meaning*: All contributions are recognised, supported and valued even if they differ from our own.
- *Growth*: Different opportunities are provided that promote a sense of pride and achievement, along with provisions not only to support existing skills but also to learn new ones.
- *Joy*: Supporting fun and celebrating achievements and successes.

Summary

What is quite clear from the literature and from looking at the role of Memory Cafés is that they can be an excellent opportunity to provide further support to both those living with dementia and their relatives.

Additionally, they also an excellent resource for promoting relationships whilst providing meaningful engagement and activities, and also for identifying and delivering guidance and information to an audience that otherwise may not have access to such support.

Developing and delivering such a resource clearly requires careful thought, consideration and preparation, both initially and ongoing. I truly believe, however, that by supporting care homes to look at this approach we are one more step forward in ensuring that, regardless of where someone may be on their journey with dementia and regardless of where they may be residing, everyone has an opportunity to continue to learn and to live life to the fullest potential.

Suggestions and ideas for implementation

- Look at the suitability of the environment and when choosing a space ensure it does not impede on the residents' home.
- Discuss with those living at the home as well as their relatives the purpose of the Memory Café and what they would like such a resource to provide for them.
- Develop in-depth best-practice guidelines to provide ideas and suggestions for developing Memory Lane Cafés, incorporating all areas.
- Identify key staff who feel confident and supported in delivering such a resource.

- Look at what services, whether internal or external, can provide information and give support.
- Ensure there are adequate resources to promote meaningful activities.
- Regularly seek the views and opinions of those attending to ensure it is continuing to meet all needs.