

THE ALZHEIMER CAFÉ

A Guideline Manual for setting one up

(Original document entitled, 'Handleiding Alzheimer Café' by Bère Miesen and Marco Blom) ,

(Translated and adapted from the Dutch Alzheimer Society document by Gemma MM Jones with special thanks to Ray and Elspeth Moran, April, 2001)

1. How it all started

On September 15th, 1997, the first Alzheimer Café opened its doors. The long-brewing idea of Dr. Bère Miesen, Clinical Old Age psychologist at the specialist research centre for old age psychiatry, 'Mariënhaven', in Warmond, the Netherlands, had become a reality. After several months of preparation, together with the Alzheimer Association in northern 'Zuid-Holland', he succeeded in launching something, which is now being increasingly copied.

In his contacts with people with dementia and their families, Miesen had noticed that talking about the illness, even between partners or within a family was often taboo. He was not alone in noticing this. Knowing that making dementia discussable, and providing information about it and its consequences, is very important for the acceptance of the illness, Miesen 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. There would then be a place where people could share their experiences and sorrow.

Quotes from Bère Miesen

"Dementia is a complete catastrophe. Both the person with dementia and their family deserve to be well supported. The recognition and admission of mental suffering can make life liveable again".

From: De Telegraaf, September 1999

"In the outside world there is little recognition of the fact that both the person with dementia and those close to them are going through a grieving process."

From: VWS Bulletin, June 1999

What is understood by the word "Café"?

How could such a 'relaxed atmosphere' be better described than with the word 'café'?

Miesen's idea of an Alzheimer Café first became reality in a lecture room of Leiden University. About 20 people attended the first meeting. A month later there were 35, a month later the number had risen to 54, and after 3 months the lecture room contained 80 people. It was clear that the initiative met a real need.

People from the whole country started coming. It appeared that there was a great need for a place where persons with dementia and those involved with them, could talk calmly about the disease. People left the meetings feeling more resilient and also, importantly, with tips on how to deal with people with dementia. There was also interest from the national media. The fame of the "Alzheimer Café" also grew as a result of the seven, half hour, television broadcasts in the series "Living with dementia"- which were recorded by Teleac/NOT in the Alzheimer Café in Leiden.

Good Examples Will Be Followed

The enthusiasm grew: soon, an average more than a hundred people were visiting the Alzheimer Café. A new meeting place had been found at a hotel in Leiden. Amongst the regular visitors were several representatives of other branches of the Alzheimer Association. They also decided to start Alzheimer Cafés in their regions.

Alzheimer Cafés were thereafter established Delft and Utrecht. (Zwijndrecht and Groningen now also have cafés. Other districts have since started and still others begun planning and preparations.) The wide interest resulted in a meeting on 'How to Establish an Alzheimer Café', organised by the Dutch Alzheimer Society. People from more than 15 districts took part. Several specialist Nursing Homes and Care Centres are also keen to use this concept. This led to similar initiatives in Dordrecht and Den Bosch. (For an up to date overview of the places where Alzheimer Cafés are organised you can consult the website of Alzheimer Nederland, <http://www.alzheimer-ned.nl>)

Variations On A Theme

To avoid reinventing the wheel, many initiators have made contact with the original founders or have made orientation visits to one or more Alzheimer Cafés. Nevertheless people are also looking for ways to make the idea more applicable to regional needs: different starting times, different locations or even another name, because the term Café might be too restrictive. What remains important however is keeping to the original concept, which has turned out to be so successful.

This is one of the reasons for putting the existing experiences down on paper. Initiators can make a considered choice before starting a Café. They can benefit from the practical information in their preparations. Then they can devote their energies to running the meetings. If we think of all those having dementia, and their carers, we realise that the quality of support can never be high enough. That is the single most important thing.

In a brief outline such as this, it is difficult to fully describe the fundamental principles, theoretical starting points and underlying vision of an Alzheimer Café. For this you really should attend one of the first meetings (of the thematic presentations) of the Alzheimer Café, and be closely involved for a longer time.

We have been helped by several articles by Bère Miesen which started off the development of an overview of the Alzheimer Café phenomenon. The core of his vision can be found in the following passage from the introduction to his book "Leven met Dementie (Living with Dementia)".

Underlying Vision

"The Title 'Living with Dementia' can be explained in two ways. On the one hand, it indicates the bewilderment, which starts when it becomes clear that a catastrophe is about to descend on the lives of the persons with dementia and their family. 'How do I handle an illness that threatens my life irreversibly?' The illness, either your own, or that of someone close to you, suddenly gets full attention. On the other hand, the title indicates that the moment that persons with dementia and their families have more or less accepted that a catastrophe has occurred, they can ask a new question, 'How do I lead as normal a life as possible, despite the illness?' Now, it is no longer the illness, but someone's life that is the focus of attention. The illness has, despite everything, been faced up to. This is the more positive approach to a process, which is often a long one, with a distinct beginning and an end.

The Alzheimer Café, a meeting place for persons with dementia, family, carers and other interested parties, helps with this process: to get from one point to the other, with as much support as possible. In short, the Alzheimer Café can be regarded as an intervention with aspects of both education and support. All the advantages of having a 'low threshold' (all inclusive), informal advice and consultation and 'self-help group type contact' with 'companions in distress' are offered/combined in a relaxed atmosphere. The term 'companions in distress', also applies to persons with dementia themselves. However, we don't hide from the facts; dementia represents a major catastrophe in their lives of all involved; it usually occurs unexpectedly. The mental pain, the powerlessness, the dislocation and the distress of the person with dementia and those close to them, therefore, form the starting points for discussions. How each person copes with the pain is very different and individual. If someone visits the Alzheimer Café he/she admits his/her sorrow and faces up to it. It is clear, that only then can someone go further.

Dementia is a chronic brain disorder that leads to psychological trauma, and for some reopens 'old wounds'. That is to say that each person has to work through the reality that he/she is losing the control over his/her life. And for some, earlier feelings, which arose in a comparable situation of distress, can re-surface again. For example: emotional memories of powerlessness in situations of incest, POW camps, and violence in war, being deserted, or other traumatic experiences can be triggered again. The suffering is then doubled. The person with dementia is more aware of the illness and the situation than it would appear on the surface, even if he denies the illness and will not talk about it. The emotional situation of the family is also difficult, because it concerns an 'intangible loss'. Relatives face a complicated grieving process. The family starts to lose someone, while he or she remains 'visibly' with them for a long time.

It is important to gain certainty about the diagnosis as quickly as possible, and to lose as little time as possible in denying what is going on. This is the only way someone can take hold of their own life again, and to take the steps or decisions which are necessary. This allows a person to take control,

not only of his own life again, but also to restore mutual contacts, albeit not necessarily in the same way as previously.”

Some starting points

For the person with dementia. Some things may be going wrong, or difficult for you, but you are not crazy. Try to make the changes that you notice happening in yourself, clear to those around you. Have your complaints investigated; nothing is worse than anxiety and uncertainty.

For the family.

It is good to think of your own interests. Draw attention to the grieving process that you are going through. Seek emotional support from people you trust or your ‘fellow companions in adversity’. Sometimes that can be a professional or caregiver who is more distanced from your situation. The attention you give yourself can also benefit the person with dementia. Seek help early for the practical problems; get enough sleep.

For others close to the person with dementia and their family

If you suspect or know that someone has dementia, don’t be too quick to assume that the person ‘doesn’t want to speak about it’. Such a discussion might be easier than you think; often all you have to do is listen. Don’t forget to ask the partner or children what the illness means to them; their problems are often greater than one realizes at first sight.

For professional caregivers

*Try to make sure the diagnosis is established as soon as possible. Inform the person with dementia and the family about the meaning of the diagnosis. Inform them about how and where they can get help. Make sure the person with dementia and their spouse/partner get help, as a couple. That way they can try to share their pain, reduce their feelings of loneliness, and be stimulated to work through their grieving and feelings of loss. (From: *Mijn Lied, Mijn leed*, 2000, Kosmos, Utrecht, English version *Dementia in Close Up*, Routledge Tavistock, 2000 see reference list at the end)*

2. What is an Alzheimer Café?

By talking about the problems that having dementia brings, persons and families can better manage their own situations. Making the illness ‘discussable’ gives the person with dementia the feeling of being able to influence his situation. He/she also meets people in the same boat as him/herself. The family see that they are not the only ones with the feelings of powerlessness, dislocation and distress. With the coming of the Alzheimer Café, there is a place where they can go together and find out how others deal with the illness and its consequences. The visitors feel they belong and find recognition and acceptance. That in itself is unique. Furthermore, the Alzheimer Café brings together various aspects that the usual ‘information evenings’ lack. Although the meetings are partly therapeutic and have a strong educational side, a part of the evening is specifically for making informal contacts. In addition, its low threshold environment is unique. The range of people that visit a Café is great. Besides persons with dementia and relatives, friends, professional carers and students, other interested persons such as policy makers, journalists and representatives of the regional and national media sometimes attend.

Objectives

The Alzheimer Café has three main aims. First, information is provided about the medical and psycho-social aspects of dementia. Secondly, it emphasizes the importance about speaking openly about problems. Recognition and (social) acceptance are essential to this. Thirdly, the Café promotes the emancipation of persons with dementia and their families, by preventing their becoming isolated.

This all sounds rather therapeutic. However, as mentioned earlier, that is not to say that the course of an Alzheimer Café evening is as therapeutic as this sounds on paper. It is of prime importance that visitors can talk to each other informally and without interruption, exchanging experiences for example, or informally consulting carers and specialists. It is precisely this relaxed atmosphere, which breaks down the taboos and gives people the important feeling of belonging...the acceptance, acknowledgement and recognition mentioned earlier.

Changing Themes

The Alzheimer Café has a different theme at each meeting, but the timing of the evening follows a fixed structure. After the welcome with coffee/tea, comes a half hour of information. This could be via live interviews with persons with dementia and their family members, or videos of discussions with others who have visited the café. Often there is a lecture or a specialist is interviewed before a video is shown. It will be evident that this is dependent on what the organisers and/or the guests prefer. After a break those present can discuss the evening's theme or bring up other topics. Hereafter, the meeting closes with more informal socialising and refreshments.

At the original Café in Leiden the order of the topics is not fixed, but a certain 'thread' is followed. In each series topics generally follow themes related to the chronological course of the illness. Naturally, all sorts of topics can be brought into this. The general 'thread' of the themes can be seen hereafter, from the list of topics covered in the Teleac television series that was broadcast in 1999.

A What's the matter?

A neurologist explains what dementia is, how it is diagnosed, and emphasizes the differences between normal forgetfulness, depression and dementia and provides relevant examples.

B How does memory work and what happens in dementia?

A neuropsychologist explains about memory, how people remember and forget things, how 'memory testing' is done, and gives tips to help support memory functioning in the early stages.

C It's getting a bit much for me!

A researcher explains that as dementia progresses, feelings of powerlessness increase and communication becomes more difficult. This is tied up with the realization that the person with dementia has, that 'something is wrong', and their need to work through this emotionally. An overview of possible types of help is provided.

D Who can I turn to for help?

A Community Health nurse and/or Social Worker are interviewed to answer the questions: 'May I turn to others for help?', 'When?', 'Where?' and, 'How do I start to do that?'

E Admission to a Day Care/Residential Care Facility?

A psychologist is interviewed to speak about: When the person with dementia can no longer be cared for at home full time, how is the decision to admit the person into a day care/residential care facility made, and, what does this decision mean to all those involved?

F How do I go on now?

A Nursing Home chaplain and former carer are interviewed. The person with dementia has gone through the last phase of their illness. After death, how do those emotionally attached to the person with dementia work through their grief? How does one look back when everything is finished? How does one pick up the thread of one's life again?

There are also Alzheimer Cafés, for example, those in Delft and Utrecht, that change topics and consider regularly which topic is in the news. Of course it could also be that the public asks for a specific topic which could be followed up, also during the meetings. The following topics are amongst those that have been discussed:

- causes of dementia
- symptoms of dementia
- what dementia means: the first questions and uncertainty
- dementia at a young age
- living with dementia
- communication
- available help

Very often, after a theme has been discussed, there are many comments made, questions asked and personal reactions given. The interviewer leads this discussion with the visitors. Those attending

(including the professionals) are there as a sort of 'living example and resource' from which to draw further responses and concrete information.

Frequency and Starting Time

Meetings are held monthly, always on a fixed day, for example every first Monday in the month. The time and length of the meetings are also fixed. In general, gatherings are organised 10 times a year, avoiding the holiday seasons. The opening times of the existing Cafés vary somewhat. Some operate in the evenings, others during the day. Both have advantages.

Evening Cafés attract more people, because family members and professionals are home from work then. However, it can be that some people don't come because they don't want to go out in the evenings. This is especially so in winter. If you plan to hold your café in the afternoon, the reverse is the case. Working people, such as the children of the persons with dementia and the professionals often find it hard to get time off. Therefore, consider carefully who form your target group and adapt your opening hours accordingly.

Type of Location

The choice of location is important because the character of an Alzheimer Café is a low threshold one, appealing to as many persons as possible. Nevertheless, some districts have chosen to hold their meetings in a nursing home. The cost of accommodation and the desire of a nursing home to have a greater public profile can influence the choice of location. In Utrecht, the large café room of a Care Centre is used, in 'The Hague' the café is held in the City Hall. Whatever organisations want to work in setting up a café, it is extremely important that they work towards the same objectives. It is essential that person with dementia and family (especially if persons have only been recently diagnosed), feel comfortable visiting a Alzheimer Café. Since the meetings are generally directed at persons in the earlier stages of dementia, it is usually better not to automatically choose a nursing home as a location.

Any results???....

....there surely are. Although the expected attendance at the first meeting of a new Café must not be pitched too high, practice shows that the second meeting (generally through word of mouth publicity) attracts a bigger attendance. When someone has visited a Café once, he or she often comes back. Such a person we call 'a regular' (Core person). Families who come back together are called 'Core families'. Their presence is essential to help other newcomers feel supported. At subsequent meetings the number of 'regulars' grows and new participants join.

Some Quotes

'First I find it very informative and secondly it is good that you are not the only one with problems.'

'In short? Penetrating, emotionally gripping and very recognisable'

'Initially I did not want to admit that I had it. But here it is accepted and that has helped me'

In a survey by northern 'Zuid-Holland', findings showed that the Alzheimer Café formula was well liked. Exchanging information through informal conversations was much appreciated. Visitors thought that the aims of the Café were being achieved. Communication was good, everyone was involved and many people found the desired recognition and acceptance at such meetings.

Café Lay-Out and Ambiance

There are various ways to lay out a Café. The lay-out partly determines the Café's ambiance. For example, during the discussion time, you can let the leader of the discussion to wander amongst the audience with a microphone. This ensures people's involvement and contributes to the low threshold feeling. Other Cafés provide a podium on which the Chairman and his guest speakers sit. Questions are posed and answered directly from the podium. With this form of presentation the emphasis is more on the expertise of the speakers. Placing them on the podium does create a greater distance though. It is of course nice to give an Alzheimer Café a 'café-like' appearance to get the right atmosphere. Don't go to too much trouble though: tablecloths and candles on the tables add a nice touch.

Music

As you know music is important for the atmosphere. To create the right ambiance in the Café, light café type music works well. It is perhaps a good idea to organise live music if that is possible. For example, some cafés have found having that a pianist goes down well. Naturally this depends on the venue. Of course, you can bring in other forms of live music. Be careful that the musical content of the meeting does not come to predominate so that the aim of the Café is changed.

Information and Aftercare

Providing an 'Information Stand' is a good addition to a Café. Visitors can look at information material or even take it with them. If you have chosen the theme 'Dementia at a young age' it is a good idea to adapt the brochures and folders to this theme. It is guaranteed that some people will want to read the material through quietly at home. In order to offer a broader range of material you can for example make contact with the local library. It may have some useful books to place on your stand for people to look at.

After an evening at the Alzheimer Café people sometimes still have questions that could not be answered during the evening. It is important therefore that help is available. It is preferable if this can be through your own staff or volunteers (Core Professionals). Any professionals present can also fulfil this function. It is important for the visitors that they can question the professionals informally.

We have seen that is useful to have a 'local contact address list' available. People can also be directed to the local and national Alzheimer Helplines.

3. How is an Alzheimer Café Meeting run?

Although we have already described how Alzheimer Cafés work in general, in this next section we explain this in greater detail. What elements are important for a successful Alzheimer Café evening? What are the most important things to consider? We will look at several practical issues in the course of a programme. We will also discuss the role of the interviewer or discussion leader, who is the equivalent of the spider in the web at every meeting.

Programme Planning

The programme can be roughly divided into four fixed parts; the 'arrival and introduction', 'the presentation of a video or the talk in the form of an interview', 'the discussion' and 'the informal get-together' after the formal part of the meeting. Although you don't have to stick strictly to the times, practice shows that the discussion leader must ensure that the formal part of the meeting gets enough time. Arrival, the interval and the conclusion must not take up too much time. The official educational part of a Café, on average, lasts up to one hour. Arrival and departure and socialisation are in addition to this. Each of these can take up half an hour. This is shown in the next table:

0.00	Arrivals with coffee and tea
0.30	Start, with introduction, video and/or interview/s
1.00	Interval with music and drinks
1.30	Discussion
2.00	End formal meeting
2.30	Informal Session and Departure

Arrival/reception

An ordinary café fills up slowly. This is also true of an Alzheimer Café. The visitors like to have the time to find a seat and get something to drink. About half an hour is often allowed for this, after which the evening can begin in a relaxed way. Experience shows that especially the regulars (Core members) use this time to catch up with each other and make arrangements. Some people decide to travel to the meetings together. The organisers can be sure that some people will arrive as the talks start. If the Alzheimer Café has just started and perhaps the numbers attending are not very high, it is important to layout the room so that people don't sit too far apart. It is better to keep some chairs aside, which can be put out in the case of a higher turnout. It is important for the organisers personally to welcome newcomers, to put them at their ease if necessary. They can be accompanied to a table in the room, with regular/Core family members and professionals to prevent them sitting right at the back, or alone.

Introduction, video or interview

The formal part of the meeting begins with a welcome and introduction of the theme and speakers, the presentation/video and/or the interview/s. Half an hour is planned for this. The imparting of information on the theme is key. Usually, an expert is invited to give a lecture and be interviewed. This can be a monologue, a discussion between the lecturer and the interviewer/discussion leader (with or without a person with dementia or a relative), or, an interview with a family member and/or a person with dementia. A conversation or interview can for example take the form of a question and answer session. When choosing the expert it helps to know if he or she is an experienced speaker. A good presentation encourages people to ask questions.

Another way of opening the evening is to show a video. This could also be part of the lecture. The TV series 'Living with Dementia' is suitable for use in a Dutch cafés, because they were recorded in a café setting. It is also possible, to make a recording of an interview with someone with dementia and their carer in their home environment, and to show this during the meeting. This has been done at the café in Den Bosch. The person with dementia and her daughter were present at the café the evening it was shown. Of course, permission for this has to be obtained.

Whether it is a lecture, a video or an interview, it is important that the audience can recognise itself in the material that is presented. In the lecture this can be achieved through taking statements from those involved. In using a video, guests can be asked to look out for what they recognise or have experienced themselves. Practice shows that a combination of businesslike communication of information and the recognition of individuals has the best chance of making discussion effective.

The Interval

Contrary to what the name implies, 'the interval' is a very active part of the meeting for the organisers. They will be answering questions that persons do not want to ask in public, or, they join in at a table where people are talking, whether it is about the evening's theme or not. They can use this time to collect questions and points for discussion to bring up after the interval. It is important that they know what the people's concerns are.

The information stand is often visited during the interval. The staff manning the stand can expect all sorts of questions. People with specific questions, also often approach professionals who are regular visitors. It is important to have antennae for questions that go beyond the individual and that relate well to the theme of the meeting. Instead of answering the question immediately, the person asking it might also be encouraged to raise it in the general discussion.

Discussion

After the interval it is time for the discussion. The people in the room may react to what was presented before the break. This can range from questions for clarification, to a personal response lasting several minutes. For a good discussion it is important that the discussion leader keeps control. Ideally there are questions and answers, or, discussion between the visitors. Moreover, the limited time must be properly divided between all the people who want to contribute, including those who don't push themselves forward.

To keep the discussion 'on the rails' it is sometimes necessary to agree some rules with the audience. In this way everyone knows what is allowed and what is not. This makes asking questions and the discussion simpler. If someone repeatedly dominates with many questions, or always wants to ask their question first, or give their opinion on everything said; it will be appropriate to remind them politely that others also want to have a turn. Sometimes, other visitors will point this out. In this way the Alzheimer Café can also be like a real café.

Informal Socialisation and Departures

The rounding off of the discussion is also the end of the formal part of the meeting. Some of the visitors will leave almost at once. Experience shows that others will want to go on talking with each other while having a drink just to recover from all the information and listening to other people's stories; the café atmosphere again takes over. In a number of Alzheimer Cafés, there is dancing or singing afterwards. It is difficult to say exactly how long it takes for people to leave, but it is often about half an hour.

If they wish, the organisers of the Alzheimer Café can use the informal get-together to discuss subjects for future meetings with some of the visitors. In Delft, they have the custom to ask one of the

visitors beforehand, if they want to record their impressions of the café in a logbook. At the end of the meeting the visitor can fill in the logbook and, if necessary, discuss their impressions with an organiser. Other ways of evaluating the cafés have also been used. In Utrecht, people were asked their opinion via a questionnaire. In other places, candid responses to the organizers are recorded, dated and saved.

Discussion Leaders

The same interviewer/discussion leader usually conducts the meetings of an Alzheimer Café. In the city of Den Bosch, however, there are two presenters. This has worked well. In Utrecht there are two discussion leaders, who alternate with each other. Whichever form you choose it is of the greatest importance that the way the discussion is led, and the division of roles between two presenters, is relatively similar. A great difference in style could impede the open atmosphere and can be a barrier to building a good relationship between the public and the discussion leader(s).

The discussion leaders play a crucial role in the planning of the Café. They are responsible for the smooth running of the meeting and determine to a great extent, what the participants get out of it. Ensure therefore that you appoint a discussion leader who can be relied upon to do all this. So far we have identified two variants of the discussion leader's role, the 'expert' or the 'presenter'.

The 'expert-type' interviewer can answer questions from the audience or otherwise give his opinion in the discussion. It is important that he or she is practicing as a professional and knows the professional circuit. Sometimes he/she will know the visitors through his/her work. Normally this gives a trusting relationship and can increase the public's feeling of openness and security. A pitfall for the expert is that he or she answers all the questions and does not leave any space for the mutual exchange of experiences.

The 'presenter-type' interviewer ensures that everyone who wants to speak during the discussion gets the chance to do so. He leaves technical questions to be answered by the experts who are present. It is recommended in this case, to operate with a fixed team of experts present at the café. It is helpful if the presenter can discourage the experts from using jargon and create a good relationship with the audience. A good presenter makes use of his ignorance and independence.

The perfect discussion leader does not exist. However, it is possible to list certain qualities that the 'ideal' leader would possess. These are listed in the table below. The following qualities are important: knowledge of the different forms of dementia and of dealing with persons with dementia; experience with the problems of the partner and family; wide experience in leading group discussions; a relaxed manner of presentation, and a trustworthy personality.

Qualities of the Discussion Leader/Interviewer

- complete respect for the questions and the persons asking the questions
- the ability to perceive and react well to signals from the audience
- the ability to pass on and paraphrase questions from the audience
- to be able to hold a 'companion' type of relationship with the visitors
- to be able to encourage open conversation, also in a way that could also break through taboo subjects

Perhaps you will feel from this description that an experienced psychologist would be the ideal discussion leader. This is indeed a good option, but of course not a strict necessity, especially if you choose for use two leaders or an experienced presenter in combination with a team of experts.

Whatever your choice, it a good idea to realise in advance that it is a difficult job and that you should regularly review whether the discussion leader is carrying out his/her role well and with enthusiasm. The leader must react well to signals from the audience. People with annoying questions, tears and laughter, moving stories, and insoluble problems can all be present at a café.

4. How to set up an Alzheimer Café

If you decide to organise an Alzheimer Café in your area, you would be wise to form a working party/group. A working party usually comprises 3 or 4 people from the organising institution(s). It is easiest to divide the tasks amongst the members of the working party and to agree who will stand in for whom, in cases of absence.

Once the Café is in existence, the working party need not be disbanded. Members can help with decorating the room, looking after refreshments, and manning the information stand. And of course, they can take a role in setting the themes and the programme of the Café.

There can be a considerable time between the decision to start an Alzheimer Café and the first meeting. The average preparation time is between 3 and 6 months. The opening of an Alzheimer Café often takes place on World Alzheimer Day, namely on or around 21st September.

Manual

To monitor the progress of the activities you should consider preparing a manual. A small job list can be drawn up for each area of work that comes up during the preparations. The list shows who will do what and when. At the meetings of the working party the manual with the job lists can be regularly brought up to date.

Summary of Manual

- setting up consultation group
- choice of location
- choice of discussion leader
- setting date and time
- themes and introductions
- publicity plan
- regular evaluation
- budget

Working with a manual is, in general, more practical than just going ahead and relying on everyone's memory. In the latter case things are more easily forgotten. A manual is also convenient for new volunteers. You can begin drawing up a manual during preparations for the first meeting. There is no 'standard type' of manual because there are too many regional differences. However certain matters can be described.

Consultation Group

Most of the Cafés start up with the aid of a 'consultation group', sometimes known as a 'steering group'. The consultation group is a constructive, critical group of people who together act as a 'think tank' and 'advice group' for the working party. In practice the group meets every 2 to 3 months. In the beginning, this can be more often.

The members come mostly from the regional care sector, not just from one town or institution. This is the most practical arrangement because it provides broad support. The members can also play an important role in telling persons with dementia and families about the Alzheimer Café. They are the ideal group to tell others about the Café. Ensure therefore that professional caregivers from all sectors are represented.

Choice of location

For an Alzheimer Café the location and ambiance are very important. Therefore, choose a good psychological and physical location. By a 'psychologically good location', we mean that the guests feel at home in the Café. Take the example we referred to earlier, a nursing home might be a perfect place to hold a Café, except that it can be threatening to persons who have just been diagnosed. Sometimes they don't want to be confronted in any way with persons in the later stages of the disease.

A physically good location has characteristics such as safety, ease of access, access for disabled, sufficient parking and so on. Is the entrance in a dark alley, where people will feel unsafe? Is there a good transport connection from the station? Apart from the building, the room must meet certain requirements. The most important question is whether the room is right to create a convivial atmosphere.

Apart from the practical requirements that the room must meet, (see table below) certain facilities are essential. These can vary from meeting to meeting. For the discussion you can best use a mobile microphone, so that all participants are audible. A good sound installation will be required and

perhaps a video screen. Think carefully what you will use and what equipment will be needed. For convenience make a checklist. And what are your rules on smoking?

Practical Requirements

- Is the room too big? Can it be subdivided?
- Can tables and chairs be set out sensibly?
- Can people see properly? Can the lights be operated independently?
- Can everyone be heard? Is there noise from outside?

Refreshments

There is no question about this: refreshments must be available. It is best to arrange this with the manager of the location. Which drinks are always provided? Only coffee and tea, or also soft and alcoholic drinks? Are you going to provide the drinks yourself or use the on-site catering? This affects the costs. Are you going to let the visitors pay for any/all of the refreshments, or, only for alcoholic drinks? Is the first coffee free? Will there be nibbles provided for table?

Planning the Meetings

In the preparation phase, it is wise to agree the topics for the first three or four meetings. Do this with the consultation group. The speakers can be invited as early as possible, and any videos can be organised. Usually the speakers are prepared to appear, as a favour, or, for expenses only. Confirm everything in writing, and provide practical information such as the route to the Alzheimer Café and where to park.

Sometimes the opening of an Alzheimer Café is enhanced by a regional symposium or an information campaign for the wider public. Ensure that the date, time and location are the same as the regular meetings. It is then more likely that your guests will be able to come at this time in the future and it will avoid unnecessary confusion.

Whether it is the first meeting or the hundredth, it is wise to evaluate every meeting. What went well? What went wrong? What could/must be improved? Show this evaluation regularly to the consultation group. Together you can ensure a good programme of meetings. Put the evaluation in writing. You or others may benefit from this in future.

Contacts with the Press

You will, of course, want the Café to become known, so that people come to it. Therefore it is wise to inform the local press about your plans at an early stage. Ask all the media for lists of copy deadlines. It can also be helpful to ring a newspaper and invite the editors to the first meetings of your Café.

Once you have made contact with the Press, they'll be more receptive when you inform them about another meeting. This can be important for free publicity. You can announce the meetings in regional and local papers, free newspapers, on cable TV, or via regional television. You can also put up posters at the chemists, health centres, supermarkets and mobile shops.

Getting known in Care Organisations

Care organisations, especially the local Alzheimer Society groups, are important for referring to people to your Alzheimer Café. A number may be represented on the consultation group. Anyway, tell them about your existence. Apart from all mentioned above, also contact GP's, hospitals, social workers, church organisations and women's groups etc. etc.

You can send these a press notice or brochures, offer to talk to them or send them an article for their house magazine. If you know people personally, invite them directly to visit the Alzheimer Café.

Acquiring Visitors

Through the publicity in the press and the contacts with the institutions, you increase the potential number of visitors. People know of the existence of the Alzheimer Café. But of course that does not mean that they will also come. Some people come straightaway; others need coaxing.

First time visitors often have a watchful approach. Sometimes their partner or carer comes alone to have a first look to taste the atmosphere, see whether it is of any interest for them and whether the person with dementia will feel at ease. In this context every meeting of an Alzheimer Café must prove itself anew. Staff at the Café give newcomers a special welcome and explain to them what happens.

They can explain that visitors are free to come and go. Of course it is important to ask them afterwards what they thought of the meeting, and to invite them for the next time.

Word of Mouth Publicity

Don't expect 80 visitors for the first meeting. Assume that not everyone knows about the existence of the Alzheimer Café. Publicity needs time to take effect. Knowledge of the Café will grow slowly. Keep contact with persons who have the potential to refer the café to others and try to get regular publicity. Once the Alzheimer Café is on the go, numbers will rise. Many persons with dementia and carers who come to a meeting for the first time, do so on the recommendation of regulars or other frequent visitors of the Alzheimer Café. Professionals who are enthusiastic also encourage people to take part. The best advertisement therefore, is happy customers. You can make use of this by including the experiences of visitors in the brochure, press release or flyer. And if you can use your local radio station, don't hesitate to invite 'a regular attendee' to tell his story. This usually generates plenty of response from the listeners. The internet could be another medium to become known.

5. Alzheimer Café an Open Book?

In this guideline manual a number of frequently raised topics have been covered, which may be useful to those interested in starting an Alzheimer Café. Much more could be said, some of it anecdotal, some very practical. To have this on record, we regularly gather all sorts of ideas, cries from the heart and pitfalls. We make this information available to interested parties. Hopefully this generates more reactions. In this way we continue to discuss and develop the concept. The next section illustrates some of the comments received to date:

Having Persons with dementia present in the Café

It is not always easy to attract persons with dementia to the Café initially. We found it difficult to reach them. We went to the neurologist at the Memory Clinic and to several staff at a Day Centre and asked for their co-operation. They are in close regular contact with persons in the earlier stages. We should have thought of going to these contacts earlier.

Consultation with Visitors

If visitors like the café, they come back more often. In that way you automatically get a 'group of regulars'. It is nice if these visitors themselves suggest some themes. We think that through this consultation the visitors come to view the Café as their 'own'.

Proposals for Discussion

We have had good experiences with using proposals to get a discussion going. It does add an element of control to what is being discussed. You should prepare it well with the presenter. You have to know what he/she is going to say before the interval.

Keep the Music Volume Down

You must have been somewhere where the music was so loud that you could not hear yourself speak. It is also very irritating in an Alzheimer Café if the music is so loud that people find it hard to hear each other. For people with a hearing aid it is a problem anyway. Music is fine, but keep it in the background so it does not obstruct conversation.

Attracting People from the Whole Region

People ask us regularly if we will set up an Alzheimer Café in other places in the region. This happens, despite the fact that we have indicated that the one Café has a regional role. How do we deal with this? The existing organisation already requires lots of energy and resources.

Persons with Dementia.....

are at the centre of the Alzheimer Café. We have to try to remember this constantly and consistently. It is our aim to include persons with dementia in every way possible, in addition to them enjoying the time spent at the café. If they have special opinions, skills or talents, plan on using them; for example, exhibiting someone's art work or letting them playing the piano at a meeting. Try to be conscious of valuing them. The challenge lies in always remaining conscious of this.

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