



*Making dementia a priority:
changing perceptions, practice and policy.*

**Information about the involvement of
the EWGPWD in 2017 in the
Joint Action "Act on Dementia"**

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1. About the European Working Group of People with dementia (EWGPWD)

The EWGPWD was launched by Alzheimer Europe and its member associations in 2012. The group is composed entirely of people with dementia who are nominated by their national Alzheimer associations. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. The group meets face to face 3-4 times a year in Brussels.

The 2016-2018 EWGPWD Board:

- Helen Rochford Brennan (Ireland), Chairperson
- Alv Orheim (Norway), Vice-Chairperson
- Chris Roberts (UK - England, N. Ireland, Wales), Vice-Chairperson

The members:

- Idalina Aguiar (Portugal)
- Nina Balackova (Czech Republic)
- Karin Gustafsson (Sweden)
- Amela Hajric (Bosnia and Herzegovina)
- Carol Hargreaves (UK - Scotland)
- Helga Rohra (Germany)
- Petri Lampinen (Finland)
- Tomaž Gržinič (Slovenia)

Further information about the members of the group, is available at <http://www.alzheimer-europe.org/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia/Current-Members>.

2. Involvement of the EWGPWD in the JOINT ACTION “Act on Dementia”

Throughout 2017, during the meetings of the group, AE staff has provided relevant information to the members of the EWGPWD about the Joint Action work packages (WPs)’s activities and meetings. The EWGPWD has had the opportunity to be more closely involved with the work of the following WPs: “Dementia-Friendly Communities”, “Diagnosis and post-diagnosis support” and “Residential care”.

2.1 WP “Dementia-friendly communities”

A half-day face-to-face consultation was held in Brussels in December 2016 on the topic of dementia-friendly communities. All members of the EWGPWD received information about the WP activities and the aims of the consultation prior to the consultation (please see Appendix 1 for further details).

The consultation was facilitated by Imogen Blood and Steve Milton with support from AE staff. The feedback provided by the EWGPWD was included in the report produced by the WP. The members of the EWGPWD and AE staff provided feedback to the report in February 2017. A summary of the main topics discussed during the meeting is included in page 6.

2.2 WP “Diagnosis and post-diagnosis support” and “Residential care”

In collaboration with AE staff, leaders of these two WPs developed a number of questions of interest to the work developed within these WPs. These questions were the basis for the discussions during a face-to-face meeting of the EWGPWD in December 2017. Ten people with dementia and their supporters took part in the discussions.

Relevant information and the questions to be addressed in the meeting were sent in advance to all members of the group and their supporters (please see Appendix 2 for details).

The questions on timely diagnosis mainly referred to the meaning of the term, its main challenges and benefits, and how GPs could encourage timely diagnosis and address stigma. The questions for the WP on residential care were related to four

topics: person centred care, palliative care, BPSD and antipsychotic medication. The WP leaders wanted to know about their experiences with or views on each of the four topics, how to address them in residential care facilities and feedback on the recommendations that they had developed for these four topics. For the questions and feedback for the WP on residential care the group was split in two subgroups. Each of the subgroups addressed two of the topics.

AE staff facilitated the discussions and drafted a report containing the feedback from the group. A draft of the report was circulated to the members of the EWGPWD and their comments and suggestions included in the document (report on diagnosis p.9, report on residential care p.14).

3. Dementia-friendly communities (DFC): Feedback provided by members of the EWGPWD and their supporters

Awareness, education and changing attitudes to and understandings of dementia

- As a (name of country) citizen with a European mind, it is a matter of mentality, people should know more about dementia and why do they need to be friendly with people with dementia, it is about teaching people what dementia is and that we need a different approach than other disabilities.
- People do not understand what it is like to live with dementia, it is not only about memory and forgetting things. Also people with dementia themselves should also receive more information about living “well” with dementia.
- It is about understanding and openness.
- To be open minded, for people to be prepared to listen to my story, not just to read from books, we are also experts.
- It is a “hidden illness”, we look normal and it is hard even for family to acknowledge that we have dementia.
- The education and awareness should start with the doctors, tell them that a person with dementia still has many abilities after diagnosis.
- There should be more advocacy work. There are too many myths, and people in the media talking about dementia who have no clue about dementia. People living with the condition should appear more in TV and talk and people will listen.
- If we educate people, and use our disability rights, the world would be a better place to live, as people will understand dementia. To be integrated with a hidden illness is difficult, we need to stand up and tell them.
- I don’t want people in the community to feel sorry for me. Just to support me, to stay with me. I do a lot of media work and that helps, so others can see what is like to live with dementia. They say to my husband, (name of person) looks great. And I think ... what did I look like before?
- Once people in the community are educated people with dementia will be supported, once people know, they will help.
- In (name of country) there is a program run by the Alzheimer society, we are training people working in the shops to be more observant and assist the person if necessary. The municipality needs to sign to be part of this

programme, if they want to be part of the movement. We don't know about the long-term effect but it's a way to start.

Contributing factors /aspects to be considered / facilitators

- A DFC should be built around us. It is about getting people with dementia together and talking to each other, ask them what they want to do.
- It is about a place where I can go and just sit and chat about living with dementia.
- A key word is safety, I feel safe in such environment, for example if I travel alone that I feel safe on the bus. Thanks to my wife I am fighting the uncertainty, otherwise it would not be possible.
- It is about the "community spirit". Solidarity. In small rural communities people help each other no matter what, neighbours take care of each other and are supportive.
- For me it means inclusion and living autonomously.
- Dementia is a small part of my life. I can contribute in other ways to my community. My life is not just around dementia, people need to stay involved with things they were involved before dementia. The community should see me speaking about things that are important for the community and are not just related to dementia.
- People need to understand I am still (name) but I have now an illness that makes my life different.
- In order to get help form the community, I need to be open about the fact that I have dementia, we need to be open minded, educate others, it goes in circles. All people in shop, bank etc in my community know I have dementia – they ask to me "do you need some help today?" I if I need help I can decide.
- Peer support is key, to be part of the Alzheimer society, of working groups. Dementia is not the first thing I think of in the morning – my life is more than dementia.

Challenges related to DFC

- In some countries and in remote areas there is no information about DFC.
- I think the term should be “dementia-supportive community”, if you get it right for dementia you get it right also for other people. Put the spirit that will help everyone. Educating is key.
- I have questions around the term DFC. I am no different. I want to be part, to be included, I don’t want people feel I am different from the person I was.
- I honestly believe that things should be “disability friendly”, dementia should be part of the greatest umbrella. I am no more special than any other person in the community with any other disability.
- Often the DFC are not about us, they don’t engage with people with dementia.
- The DFC concept puts us in a little box which makes dementia worst, in the box stigma is worst. We should be part of the community.
- Some people with dementia may not want to leave the house, a DFC should also consider people who are in their houses and don’t leave the house and are not engaged.
- In (name of country) it is difficult and most people don’t say they have dementia. We were asked to go to TV, six other people and I. We all agreed but, at the end, most families did not want to do it.
- There should be national guidelines in each country. In many cases what is being done so far is tokenism – people with dementia are not involved. DFC has introduced too much bureaucracy.

4. Timely diagnosis of dementia: Feedback provided by members of the EWGPWD and their supporters

Members of the EWGPWD agreed that a diagnosis of dementia is a life-changing event, it changes the lives of people with the condition and also of their families and even affects their friends. However, the group felt that many people, especially when diagnosed early, can still live a good life after diagnosis. Particular emphasis was placed on keeping a positive attitude, staying social, cherishing the present and carrying on with your life.

Diagnosis does not have to mean that your whole world falls apart and that your life ends. (...) My friendships are still strong and my quality of life is good, I did not give up any sports or hobbies. The "present" has become more precious as I don't know what is ahead of me.

The time when the individual first experiences symptoms and seeks help was described as very difficult for the person and his/her family. Also, they referred to the many different emotional responses people may experience, often it can come as a shock, whereas others may feel it is a relief for the person and the family to eventually have an explanation for the symptoms.

Receiving the diagnosis ... It was a shock, a shock.

It was a confusing time, knowing that something is wrong. And it was a huge relief to get a diagnosis. (...) It was also good for family members as it was the end of going to hospitals, seeing specialists and different doctors about a hundred times. It changed our lives, because now we know the diagnosis, having dementia doesn't mean you are "mad" or going to die.

The group also highlighted some other challenges linked to the time of first seeking help from the doctor. The most important challenge was "not being believed" by the doctor. Other relevant ones included the doctor refusing to diagnose, getting a wrong diagnosis and being prescribed medication that is not suited to the person.

It can be horrific, as you know there is something else but your GP doesn't believe you.

Not being believed, it being mistaken by something else, but the GP does have to go through his protocol to rule out other things, also one of the big

barriers are the GPs refusing to diagnosis is their own stigma and misconceptions.

Often, first symptoms are confused with depression or burn out.

At the beginning he was prescribed medication for depression, sleeping pills, medicines that were not suitable for him and.

The group also discussed about to the meaning of "timely", and felt that the term can have different meanings to different people, but also, it can have different meanings within one family. The diagnostic process should start as soon as symptoms present and are noticeable either to the person with dementia or in some cases, a family member.

It is difficult to know when is the best time to have a diagnosis, it depends in every person (...) I would say the earlier the better.

Timely also means a correct diagnosis, a diagnosis when I start to have symptoms, that maybe I didn't notice but my family do.

The role of the general practitioner (GP) in the diagnosis of dementia was also discussed. The group acknowledged that, in some countries, the person needs to be referred by the GP to the specialist, whereas in other countries the GP may be able to establish a diagnosis. Some mentioned the GPs should have a key role in identifying symptoms and could even trigger the process of diagnosis, others felt this responsibility lays mainly with the person and/or his/her family. Raising awareness of dementia among the general public, was another factor that could help to recognise symptoms of dementia and act promptly.

To put it very bluntly, as soon as possible. As soon as possible when the GP recognises any changes or in my case, my wife recognised the symptoms and made comments.

A GP can't diagnose, if we don't go to the GP and say there is a problem, so that means we need to also be proactive.

I think that it is important to provide information about dementia to lay people, for the general public. So, they can realize that something is strange with their loved ones.

The meaning of "timely" may also need to be considered together with other factors, most importantly waiting lists, lack of specialists in the country and other accessibility issues. For many people the diagnostic process can be lengthy and frustrating.

When we present to the primary care physician or GP with issues ... with the problems that started to come up, that you don't know what it is, you don't want to be waiting 20 months and some people may be even years down the line.

In (name of place) there are only four neurologists and we have to go to mainland, to have a second opinion. So accessibility and having to travel long distances to see a GP can be a problem for some people.

In (name of country) an important challenge is the lack of specialists (neurologists etc.). Also, the GP has only seven minutes for seeing the person, but the specialists have more time to engage. There is also a lot of waiting time, it can take years to see the specialist, and in this time your symptoms will progress.

In addition to this, a member of the group referred to people with more complex situations where diagnosis can be more challenging, as for example, in her case, as she has a mental health problem which made her diagnosis more difficult.

My diagnosis came about two years late because I am bipolar, this can make it more challenging, the GP felt that symptoms were linked to this, but I knew it wasn't. Eventually, my psychiatrist realised it wasn't.

In terms of the many benefits of a timely diagnosis the group emphasised social inclusion. Some members of the group explained, the diagnosis had also had concrete positive consequences, for example the opportunity to contribute to or write a book, advocate for dementia, speak at conferences or provide training as an expert by experience. These are positive experiences their diagnosis had brought about. From the point of view of carers timely diagnosis meant that *"the carer can manage the condition in a much better way to prevent a lot of the problems that we come with not having the diagnosis, the difficulties everything that goes with it"*.

The group discussed at length about the importance of providing appropriate information and support to the person and family at the time of diagnosis. This information and support should empower the person and help him/her to live well. If the information is provided in a supportive and positive way this may help the person to make decisions and feel in control of his/her life. Taking into account the complexity of the condition, the diagnostic process, including the disclosure of diagnosis and provision of information and support, should be led by an interdisciplinary team. Unfortunately, overall, their own personal experiences had not been very positive in this regard.

A diagnosis is only as good as the information that you are given and the support you are provided. The majority of diagnosis is very negative, it needs to be more positive, they need to tell us what we can still do, not to just talk about everything we can't do anymore, give us more support, and make us realise we can live with dementia.

We also had a very negative experience, "you have Alzheimer's" and this was it, nothing else.

This would have a "real" impact on my life, if I had been told from the time of diagnosis, provided the right information ... it could even save some money to the public system or to the insurance, if you have the right "guidance" from your doctor.

This should be done by a team, an interdisciplinary team, not just one single doctor.

On the other hand, GPs may not want to provide a diagnosis to protect the person's rights and autonomy. This may be particularly important in countries where the medical model of understanding dementia prevails.

For my mum it was far too late when it (diagnosis) came, we knew there was something wrong and the GP knew, they gave her antidepressants for a number of years. I think the GP knew what she was doing, because when she received the diagnosis her rights were taken from her, immediately. She didn't get a chance to do anything, her bank account was stopped by the bank manager and mum had no rights.

Combating stigma and raising awareness of dementia were highlighted as particularly important aspects linked to the diagnostic process.

Because of the ignorance around the diagnosis people think once you are diagnosed ... they don't understand the difference between Alzheimer's and vascular dementia or other types of dementia. Everything is like "the person is gone" they don't understand they can engage anymore, so it is awareness building.

The main message should be: "get dementia away from stigma". Dementia is something that is quite normal to some people at young age and to many people at older age, so why to make a big issue? It is just part of normal life. We should tell people that you have dementia. We should reduce stigma ... let people know at the European Parliament that this is just a normal part of life.

In addition to providing appropriate information and support, combating stigma and raising awareness, the group felt that dementia training and education for GPs were of utmost importance. Such training should be done in collaboration with people with dementia themselves. People with dementia should be involved in developing and providing this training, as they felt listening to the experiences of living with dementia from the perspective of the person could help to change attitudes and spread good practice.

They (GPs) can read all books they like, but until someone like Chris, Alv, Helga ... stands up in front of them and helps to deliver the training and by the end of it says, ah and by the way, I have dementia, that's what would change them.

I think what is needed is to have more education or training on dementia in the University, for the students. This should be compulsory.

Finally, the group referred to the importance of the work carried out by working groups of people living with dementia themselves and also of the Alzheimer societies which make this work possible.

5. Residential care: Feedback provided by members of the EWGPWD and their supporters

Four different topics relevant to residential care were discussed by the group: person centred care, palliative care, behavioural and psychological symptoms of dementia (BPSD) and use of antipsychotics.

The group was split in two subgroups according to their own preferences on the topics. Each group was composed of a mixture of people with dementia and supporters and each had around 10 participant in total. Each group addressed two topics and their associated recommendations (i.e. group 1: person-centred care and palliative care; and group 2: behavioural and psychological symptoms of dementia, use of antipsychotics).

This report has been drafted by AE staff based on the discussions in the meeting. The report was circulated to the members of the EWGPWD and their supporters and their feedback included in the report. The text in italics represents direct quotes from the discussions in the meeting.

5.1 Person centred care

Person centred care (PCC) is an extremely important topic for people with dementia and their families. One of the main discussions was around staff providing care in care homes. It was felt that, above anything else, at the point of hiring staff, it should be ensured that the person has the "correct skills" and is willing to embrace the values of PCC. These skills / attitudes were perceived as the basis for implementing care which is person centred.

It is also when they are recruiting staff, if they haven't got the correct skills, no training in the world is going to ...

It is the attitude what makes the difference.

I agree, the attitude of staff and validation is very important, staff needs to understand and respect the key values of person centred care, this is the most important aspect and then the more technical aspects of PCC.

Training, monitoring and the provision of ongoing support to staff was another relevant aspect highlighted in the discussions.

The training brings everything, is the atmosphere of inclusion, respect, validation.

Continuing evaluation and monitoring, that means it is a continuous process for the staff ... that they are provided with the support they need. This is important too.

Some other aspects highlighted were staff shortages and turnover in care homes which could have a great impact on the care provision, and it was discussed that staff working in care homes are often not sufficiently valued. This makes it difficult for staff to engage with residents and provide PCC.

It would be different if in care homes the job was more valued and they were appreciated and paid correctly, is it there enough staff?

In care homes is all about staff in short-term contracts.

The team is very important. The continuity of the team.

Some staff who are engaged, they leave the agency because they are so badly payed. Two of them, they went to work into a nursing home, one of them did the night, the other the days. And she actually just broke down, she couldn't do it anymore, she is out sick at the moment, because of the conditions and she was heartbroken.

There are no relationships with the residents, almost every day there is a different person working in the care home.

Relationships are central to the provision of care. Relationships between staff and the person with dementia, and also between staff and the family, should be improved. This could, in turn, facilitate a greater involvement of the person and/or family. Key aspect of this relationship include validation, autonomy, respect and dignity.

It is also about decision making, that means that the person can decide on her own, what she wants. Validation, respect and dignity are all very important.

In (name of country) the family can only visit for a limited period of time, the person with dementia needs to be more involved. I was allowed to visit my mum only 1 hour, at that particular time of the day. And each day she was waiting for this time. It is about the relationship with the family, it should be improved, this way we could be more involved.

The diversity of cultural and religious backgrounds of both, people living or working in the care home, is something relatively new and has to be taken into account. It was summarised as the need to provide “diversity-sensitive care” which recognises the cultural beliefs, attitudes and health practices of diverse populations living and/or working in the care home. This knowledge should be applied in the daily practices.

There are also cultural differences, different confessions, sometimes to consider. From the people living there, also the staff.

At the end of life, for the Muslim women is a very different process than it is for ..., they have their rituals ... so that mustn't be forgotten, the diversity of the culture and religion, the different rights if you like or actual needs at the end of life to ensure that religion is considered.

This was also linked to the need of staff to know well the person including his/her biography and understanding and respecting differences. Also, some other cultural and practical aspects in the organisation of the care, including for example that for a woman it may not be acceptable to be cared for by a male care assistant. Care and gender were highlighted as particularly important, especially in relation to the more intimate aspects of care (e.g. showering).

What it is important is to know the biography of each person, who lives here... one may be catholic another Muslim, another may be gay.

And that's PCC, it is about the practicalities of having female assistant to shower a female ... take into account the gender and background ... everything.

Another central aspect of PCC was linked to the physical environment (both indoors and outdoors) which should be homely and accessible.

To me, the point about to evaluate the physical environment is also very important, particularly to change an institution-like environment into a more home like, because then you can recognise, if it is an institution-like environment you have no idea of where you are, it is just confusing. There is nothing homely about it.

For my mum, her room would be very important, this is her private space and she would not feel comfortable if she had to share the room with people she doesn't know.

And the other thing about care homes is that once someone gets in there, you never see the light of day again, you are never brought out, just to go out. Terrible. I think every care home should have an outdoor space, should have a garden ... a sensory garden.

A major topic discussed by the group was the provision of activities and stimulation to people with dementia living in care homes. They had very strong views about what should (or should not) be considered as an "activity", for instance just watching TV should not be considered an activity. The idea of people in care homes just sitting all day and being "locked up" was very recurrent, and it was suggested residents should be offered opportunities for being involved in meaningful work outside of the care home.

They are just sitting all day in a chair and is so sad.

And the activities and stimulation they (care homes) get away with it, they do nothing, just turning on TV, and somebody may come in once in a blue moon.

In the country areas, we were thinking why can't they go out and get some physical activities instead of being locked up. They should have an outdoor area where people could move turf or logs about so they feel like they are still part of society and can have some physical activity that they were used to. In our nursing home, there are two guys, and one has died. All they do all day is go around stir crazy. In their mid-50s they were working outside all their lives and now they are locked into one room and go around touching the walls. That's human rights, that's like their human rights are being denied.

However, whilst activities and stimulation are important, it was highlighted that the focus should be on facilitating that residents with dementia could be involved in and be part of the day to day of the facility, not just in doing activities. This provides the person with a sense of continuity and value. It was felt that just "offering activities" was not enough.

There should be smaller units where people with dementia can help out with setting the table, clearing the dishes, peeling the potatoes, whatever.

With the "real" activities that we all do at home. Sometimes you don't need a "toolbox" with activities, you have the kitchen, get the people involved, and that's a meaningful activity to be involved in the day to day of running the care home, to peel the potatoes.

5.2 End-of-life care

The group agreed that palliative care and end-of-life care are relevant to dementia. There was a preference for the term palliative care (as opposed to end of life). The concepts are similar but not the same. End-of-life care refers only to the care of people who are nearing end of life. Palliative care, on the other hand, involves care across the continuum of the person's journey with the condition, including the end of life. This term was associated for years just to other conditions such as cancer, but people with dementia should also benefit from this type of care. Awareness and information, involvement of the person with dementia, and training for staff are all key elements for the improvement of this type of care in care homes.

Palliative care should be offered to people with dementia from the time of diagnosis. The ideas of "communication" and "opening up discussions" were highlighted as particularly relevant.

I agree that we should be offered palliative care at the time of diagnosis, but also not too forget that we are all different and should be treated different.

Also to have the family involved. We had this conversation with all the family and she decided what she wanted. It is really important to have this

dialogue among the family to know what the person wants, to have this involvement.

The question "What matters to you?" is essential and should form the basis of the discussions with the person with dementia. This question can reveal what matters to the person and can help to make better decisions at critical times.

What matters to you? This is the key, this is what should be asked, and it has to be asked not when the person is sent to hospital, but at the beginning, not when is about to die. So that the person can die in the care home, if that what he wants, and not to be sent to the hospital and be taken back within hours.

Discussions were also around the need to have these discussions early on and to involve the person with dementia, otherwise, at more advanced stages it may not be as meaningful or even not possible at all.

My experience of people with dementia going into care home is usually long after the end of life discussions should have gone ahead. It needs to happen before they go into care because once they go into care is too late.

They should to think ahead, it needs to be done early on. Otherwise you need to accept what other people are going to decide for you. If we can't raise the dialogue earlier, then ...

In the case of dementia, you need that time in advance.

Another relevant discussion was about "conflicts". These conflicts could involve different members of the family, the person and even the treating doctor or staff members. These conflicts also demonstrate the complexities of the emotions and circumstances surrounding end of life.

Sometimes families may press the doctor, if a person has a pneumonia and is in very poor help, he may be inclined not to treat, but the family may want to show that they care about the person, and press him to do something, to treat the person who may not have wanted the treatment.

There are also conflicts within the family, because one sibling may want this and the other another thing, leave him to die in peace. So you are in a conflict.

Preferences and wishes, regarding medical treatment at the end of life, have to be clearly written and recorded, and all staff should know about them. However, it was also discussed in some cases, a doctor could rule out these decisions. Practicalities are also important, as in some countries, advance directives regarding medical aspects may be limited on time or people with dementia may not be allowed to write them after diagnosis.

Also it is important that the medical decisions such as not to resuscitate are clear, and staff know about them. Actually this should apply to every person, even to people who don't have dementia. But also the opposite, they are important also when you have dementia, it is important to talk to the person about this before, when the person is still able to express the choice, at the very beginning, so this is part of the person's biography. And also the family. But I don't know if this is the same in all countries, if all have the same standards.

Yes, this is important but also a doctors can overrule this.

Staff training in this area should also be one of the top priorities.

Finally, the group felt that the recommendation number 6 (and in particular the term "system thinking") has not been clearly phrased: "Reflect about the necessary changes in system thinking and development of the advanced care planning process toward the end of life for people with dementia".

5.3 Behavioural and psychological symptoms of dementia (BPSD)

The group referred to BPSD as a complex phenomenon. It was felt that overall BPSD are still poorly understood.

This is something where they don't know enough and we don't correspond to a certain scheme they'd learnt and this is why it is challenging.

BPSD were described by a member of the group as the consequence (a resulting distressed response) of lack of training or understanding of dementia of people surrounding the person with the condition. BPSDs have negative connotations and, the group felt, the person with dementia is often somehow "blamed" for the behaviour and perceived as the problem. The emphasis, however, should be shifted from the person to the lack of understanding of the condition.

The majority of challenging behaviour comes from people who don't understand dementia and I think that then the result is a distressed response from the person who has dementia, we get blamed for the challenging behaviour but it is them that don't understand us, because they haven't been trained, a lot of people in care homes have not been trained properly about understanding dementia.

Training and education for health care professionals working in care homes, and person-centred care, were highlighted as key elements for the prevention and management of BPSD. The provision of appropriate information for carers was also perceived as important, however, such information should be provided in a timely fashion. There were also some discussions regarding the lack of information that people with dementia themselves receive about BPSD. This was described as a topic which was rarely discussed with the person.

I would agree. There is no training, and in (name of country) when I got diagnosed my carer got a course about challenging behaviour, and I think, is this what you need at the beginning ... just after being diagnosed...? The carer gets information but I didn't get this information. I think the person with dementia should also get more information, not only about what happens to your cognition ... they always say, you are going to forget, you may not be able to make coffee, you may lose your sense of orientation but what happens to your personality ... and this is the challenge and we don't get the information.

Yes, I agree, nobody tells us about this

The training, education and information could also help to “open up” discussions about this topic, which the group felt were very much needed.

In the nursing homes they have started to talk about how the behaviour is, and I think it is good in the care homes to open up the conversations about this and how to manage this.

We need more information about what we are going to go through and also more information for the supporters and the people in care homes and doctors. We need to be involved in all of this, it should be discussed more openly.

In addition to each person being different, also, the group highlighted that different types of dementia may need different approaches. For example, fronto-temporal dementia (FTD) was mentioned as a type of dementia for which understanding behaviours is particularly relevant.

More information to understand the person with dementia, and is not every dementia, because dementias are different. (...) There is nearly 200 causes of dementia now so you can't treat 200 different causes of dementia with one treatment, so people need to know about the different dementias

We didn't get much information because FTD is so different, it is very different from Alzheimer's, so when they talked to us they didn't talk about memory problems, they talked about behaviour.

Another relevant discussion was about person-centred care. Specifically, aspects related to individualised approaches and respecting the differences and the choices of the person seemed particularly relevant.

They (people working in care homes) should make individual observations, and provide the care that the individual person needs based on information from the family or the person.

We all have dementia but we are all very different ... different problems, we are different people, we have different biographies, different lives ... we are different.

And they need to understand and respect me, my choices. Like, if one day I want to stay in bed all day this should be ok, because the next day ... I am working every day, so they should respect your choices. If I decide to stay in bed, this should also be ok.

This also involved that staff in care homes needed to be creative, able to adapt to the circumstances and different backgrounds of each resident and know well the person.

All the staff need to know about the person.

You have to adapt to the different situations because one thing would not work for all different situations.

Also it is important that the staff is creative. Like this person may have a different life, a different interest, he may have lived in the mountains, so if he is sitting there all day inside, this may not work for him.

In relation to the recommendations that the WP had developed the members of the group felt that all the recommendations were relevant. For the group, training, activities and person-centred care were the top priorities. In relation to the pharmacological approach, it was also suggested that the recommendations should emphasise the relevance of considering if other drugs, which are not antipsychotics, could be used instead of antipsychotics.

The group added that, in addition to activities, a planned "routine" could also help to prevent and manage BPSDs. Their discussions highlighted a quite strong complex connection between routine, activities and sleeping.

Routine is very important too. They (staff in care homes) leave people lying in bed... people need to get up in the morning, they need to get dressed, they need to know which date it is, they need to know when is night time. In here (the recommendations) there is a reference to activities but this is something else. Because if people sleep all day then they are awake at night, people need a routine. They are sleeping all day, and when at night they can't sleep they give them sedatives.

If they give me something to do that is giving me peace or engage myself. It would be much easier to treat me because I would say yeah it is ok to go to bed now.

It was also felt that the activities should be meaningful to the person and be understood as a "job or work" to which the person could contribute to as opposed to activities the person could be involved in. Again, there was a lot of emphasis about involving the person (or the family) in this and having enough information about the person's background or interests.

They (staff) need to ask me what I would like to do, or my family, what I used to do, and not just make me play Bingo. (...) It is not just an "activity", they should offer us work, jobs to do in the care home, like (name of member of the group) would be cleaning if he was in a care home. I like to paint, decorate.

People who are kept active with a job are alert, they are happy and they don't need any medication.

In addition to this, the group felt that also being surrounded by like-minded people and at a similar stage of the condition was important. There were also discussions regarding the relevance of age and gender.

In care homes people should be grouped together with people, and even staff, with similar hobbies or backgrounds. This can help to structure your day in a meaningful way.

Also it is important to consider that older people may get tired easily, but a younger person with dementia may need more activity, this is why routines and planned activities are important. (Name of person) needs to do something all the time. This helps his behaviour.

I don't think it is all about age, it is about stage, it doesn't matter how old any one is, you have to be at the same stage.

In summary, the group felt overall that prevention is a very important area, and that care homes should have a proactive approach so that BPSDs could be avoided altogether.

They need to be proactive and not reactive, they should not wait until the problem happen, they need to discuss things and be more reactive to people's needs not to wait until someone ahhhh... and them trying to help.

5.4 Antipsychotic medication

The EWGPWD felt very strongly about this topic. In their opinion, all the recommendations are very important and the group agreed with all of them. The group highlighted the following aspects:

1. Antipsychotics should be used as a "last resource", for the shorter period and dose possible and monitored. However, many felt, antipsychotics should be used only when there is danger or potential harm for the person or others, not if it is causing distress.
2. A multidisciplinary team is very important because people have a complex personality and this type of team could, for instance, rule out other disorders and approach the person in a holistic way.
3. Person centred care and trusting (having confidence) the doctor who prescribes the antipsychotic drug are also key. Doctors should build the relationship with the person, so that the person trusts the doctor regarding the treatment she/he has been prescribed and will be taking. This relationship can facilitate the involvement of the person.
4. The side effects of drugs are very important, in some cases side effects can be very distressing.
5. The consideration of a different drug and the different subtypes of dementia should also be considered.

6. Conclusions

- The involvement of people with dementia and training for staff/health professionals were crosscutting topics which were highlighted in all the discussions (DFC, diagnosis and residential care). The involvement and participation of people with dementia should be increased and strengthened, in particular, in areas such as BPSD and medication, where they are often not sufficiently involved.
- Staff training was also a very prominent topic. Training should involve medical aspects but also other psychosocial issues such as communication (e.g. diagnosis disclosure, participation of the person in treatment decision making etc.). Staff/health professionals' attitudes and values were also considered as very important.
- Timely diagnosis is important for people with dementia, however this is only meaningful if the process includes the provision of appropriate information and support to the person and family. In some countries, the medical model of understanding dementia is still prevalent, and a diagnosis of dementia can be perceived as a detriment for the person's rights and autonomy. Raising awareness of dementia and promoting a more positive understanding of the condition are very important aspects.
- In residential care, PCC is a key aspect of care. Staff shortages, the high rate of turnover and the work of care assistants not being sufficiently valued were all highlighted as limitations for the implementation of PCC. Respect to diversity and to the individual's cultural and personal background are key aspects of care. This diversity and respect should include both people living and also the people working in residential care.
- Finally, there was agreement about the relevance of meaningful activities for people with dementia. However, the group felt this should go beyond "structured activities" offered to the person and include participating in the day-to-day of the facility and establishing routines which are meaningful to the person.

7. Acknowledgements

This work has been drafted / reviewed by:

- Ana Diaz
- Dianne Gove
- Jean Georges
- Sébastien Libert
- All members of the EWGPWD and their supporters

APPENDIX 1

Information for members of the EWGPWD about the session on the morning of Tuesday 13th December

Who are we?

Imogen Blood

and Steve Milton



Imogen runs the independent research consultancy, **Imogen Blood and Associates**.

We work with governments and services to make services and policies fairer and better.

We are passionate about using research to make sure that diverse (and often unheard) voices are at the heart of this.

You can find out more about us at: www.imogenblood.co.uk

Steve is a director of **Innovations in Dementia** - a social enterprise focused on the voices of people with dementia. Innovations are probably best known for the DEEP project - a network of groups of people with dementia in the UK.

You can find out more at www.innovationsindementia.org.uk

What are we doing?

We are doing a piece of work for the UK Government (Department of Health) as part of the European Union's Joint Action on Dementia.

This involves drawing together what is already known about how to create 'Dementia Friendly Communities' across Europe and beyond.

Our findings will inform a toolkit and some pilot projects across Europe on Dementia Friendly Communities in 2017.

We hope that people involved in developing Dementia Friendly Communities across Europe will read our report and use it to help them:

- Understand what makes communities 'dementia friendly' (and what doesn't);
- Come up with ideas of actions they might take in their communities;
- Involve people with dementia in this work in a meaningful way; and
- Understand whether what they are doing is actually making a difference to the quality of life of people with dementia and those who support them.

Our report needs to be written by Christmas.

How have we gone about this?

So far, we have:

- Met with two small groups of people with dementia (in Redditch and Bradford in the UK) to hear what they think makes a community 'dementia friendly';
- Found and read over 70 reports and articles relevant to 'Dementia Friendly Communities'. We have been particularly interested in what has been learned so far from these projects, what works well and what difference it makes to the lives of people with dementia;
- Sent out an online survey to national representatives in each of the European countries and asked them to send these out to anyone with an interest in Dementia Friendly Communities. These have asked people what makes their communities accessible/inaccessible and what has been done to improve this. We have had over 60 responses; and
- Interviewed around 20 people involved in Dementia Friendly Communities across Europe. We have done most of these by phone, but we have been out to visit some local projects in England and this has included meeting people with dementia who are involved.

Why are we coming to your meeting?

We are looking now at what we have learned from all this and starting to write it up into a report.

We are really keen to share some of the headlines with you and see whether these fit with your experiences and views and whether you have things to add.

We are particularly keen to feed in your practical advice as to how people with dementia can be engaged at the start and heart of Dementia Friendly Community initiatives.

We are really delighted that you are setting aside the morning session of Tuesday 13th December to help us in this.

We will be arriving at the hotel the evening before and hope to meet as many of you as we can over dinner on Monday evening and/or breakfast and lunch on the Tuesday. This should give us a chance to get to know each other better and to hear your views in a more informal setting.

What will we do during the session?

Part 1: What are your experiences in your local community?

We would like to spend the first part of the session hearing about your individual experiences and (where you feel in a position to do this) those of others with dementia about the accessibility of YOUR community.

Questions will include:

- 1. What helps you (and/or other people with dementia) to take part in day-to-day life in your local area?**
- 2. Which people or organisations help this to happen?**
- 3. What stops you (and/or other people with dementia) from taking part in day-to-day life in your local area?**
- 4. Which people or organisations can remove these barriers?**

Part 2: Sharing key messages from our project

We would then like to share with you some of the key messages from our project.

We will present a slide with one or two bullet points on it; explain what we mean by this then pause to find out whether you think this resonates with your experiences.

We expect to share between 4 and 6 of these headlines depending on the time.

We haven't yet decided on these headlines (as we will be working on them between now and then!) but an example might be:

“A ‘dementia friendly community’ is more about the people than about the physical environment”

Part 3: Practical examples of how best to involve people with dementia in ‘Dementia Friendly Communities’

Have you been involved in creating ‘Dementia Friendly Communities’? If not - you will have been asked to be involved in dementia-related discussions.

We wondered if you might think of two examples:

- When your engagement went well - and why.....
- When it did not go so well, and why.....

Given these experiences, what advice might we give to those planning to set up Dementia Friendly Communities about what they need to do to make sure people with dementia are involved at the heart and from the start?

We will take a 30 minute break in the middle of this session.

If everyone is happy with this, we will record the session so we can capture your views accurately.

We hope to use some quotes from the discussion in our report to make sure that the voices of people with dementia speak out through it. However, we will not say which individual said each quote. Do let us know if there is anything you would rather we did not include.

We really look forward to meeting you in Brussels.

If there are any questions before the meeting, you can get in touch with us at:

imogen@imogenblood.co.uk

steve@myid.org.uk

Information about our visit to your meeting on 13th December (short version)

Who are we?

Imogen Blood and Steve Milton



Imogen runs the independent research consultancy, Imogen Blood and Associates.

Steve is a director of Innovations in Dementia

Why are we coming to meet with you?

- We are doing a piece of work for the UK Government as part of the European Union's Joint Action on Dementia.
- This involves drawing together what is already known about how to create 'Dementia Friendly Communities' across Europe and beyond.
- We have already spoken to lots of people. We want to tell you what we are finding out - and find out what you think
- We'd like to find out about your experiences of 'dementia friendly communities' and what that means to you.
- We'd also like to find out about your experience of being involved in creating 'dementia friendly communities' - and what has helped, or been a barrier.

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APPENDIX 2

Introduction - Joint action on Dementia

- “Joint actions” are designed to encourage governments, academics and other non-profit organisations to join forces across Europe to tackle problems shared by many EU Member States. Joint actions are co-financed by the European Union and the competent authorities that are responsible for health in the Member States.
- There are different joint actions such as on mental health, cancer, etc. There have been, so far, two joint actions on dementia (Joint Action I from 2011-2013 and Joint Action II from 2016-2018).
- The Joint Action on Dementia II, aims to promote the implementation of coordinated actions to improve the lives of people living with dementia and their carers.
- The Joint Action on Dementia II is working on four areas:
 - 1) Diagnosis and post-diagnostic support**
 - 2) Residential care**
 - 3) Crisis and Care Coordination
 - 4) Dementia-Friendly Communities

During the EWGPWD meeting (morning of 6 December) we will talk about the work that the Joint Action on Dementia II is doing in relation to the first two areas, i.e. (1) Diagnosis and (2) Residential care.

In this document you can find some background information and the questions that we will address on the day.

AREA 1: DIAGNOSIS OF DEMENTIA

Questions for the EWGPWD (5 questions)

1. What does “timely” diagnosis mean to you?
2. What do you think the main benefits are?
3. What do you think the main challenges or risks are?

Previous research has identified the stigma of dementia as an important barrier for the timely diagnosis of dementia:

4. What do you think General Practitioners (i.e. family doctors) should be doing in order to encourage timely diagnosis and address stigma of dementia?
5. For General Practitioners’ who are not doing this, what could be done to make them more aware of the benefits and challenges?

AREA 2: RESIDENTIAL CARE

The focus is on residential care, in particular:

- Person-centred care,
- Behavioural and Psychological Symptoms of Dementia,
- Reducing the use of antipsychotics,
- End-of-life care.

Questions for the EWGPWD

1. What are your experiences with or views on: person-centred care, Behavioural and Psychological Symptoms of Dementia and use of antipsychotics in residential care settings?
2. How do you think these issues should be addressed?
3. End-of-life care: Is this important for people with dementia? How/ when should a person with dementia be approached by healthcare professionals to discuss about this?

We have developed a set of recommendations for each of these topics (see the recommendations at the end of this document).

4. For each topic, do you think any of the recommendations that we have developed, are more important than others?
5. How do you think these recommendations could be implemented?

Recommendations and glossary

RECOMMENDATIONS: Person-centred care

We recommend that every residential care unit:

- Has a program to follow up each resident regarding medical and physical discomfort, with a specific focus on pain.
- Creates a shared vision of person-centred care that makes it possible for the staff to know what it means in practice.
- Makes an effort to create an atmosphere of inclusion, respect and validation throughout all levels of the service.
- Has a program for the implementation of person-centred care. It is recommended to use a well-documented program adapted to the local context. The program should include:
 - Teaching of staff
 - Leader responsibility (at all levels)
 - Continuing evaluation
 - Supervision
 - Support to report and manage ethical issues
- Offers tailored activities and stimulation adjusted to the residents' practical and cognitive functioning.
 - We recommend that every residential care unit has a “toolbox” with different meaningful activities that easily can be used in the daily life of the institution.
- Trains staff in communication skills, including knowledge on how to observe and interpret behavioural changes as signs of unmet need, e.g. pain, frustration and emotional or psychological distress.
- Organises the staff in line with the principles of primary nursing or primary teams to ensure the possibility for attachment, personal knowledge and security.
- Evaluates the physical environment and aim to change an institution-like environment into a more homelike/normal environment.

RECOMMENDATIONS: End-of-life care

We recommend:

- Establish early and open communication with the person who is diagnosed with dementia, and, if possible, his or her family.
- Ensure that the advanced care planning process is initiated in due time, preferably by the general practitioner who knows the patient and the family.
- Be aware that the most important question in the dialogue is, “What matters to you?”
- Be aware that advanced care planning is a multifaceted process of repeated communication and discussion over time, not a single event.
- Seek advice from experienced colleagues to participate in the communication process, as dementia is complex and the trajectory has a long-lasting nature.
- Reflect about the necessary changes in system thinking and development of the advanced care planning process toward the end of life for people with dementia.
- Be aware of individual differences regarding needs and wishes with regard to spiritual and cultural factors.
- Ensure necessary information regarding the person’s diagnoses and medical conditions, treatment options, and prognoses are available, as they are prerequisites for such communication.
- Discuss themes with regard to hospital admission, such as “Do not resuscitate”, nutrition, pain and symptom assessment, and treatment, if necessary. Address these topics carefully and adapt them to the patient’s and family’s situation.
- Give the resident and his/her relatives the opportunity to address important questions and organise necessary follow-up.
- Remember to document the content of the talk and results of the discussion with the aim to inform your colleagues and other important individuals.

RECOMMENDATIONS: Behavioural and Psychological Symptoms of Dementia

For the treatment and prevention of Behavioural and Psychological Symptoms of Dementia, we recommend:

- That residential care settings have programs to implement a set of activities as sensory interventions (music therapy, aroma therapy, massage) and structured activities (dance, exercise, gardening and other hobby activities).
- We recommend that all residential care units implement routines for a systematic approach to challenging behaviour based on the principles of the “four D”, “TIME” or “DICE” models (see glossary pages 9-10 for brief explanations of these approaches).
- Staff training is essential:
 - Train the staff to understand challenging behaviour.
 - Train the staff in communication skills, especially in demanding situations.
 - Train the staff in the use of the use of personalized music to calm down situations.
- Staff shortages resulting from economic restrictions cannot justify the inappropriate use of pharmacological approaches to Behavioural and Psychological Symptoms of Dementia.
- If medication is considered, we recommend that the ABC approach be used. (ABC approach: A stands for antecedents (triggers), B for behaviour, and C for consequences).

RECOMMENDATIONS: Antipsychotic medication

We recommend:

- Assess type, frequency, severity, pattern and timing of the Behavioural and Psychological Symptoms.
- Rule out other psychiatric disorders, acute or chronic medical conditions, delirium, physiological needs, pain, psychosocial and environmental causes and current medical treatment.
- Take into consideration the subtypes of dementia.
- Prioritise non-pharmacological treatments & adequate dementia treatment.
- Use antipsychotic medication for the treatment of the Behavioural and Psychological Symptoms of Dementia, only when moderate to severe symptoms are present and cause significant distress to the resident or danger to him/herself self or others.
- Develop a person-centred treatment plan that involves the resident (if clinically possible), formal or informal carers, and staff and focuses on weighing the potential risks and benefits of antipsychotic treatment for Behavioural and Psychological Symptoms of Dementia.
- Consider as a specified, short-term strategy when using antipsychotics in Behavioural and Psychological Symptoms of Dementia treatment, aimed at treating with the adequate agent, minimum doses, planned regular monitoring, and the goal to taper off and discontinue as soon as possible.
- Appropriate support to maximise the potential of the person with dementia to express him/herself, contribute towards decision making, and understand what measures are eventually decided.
- Caregiver involvement.
- Electronic Medicines Management System.
- Antipsychotic prescribing tool kit.
- Multidisciplinary team.
- Antipsychotic revision.

GLOSSARY

Person-centred care

- Person-centred care involves tailoring a person's care to their interests, abilities, history and personality.

Behavioural and Psychological Symptoms of Dementia

- The symptoms of dementia are often only understood in terms of the neurodegenerative processes in the brain. However, there has been an increasing awareness of the importance of other factors. There seems to be a quite broad agreement that the symptoms of dementia (thus, also BPSD) have a biopsychosocial aetiology. In addition, there is clear evidence that agitation and hyperactivity in dementia are very often a result of unmet needs.
- BPSD comprises a broad spectrum of non-cognitive symptoms including physical aggression, agitation, hallucinations, depression, delusions and sleep disturbances.

The “Four Ds” approach

- (1) Describe; 2) Decode; 3) Devise and; 4) Determine).
- First (Describe stage), the provider works with the caregiver to place the problem behaviour into context.
- In the Decode stage, possible causes of the problem behaviour are investigated.
- Next, the provider creates a tailored treatment plan incorporating patient/caregiver preferences.
- Finally, the provider and caregiver assess the efficacy of interventions

DICE approach

- (Describe, Investigate, Create, Evaluate).
- Describe means that the caregiver describes the problematic behaviour (e.g. context, social and physical environment, residents' perspective, and degree of distress to patient and caregiver).
- Investigate, the provider investigates the possible cause of the problematic behaviour (e.g. medical side effects, pain, medical conditions, sensory changes or fear, sense of loss of control, or boredom).
- In the create step, the caregiver team collaborate to create an implemented treatment plan.
- Finally, the effect and safety of the intervention are evaluated

TIME approach

- The core of the procedures is a gathering of all involved staff, including the physician, to reflect over the description and findings in the investigation phase to find (create) new approaches to the “challenging behaviours”.

Antipsychotic medication

- Antipsychotic drugs (also known as ‘neuroleptics’ or ‘major tranquillisers’) are a group of medications that are usually used to treat people with mental health conditions such as schizophrenia.
- They are also the drugs most commonly prescribed for behavioural and psychological symptoms, such as aggression or hallucinations, in people with dementia. In some people antipsychotics can eliminate or reduce the intensity of certain symptoms. However, they also have serious side effects.