

## Safeguarding Views & Perceptions

**A total of 2 focus groups and 3 1:1 interviews were carried out with people with dementia and carers**

Q: What does being safe mean to a person with dementia?

For participants with dementia, being safe means very practical issues in the home, such as turning off cookers, candles, being aware of the danger of falls and ensuring practical supports to live well. Being safe also means feeling “comfortable” and “confident” and feeling a sense of “security”. This makes it somewhat easier to deal with a diagnosis of dementia.

Being safe means being able to live a life that is “free from harm” and having one’s human rights protected and upheld. In a nursing home being safe means being respected as an individual and having one’s privacy respected. Irrespective of how agitated the person with dementia is, the person should be respected. Very often care staff are not trained and do not understand that agitation may relate to needs that are not being met. If a carer does not understand this, the person with dementia may feel unsafe and the agitation or fear can escalate. People with dementia need to be understood in order to feel safe.

Some participants described “touch” as important for feeling safe, for example, holding the person’s hand. One participant described how her mother may not know where she is, but she knows that she’s somewhere safe. “A safe environment” means to be somewhere that the person with dementia recognises, “it’s somewhere familiar or somebody they can trust”. Participants highlighted familiarity and structure as contributing to feeling safe, as one day care centre client explained, “everything happens in the same place, in the same way, and I’m with people I know and they understand me”. Participants described the importance of using a non-threatening approach to make a person feel safe by smiling and being friendly.

In the focus group, carers felt that “education of the (family) carer is a critical issue” in enhancing safety. For example, one participant felt he was not adequately educated and did not recognise the signals that could lead to his wife having an accident or fall. It was explained that family members should be allowed to call to the nursing home at random times to check on their loved one and ensure they are being well cared for.

Q: What does being unsafe mean to a person with dementia?

Participants described being unsafe as a feeling that is “frightening” and “uncomfortable”. For them it means “not being understood” and a lack of understanding of the condition from people around them can leave a person with dementia feel very unsafe. One participant felt that the number of people in a room and the tone of voice some people many use can be very distressing for a person with dementia and that many people will feel safer and more secure with one-to-one interaction. Adequate support and understanding were emphasised as crucial to feeling safe. Interestingly, participants with dementia tend to define ‘unsafe’ as a feeling rather than an action or behaviour, such as feeling scared, intimidated,

uncomfortable, being ignored or not heard or listened to.

Participants discussed how the turnover of staff in nursing homes can be very frightening for a person with dementia. There was a discussion about the approach in acute and long-term care and participants felt that staff members need to be clear and reassuring before they start getting a person out of bed, washing or dressing them etc.

Participants agreed that people with dementia are very vulnerable and are at the mercy of people calling to the door or out in the community. One person gave an example of a woman with dementia who used to get her hair done once a week, but then began to forget she had it done and so went every day. Instead of trying to support her, the hairdresser let her pay €40 each. There were numerous examples given of people with dementia being “taken unfair advantage of financially” and certainly participants with dementia were aware of their vulnerability in this regard.

Q: Should the word vulnerable be used to describe people with dementia?

There was unanimous agreement that people with dementia are vulnerable, even prior to a diagnosis and certainly from the point of diagnosis. They are vulnerable when living on their own and also in nursing homes as people providing care are not always monitored. People with dementia may not be able to speak up, express need or ask not be treated in a certain way. Having limited capacity means one is vulnerable.

People with dementia are vulnerable particularly in terms of physical safety. Several carers described concerns around physical safety how their loved one put a hot kettle on a hot plate and the dangers this and other actions posed to the person themselves and their families. One participant spoke about how his wife wanted to go walking without him, but would get lost so he would follow her in his car to ensure she was safe, “the person themselves may have no awareness of their safety”.

Participants with dementia explained that not being treated as an equal citizen can leave them feeling vulnerable. They might be excluded from conversation and feel demeaned because of their condition.

Participants highlighted the lack of care assistants for vulnerable people, including people with dementia, in hospitals as a problem that must be addressed. A carer highlighted the practice in St Vincent’s Hospital of putting a pink ribbon on the end of the bed of a vulnerable person as a positive example. This would remind staff that the person needed extra support with eating etc.

Q: What makes a person with dementia feel safe/unsafe in their home or in the community/day centre?

Support from service providers can empower a person to live well, and this feel safe. Practical supports can make a person feel safe such as a panic button, using GPS when outdoors, having someone who can check in on them. Planning ahead is important, while one can, and the ‘Think Ahead’ document is very useful for people with dementia. Planning ahead requires certain awareness and skill.



Experiencing difficulties navigating or becoming lost can be very disconcerting and frightening for people with dementia. In addition, responses from other people to dementia can make one feel unsafe. Not feeling understood or being made feel awkward can make a person feel unsafe. The fear that one is perceived as “weird”, “strange” or to be avoided can also contribute to feeling unsafe, and the person with dementia may be fearful they will not be helped or supported if needed.

Q: In what other ways might a person with dementia be abused?

Participants gave numerous examples of how a person with dementia can experience abuse:

- A participant informed the group that a carer washed her husband with cold water, even though hot water was available and it was only when she intervened that she stopped.
- People discussed the pressure staff members are under in nursing homes and that there may only be time to look after a person’s basic needs with no time to interact. While participants recognised that the job of a professional carer can be very difficult they felt that a person should not be in that job or they should remove themselves from the situation if they are starting to feel annoyed.
- The tone of voice used by professional carers is very important. They may be under pressure and therefore very frustrated. One participant shared an experience where a carer had shouted at her husband with dementia, “sit down and have your tea”. She had to explain to the carer that he would respond much better if she spoke to him gently.
- Participants highlighted their concern for people with dementia who do not have family members to advocate on their behalf.

Uninformed or negative perceptions of dementia can make this cohort more vulnerable, as participants explained. One noted that, “The person disappears and the disease defines them. They become a problem”. Another commented that it is upsetting that things have not improved for people with dementia – “food being shoved into [a person’s] mouth with a dessert spoon, too fast...On the ground little things haven’t changed”. Another explained, “In acute hospitals a person with dementia is “always a problem patient and a mobile person with dementia is a nightmare”.

Q: If a person with dementia was being abused who would they tell?

Participants with dementia reported they would tell someone they trust or someone they know well, such as a family member, friend or a Dementia Adviser. They agree that the trusted person should then tell someone else who could also help. However, in the context of a nursing home, reporting abuse might be more challenging. As participants with dementia pointed out, diminished cognitive abilities means the person with dementia may not be recognised if they are being abused and may not be aware of it. While physical abuse might be visible, emotional abuse can be subtle. The person with dementia may be fearful of not being believed or that reporting abuse may compound the distress and make life more difficult.



Similarly, carers of people with dementia, explain that their specific condition and cognitive challenges means “they may not realise they’re being abused”. One participant explained that her mother had overpaid a number of workmen by significant amounts and instead of saying anything they had just cashed the cheques and taken her money. In that instance her mother didn’t realise that she was being abused. Another carer described how all her mother’s bank accounts were emptied and the family still are not sure exactly what happened. Someone else described how her husband was put on medication for aggression when he went into respite, even though she explained that he just needed time to settle into a new place. When he came home he began to have falls because he was over medicated and he then had to be weaned off that medication. Carers were of the view that the voice of a person with dementia is not taken seriously and when a person with dementia makes an allegation of abuse it may not be taken as seriously due to their condition.

Q: If a person with dementia reports abuse, what should happen next?

Participants offered the following suggestions about what should happen when a person with dementia reports abuse:

- “I would like to be recognised, heard, validated and acknowledged.”
- “Family members and people involved in my care should be informed immediately, including members of my multi-disciplinary team”.
- “I would like someone to check it out, and see what has happened, how a safe environment can be created for people with dementia like me, and also the care workers”.
- “The person with dementia should be removed from that environment immediately” and/or should be distanced for the particular member of care staff.
- “There should be an independent investigation”. Participants said that there should be an independent body like HIQA to investigate reports of abuse.
- Participants believe it should be investigated if such abuse has happened before, and to explore if care staff need further training in caring for dementia clients.
- People with dementia should be informed of progress of the investigation if they have the capacity to understand. But if it causes further distress then the person with dementia may not need to be informed. There is no ‘one size fits all’ and the specific needs of the person should be taken into account, and a person-centred approach should be adopted.
- The service investigating possible claims of abuse should visit the person with dementia to give an update on the investigation. But again, this is dependent on the capacity of the person to understand and the stage of dementia.

The group discussed the difficulty people with dementia may have in reporting abuse, as a result of the condition. A participant called for a social worker in all hospitals and nursing homes who will monitor the treatment of people with dementia. Interestingly, a carer highlighted the fact that no one is checking whether her husband is being cared for properly at home. She believes that a social worker or someone

should check in on families every once in a while. Another person said that every person with dementia should have access to a Public Health Nurse who visits regularly.

Q: What would make it difficult for a person with dementia to report abuse?

The specific nature of dementia and its symptoms can make it particularly challenging for the affected person to report possible abuse. Verbal difficulties mean “they can’t tell people what they need or want”. A carer explained that when her mother was grinding her teeth she knew something was wrong. But this was the only signal as she did not have verbal skills anymore, and therefore “you have to take the signs and interpret them”. Another participant highlighted the experience of her husband who is in long-term care. She explained that he does not cooperate with the staff to wash because he is frightened and they move too fast for him for he is unable to verbalise this, “I want him to be looked after to the highest possible standard, that’s not too much to expect. The one thing that really does matter is respect and care for the person”.

As above, fear of not being believed because of dementia, allegations being taken less seriously because of dementia are all factors. Perceived power imbalance between the person with dementia and service provider/care staff would also hinder a person from reporting abuse. Participants feel that abuse claims are not often taken seriously and properly addressed. People with dementia reported feeling fearful they will be “turfed out” of a service if they complain and often feel bad even about raising questions, “I would be afraid things would get worse, that I would be intimidated, and it would go on and on.” Interestingly, participants from day care centres also noted they would feel guilty about reporting someone, especially if it was a family member.

Other Observations

- Participants agreed that education of staff is key and one commented that a lot of care is driven by personality. One carer will make heavy weather of something and another won’t.
- Participants discussed the fear that informal carers have of accidents, falls and somebody walking alone and getting lost. Despite these fears, there was agreement that it is important not to overreact to incidents and go overboard with safeguarding measures.
- “Respect, dignity and love. If you have that approach other things will fall into place”.