

The East Kent Forget Me Nots, over two small group discussions, looked into how Dementia affects their emotions and how they access service-user involvement groups, other services and day to day life. Since DEEP are interested in finding ways to manage conflict and needs for support in dementia service user groups the FMNs felt that sharing these may be useful for advising other groups/ organisations related to dementia.

When discussing whether any changes in emotion have been noticed since being diagnosed with dementia the group agreed there are clear changes. The FMNs suggested emotions are far more intense, and they now have less tact or their 'filter' is diminishing. Further to this, the change of roles within family and peer groups can have an emotional impact. Another key change noted was that as the members can rely less on their memory they rely more on their emotions and at times emotions are more powerful than emotional reasoning. The group felt 'emotions are now more important, as they are now more potent'.

When looking into specific emotions those experienced more strongly now included: guilt, overthinking, appreciation, fearfulness, cautious, anxious, anger, frustration, irritability, agitation, dependant and loneliness. Emotions experienced less strongly now included: patience, tolerance and confidence. When reflecting these changes onto the impacts they have on relationships in day-to-day life the group suggested that this varies. However, others expectations of a person with dementias abilities changes, and furthermore there is often a great shift in roles and dependency within relationships and this can have both an emotional and negative impact on all involved. The FMNs suggested they find themselves withdrawing from relationships due to fear of telling others about their diagnosis, which is linked to the reduced contact from peers since diagnoses in some cases. The FMNs also felt that at times people around them may take offense even when they do not mean to offend.

When linking this to the effects it can have on accessing groups and services the FMNs suggested that everyone is different thus it is difficult to manage a group situation wherein everyone has individual experiences with dementia. The FMNs feel because of their dementia they get frustrated with other group members quicker than they may have done in the past, alongside being more aware of others frustrations within the group. Another change discussed was that opinions can be stronger or harder to challenge, and at times taking advice is difficult. Consequently this can cause conflict especially due to a loss

of resilience also being reported meaning high levels of emotion can take a greater toll on individuals.

Due to the challenges described above the group went on to discuss how best facilitators can support individuals to access groups. We split this discussion into three parts:

When people misremember situations it would be most helpful to:

- State things like 'I remember differently' or inform them of the truth in the situation kindly
- Sometimes agree to assist in moving on from a topic
- Refer to previous minutes/written documents

When people become upset due to misunderstandings it would be most helpful to:

- Help provide a balanced environment- some may like one thing whereas somebody else may prefer the opposite, therefore it is important to do a bit of both.
- Professionals/facilitators to be more accessible to talk through these feelings
- For facilitators to broaden the discussion to try and discontinue upsetting miscommunications.

When people care about different things in different amounts it would be useful to:

- Stick to a written agenda- perhaps adding time limits to items and sticking to them
- Not remain so 'buisnessy' and attempt to keep things informal at times
- Ensure everyone gets the opportunity to speak

