

# Hear me, See me, Understand me



## Understand the experiences of people with Learning Disabilities and Dementia



People with learning disabilities are living longer putting them at a higher risk of developing dementia. Understanding the experiences of the person with dementia is important to consider when providing care and support to ensure that the persons needs and wishes are being met.

*"Sometimes I am on my own when I forget, I look for things and they are not there, I feel silly and so sad."*

### Hear me

- Listen to the person, take into account how they want to be supported, their values and beliefs.
- There are times when the person might feel frightened, sad or be in pain and trying to communicate this by making connections to other situations or past events.
- The person might be frustrated, and shout/cry or behave differently if they are being misunderstood. Find another method of communicating if they are not able to make themselves understood verbally. Use visual aids to help conversations.
- Relatives also have concerns and need to be consulted in the support and care that their loved one will receive.

### See me

- View the person from all aspects of their lives not just the dementia. Always consider the persons wishes and feelings and ensuring that the persons basic needs are met.
- Be aware of changes in behaviour and how this impacts on the individual's self esteem and sense of self. Offer comfort and reassurance.
- It can be easy for the person to become isolated from others who find changes in the person's behaviour difficult to understand. Take time to explain the experience of the person with dementia to help others to understand the changes.
- Family members also experience the same range of emotions as their relative.

*"I cried when I was first knew and I worried about where he would live , I thought he would be asked to move out." (Parent)*

*"It is natural to worry, but we had to get on with it, this is how life is, we thought 'what can we do to make sure that he has everything that he wants and needs to keep his life as it is now'" (Parent)*

## Understand me

- The diagnosis of dementia needs to be discussed with the person to ensure that they understand what will happen. It may be necessary to find different ways of communicating this as the diagnosis could cause the person distress, anger or frustration.
- The diagnosis needs to be discussed even if the person does not appear to understand. This shows value for them as a human being.
- If the person is tired, embarrassed or frustrated at a situation, it could lead them to behave differently. Consider what is being non verbally communicated .
- Talking with the person about how they feel is important to gain an understanding of why they have acted or reacted in a certain way.

*"Laugh with me, that makes me happy, I don't want to be serious. I want to be happy and not worry."*

**Hear** what the person has to say, either verbally or non verbally. Listen to the concerns of the person and their family.

**See** the person not just the dementia. Look at the person's health needs, life style, environment and social activities.

**Understand** how dementia is affecting the person as it can explain their actions and feelings. Recognise that everyone is different and taking time to understand their experience of dementia will increase the person's self esteem.

*"I do feel lonely. I like my flat, but I am on my own sometimes and I jump. Then I think I have lost something and I get cross and I want to shout."*



*"Listen to what I say, I have a right to say it"*