‘What to expect while Navigating the sea of dementia ‘

*‘’Like Columbus, I am on a voyage of discovery. My route is not exact and I must make adjustments as I go along …unlike being at sea in a storm ,I know that the voyage is only going to become more difficult .It may become a typhoon or hurricane ,depending on where it takes me. This storm will not pass: I have to make suitable preparations before the force 12 hits. Let me tell you that I am lucky: I have every good friends who will be with me on the stormy ride ahead.’’*

*Voyager (2005), ’Living with Dementia’ by Alzheimer’s society*

*Voyager gives us a sense of situation that the ability of person with dementia is going to deteriorate, and the person with dementia, his family, friends, Carers need to plan well for eventualities. Person with dementia will require continued support as they progress with the disease; the deterioration in abilities comes with the fear of losing independence, insecurity about health, finances, in general losing a sense of self. Hence the support of good family, friends, and empathetic carers plays a crucial role in maintaining well-being of people with dementia .This support system of carers (family and formal) will have to offer more and more support to person with dementia as their disease progresses, causing impairment in communication and functional abilities.*

*Stages of Dementia are roughly divided into three stages*

The life expectancy of a person with dementia is unpredictable, and the disease can progress for up to **around 10 years**. Alzheimer’s society reports that it is estimated that a third of people with dementia at any one time will be in the later stages of the disease.

Let me explain what to expect from different stages of dementia.

**Stage 1 : Mild Dementia ’ Setting out on a journey ‘**

First stage that is Mild Dementia stage may start with minor lapses in memory and behaviour .These symptoms may go unnoticed to family/friends around the person suspecting to have dementia. As time passes in the mild stage itself the incidences of forgetfulness, changes in mood, apathy towards activities become frequent and the person with dementia does become aware about the fact that something could be amiss. As the disease progressed these abnormalities in behaviour might be noticed by family members, people around the person . This stage generally provides alarming changes in the person and ideally leads to the diagnosis. The person still may appear to do daily activities of living, communicating fairly well. However they will be advised to stop driving or travelling alone, cooking (from safety point of view) ,retire from work.

Person may lose interest in pursuing occupational activities, hobbies, having social interaction which they otherwise did enjoy earlier. Person with dementia may feel added pressure from family, friends to take up activities ,things that stimulate their brains like puzzle,brain games,taking up healthy routine of exercising ,walking etc. With lack of interest ,apathy which is a symptom of dementia ,person may feel disheartened, agitated ,anxious if he/she is forced to take up activities that they are not interested in doing. Person will be able to take it up short ,simple activities, and can complete them with the help of carers. How to deal with certain dementia behaviour, apathy will be discussed in the next article. (Link)

**Stage 2 : Moderate Dementia**

In this stage cognitive difficulties and associated behavioural problems become increasingly dominant. Person will find difficult to express themselves with appropriate use of language. May forget names of family members, close relatives. They will appear to be more withdrawn while doing an activity, with struggle to complete an activity. Family, carers will find it challenging to get the person to maintain personal hygiene. Person will require more care, monitoring than the first stage as person will have increased risk of wandering, may not be able to differentiate between strangers with false intentions ,will require help with taking medicines, may have confusion with day, year, seasons etc. Person can still do many activities of daily living but will require more assistance from his/her carers than the first stage. Both family and formal Carers will require more support, guidance from professionals to offer appropriate care in this stage of dementia as personality and behavioural changes are prominent may include suspiciousness and delusions.

**Stage 3 : Severe Dementia**

In this stage, person has severely impaired communication, will struggle to eat by themselves, may need more easy to swallow food, needs help with personal care, to move around. The person get more increasingly isolated in their own world. Lack of communication makes the person totally cut off from the outside world. Caring demands increase and full time care or residential care may be required. For the family, friends this stage is emotionally challenging as they see their loved one sinking in, unaware of reality, environment around them. Even in later stages, it is possible to provided stimulation activities for the person which are sensory like Music therapy, aroma therapy, reminiscence therapy etc.

The ‘stage theory’ provides us approximate layout of progression of the disease. However it is important that some people may move forwards, backwards between these stages. In dementia every person responds differently to the disease, hence it is important to plan the care according to individual’s needs, personality, biography etc.

The best strategy to offer best fit of care will be to concentrate not on what they *‘cannot do’* but on what they **‘*can do’***.

***References***

\*Alzheimer’s society

\*Dementia Care Workbook (Gary Morris,Jack Morris)

About the Author

Amrita Patil Pimpale – Dementia Care Consultant ,Mumbai (India)

E : <amrita.p@echoinghealthyageing.com>

***Founder,Lead Consultant in***[*Echoing Healthy Ageing*](http://www.echoinghealthyageing.com)*, a social enterprise working in Dementia care sector, focusing on home based therapies, counselling, Dementia care training for family carers and professional .Consultant to geriatric care facilities to implement best practices. Winner of* ***Social Entrepreneur ‘ Unltd India award’*** *for Year 2012 and 2013. Previously* ***Project Manager*** *of care home improvement project in England.* ***Certified Trainer*** *of* ***Person centred dementia care*** *from University of Bradford, UK ;* ***Dementia care mapping advance practitioner*** *(an international framework used for training needs analysis, staff development, quality improvement, benchmarking and quality assurance) and Best practices dementia care from University of Stirling, Scotland. Designed, delivered training for care staff (dementia care), NHS nurses in England and has internationally published research papers in dementia care.*