

Challenges of dementia

At some point, there will be challenges to be addressed. These may include:

- Difficulty sleeping – regular exercise and a comfortable bed may help.
- Driving concerns – road safety.
- Repetitive behaviour and speech – memory loss.
- Clinging behaviour – from insecurity or inner fear.
- Losing things, or accusations of theft.
- Hallucinations.
- Wandering – this may not be aimless.
- Aggressive outbursts – what was the trigger?
- Difficulty retaining facts and keeping to routines.
- Inability to notice mistakes, solve problems or plan.
- Incapacity to perform two- to three-step activities.
- Loss of motivation – this can be due to loss of confidence or boredom.
- Poor communication skills.
- Changes in mood and unpredictable behaviour.

The understanding of family and carers becomes very important in this process.

The value of spiritual life

When relating to God, dementia sufferers can display thankfulness, appreciation and joy in the little things, living in the moment, using creativity, music, songs, hymns and recitations previously learnt by heart. They need to be helped to use spiritual coping patterns and familiar approaches in the early stages, to reaffirm their source of value and meaning (personal faith). Sufferers need time for solitude, quiet, creative sharing of gifts, the arts. It is important to offer warm befriending relationships. Recognise that sufferers want to grow, despite limitations. A person with dementia requires opportunities as a spiritual being to find meaning and purpose in the events of life, to the extent of their capabilities.

*When you pass through the waters,
I will be with you; and when you pass
through the rivers, they will not sweep
over you. When you walk through
the fire, you will not be burned;
the flames will not set you ablaze.*

(Isaiah 43:2)

A BRIEF INSIGHT INTO

DEMENTIA

Understanding Dementia

Dementia is an irreversible and progressive intellectual disability affecting key functions of daily life. It is caused by a group of disease processes. Dementia is an umbrella term which describes a serious deterioration in mental functions, such as our memory, language, mood, orientation and judgment. There are many types: Alzheimer's disease accounts for two-thirds of cases, and is the best known. Although dementia mainly affects older people, it can affect younger people too.

Understanding the types of dementia

Alzheimer's disease: Senile dementia of the Alzheimer's type erodes intellectual abilities and living skills over a period of years, arising from changes in the brain. This is the most common type of dementia.

Vascular dementia: Caused by problems regarding the blood supply to the brain.

Lewy Body: Named after the person who discovered the small protein-like bodies distributed in specific parts of the brain which result in memory loss, difficulties with language and reasoning, sometimes hallucinations or delusions, and muscular rigidity similar to Parkinsonism. This affects the sufferer's balance, with shaking and slowness of movement.

Creutzfeldt Jakob disease: A very rare, transmissible disease caused by a slow 'virus' which can lie dormant for a number of years. People with CJD normally die within six months.

Frontal lobe dementia (including Pick's disease): Shows itself by a personality change such as lack of insight and empathy, inappropriate behaviour, loss of inhibitions. The sufferer becomes easily distracted and develops compulsive tendencies.

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Other types of dementia

There are a number of other illnesses and chronic conditions that can also include dementia-like symptoms, often in the later stages of the illness. These include: Late onset Parkinson's disease; Huntington's disease; Multiple sclerosis; Thyroid deficiency; Dementia caused by head injury; HIV-related dementia; Alcohol abuse (Korsakoff's syndrome).

Is there a cure for dementia?

Most forms of dementia cannot be cured, although research is continuing into developing drugs, vaccines and treatments. Drugs have been developed that can temporarily alleviate some of the symptoms of some types of dementia, particularly for moderate stages.

Depression is a common side effect of dementia.

Can dementia be prevented?

It is likely that our lifestyles may influence the probability of dementia occurring. Factors which may reduce the likelihood of dementia include:

- Having a good education and social background.
- The size of the memory part of the brain.
- Staying mentally active - mental exercises can also help to prevent deterioration.
- Audio-visual games, reading, board games.
- Staying socially connected - meeting with others.
- Regular sleep.
- Avoiding chronic stress.
- Avoiding obesity.
- Meditation, prayer and reflection (inner peace).
- Keeping blood pressure and cholesterol low.
- Exercising for thirty minutes five times a week.¹

1. www.thehealthguide.org

Key issues

When a person suffers from dementia, they retain their long-term store of memory the longest, and lose short-term.

Communication difficulties²

Dementia causes people to experience increasing problems in understanding what is being said to them and what is going on around them. Problems with vision or hearing may add to difficulties.

Dementia and self-esteem

Once a diagnosis has been given, sufferers are likely to experience a serious sense of loss.³

- Loss of intellectual ability, affecting short-term memory and logical thinking.
- Reduced communication through poor concentration and language difficulties.
- Reduced independence if supervision is required.
- Changes in mood.

Effects of dementia on families

The diagnosis can be devastating for the family, and may involve anxiety, anger, frustration, loneliness, tiredness, guilt and grief.

The road ahead

The dementia journey is long and hard for the individual and carer alike. The challenge is how to preserve the sufferer's sense of who they are (identity), maintain connection in relationship with others, give hope, and maintain 'personhood' and a real experience of unconditional love. How can we help preserve intrinsic God-given human worth, so that the person with dementia can wear their age as a crown and not as a burden?

2. Alzheimer's Fact Sheet 401, *What is Alzheimer's Disease?* (Alzheimer's Society, 2000).

3. Richard Cheston and Elizabeth Bartlett, 'Counselling people with dementia' in T. Adams and J. Manthorpe (eds), *Dementia Care* (London: Arnold, 2003).

Dementia treatment and support

- In the early stages, there are drugs available to halt progression of some forms of the disease.
- Counselling helps the sufferer to understand what's happening, and what this will mean for them and their family. Creating a life history can help retain a sense of personhood and be a reminder of achievements, significant life events and people.
- Sufferers require emotional and practical support in the provision of appropriate activities to retain interests, meaningful roles, sufficient stimulation and choices, inclusion in social situations, and for the prevention of loneliness, helplessness and boredom.
- The sufferer will benefit from a commentary of what is about to happen, what is happening now, and what has just happened.
- Positive communication in care-giving is crucial.

Promoting health

Maintaining physical activity improves mental health, increases physical function, and reduces hidden pain and discomfort.

Nutrition: A balanced intake is essential.

Cognitive stimulation and rehabilitation: There are a variety of exercises available to stimulate our brain.

Any physical pain should be detected early.

A socially enriched environment can minimise aggression and improve opportunities for continued social involvement.

Dementia is not an unchangeable illness where nothing can be done. It is a disability which includes an individual's unique life history, personality, general health, the specific damage to a part of the brain, and the attitudes of those caring for them.

Focus on what a person can still do and enjoy, adapting their environment to use these abilities.

Dementia wellbeing

Principles essential to our core need for love⁴:

Comfort – a sense of security and warmth.

Attachment – making special attachments with familiar people and objects provides us with a sense of reassurance.

Inclusion – being involved socially with others prevents withdrawal into ourselves.

Occupation – ensuring we have involvement with important, relevant and interesting activities.

Identity – contact with others helps to maintain our sense of personhood.

Emphasis should be on preserving relationships.

Signs of wellbeing and ill-being

Wellbeing: • A relaxed body • Love • An ability to express emotions • Values/beliefs • Sensitivity to a situation • Hope • Joy • Helpful behaviour • Showing humour • Creativity • Showing pleasure • Wonder-worship • Showing affection • Peace • Initiating social contact • Self-respect⁵

A person with dementia will show the following signs if they are experiencing ill-being: • Anxiety and fear • Withdrawal • Boredom • Despair • Apathy • Anger • Physical discomfort or pain⁶

Preserving communication

Communication with people with dementia is possible, and it's not just about talking; it is also about facial expression, gesture, posture, touch, music, art. For a person with dementia, our behaviour can be an attempt at communication. So carers and family need to stop, observe and listen to be able to identify the feelings behind our behaviour and use their extensive knowledge of us as people.

4. T. Kitwood, *Dementia Reconsidered* (Buckingham: Open University Press, 1997).

5. *Nourishing the Inner Being* - Training Video produced by MHA Care Group 2002.

6. E. Bruce, 'Looking after the wellbeing: a tool for evaluation', *Journal of Dementia Care*, Nov-Dec. 2002, 25-27.