



**Caring
for Carers**

What is Dementia?



Saint Joseph's Shankill
Dedicated to Dementia Care

WHAT IS DEMENTIA?

Dementia is an illness that affects not only the brain but effects the whole person, and of course also impacts the families of those people living with dementia.

Dementia is an umbrella term used to describe a set of symptoms and behaviours that occur when the brain stops working properly. This may result in a loss of independent function for that person. There are over 400 different types of dementia. The most common types are Alzheimer's disease and Vascular dementia and you can have a mixture of the two.

Dementia symptoms can include a loss of memory, intellect, social skills and normal emotional reactions to people, places and events. A person living with dementia may look healthy, but on the inside their brain is not working properly.

Who gets dementia?

Dementia can happen to anyone, but it is more common after the age of 65. More rarely, people in their 40's or 50's or younger can get early onset dementia (usually hereditary). In Ireland, 55,000 people are currently living with dementia: 35,000 women and 20,000 men (approx).

What causes dementia?

There are many different diseases that cause dementia, there is evidence that smoking, excessive alcohol intake, certain medications, poor diet and stress all play their part in the occurrence of some of these illnesses. But for the most part the reason that people develop these diseases is unknown.

Early symptoms of dementia include difficulties with:

- Remembering, particularly recent events
- Making decisions
- Expressing thoughts
- Understanding what others are saying
- Finding the way around
- Performing more complex tasks
- Managing finances



Memory loss

Memory loss is one of the main symptoms of dementia. But memory lapses don't always mean dementia. Other medical conditions can cause similar symptoms to dementia. It is important to get an evaluation rather than assume that you, or someone you love, has dementia. Symptoms of depression, stroke, infections, severe vitamin deficiencies, thyroid abnormalities and side effects of medications can all be mistaken with dementia.

We all forget things from time to time, but the loss of memory with dementia is different. It is persistent and progressive, not just occasional. It can and will affect the ability to continue to work, and to carry out day to day, familiar tasks. People can even get lost trying to come home, or even finding their way around the home. Eventually it may mean forgetting how to dress or bathe, or recognising people even their nearest and dearest. We all forget things; like our keys from time to time, that is normal. But a person living with dementia, may not even recognise the car keys or know what they are used for.

The changes that dementia brings

Living with dementia is a highly individualised and emotional experience. Initially there may only be slight changes in personality or behaviour. A person may become less motivated to do the things that previously interested them, or reluctant to part from familiar surroundings or routines. The person can have difficulty finding the right words, or repeat themselves all the time. With the progression of the illness the changes in someone's behaviour becomes more obvious to everyone. Of course the person is often very aware of their condition themselves, which can lead to people trying to hide the symptoms from others and can be very stressful and upsetting time for both the person and their family.

Concentration, understanding and the ability to reason and respond deteriorates. People with dementia may experience confusion, distress, mood changes and even aggression as they struggle with the frustrations of everyday life. This can lead to people becoming confused about where they are, what day it is and who people are. Everyday tasks become more and more difficult.

There are many symptoms and they all carry their own impacts on the person, initially they manifest as;

- memory loss of recent events
- personality changes, such as becoming more subdued or withdrawn
- getting lost or misplacing objects
- difficulty with problem-solving and complex tasks, such as managing finances
- trouble organizing or expressing thoughts



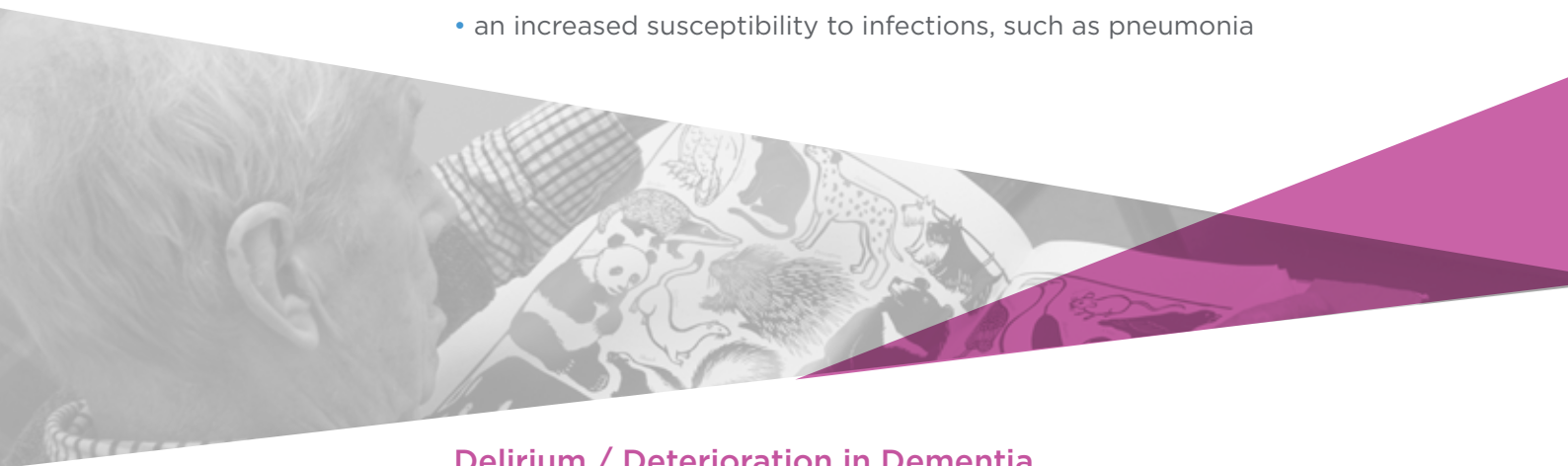
As the dementia illness progresses other symptoms become apparent;

- increasing confusion or poor judgment
- greater memory loss, including a loss of events in the more distant past
- needing assistance with tasks, such as getting dressed, bathing, and grooming
- significant personality and behavior changes, often caused by agitation and unfounded suspicion
- changes in sleep patterns, such as sleeping during the day and feeling restless at night

Later stage brings symptoms that are more limiting. Not everyone will reach each the later stage of dementia. Different types of dementia will progress differently; Alzheimer's disease is usually slow and steady in its progression, while a Vascular dementia progression is often described like a set of steps.

Later stage symptoms include;

- a loss of the ability to communicate
- a need for full-time daily assistance with tasks, such as eating and dressing
- a loss of physical capabilities, such as walking, sitting, and holding one's head up and, eventually, the ability to swallow and control the bladder and bowel function
- an increased susceptibility to infections, such as pneumonia



Delirium / Deterioration in Dementia

When people living with dementia suffer acute illnesses or hospitalisation, including fractures, infections, or dehydration they often have profound and disturbing changes in their awareness, their thinking and memory and in their emotional state. This syndrome is known as delirium. These are disorienting, fearful and distressing episodes and although they tend to resolve as the acute illness passes, their dementia may have worsened compared to prior to the acute illness.

Symptoms of each particular dementia may vary depending on which part of the brain is affected. There are many commonalities too. So at Saint Joseph's we focus on what people CAN do, their abilities rather than disabilities. We use this 'ability assessment tool' when we assess people, so we can see what stage of dementia they are experiencing.



The Four Stages of Dementia

At Saint Joseph's we work with the Naomi Feil's Four Stages Model; which has been adapted by Dementia Care Matters.

Dementia progresses differently in everyone. Each person's experience is individual to them. We recognise that there are four stages of dementia however a person may not experience each one of these stages. You will not hear GPs or consultants using these terms.

Early Experience - people living with the early experience of dementia, will be aware of the impairments that they are experiencing, they will appear to be orientated to the time of day but they may try to hide or deny that they have memory loss and other symptoms often associated with dementia. They will often be a little suspicious or defensive as they struggle with clinging to their independence.

Different Reality - This stage of dementia can be defined as when people are experiencing or living a different reality to our own. For example they may say they have to go to work or collect the children from school. When the truth is the children are now adults with their own families and they have been retired for many years. Living with a dementia they often draw upon feelings and experiences from events in their past to make sense of their feelings and experience of the world now.

Repetitive Emotion - Is a stage when people may express feelings through repetitive sounds, words or actions or utterances to communicate their feelings. The emotion is in the behaviour or motion.

Late experience - people who have intense later 'stage' dementia care needs. Verbal communication skills are often very impaired, a person may appear to have 'shut out' the outside world.

There are 100's of different forms of dementia and each has its own causes. Some of the most common forms of dementia are:

- Alzheimer's Disease
- Vascular Dementia
- Dementia with Lewy Bodies
- Frontal Lobe Dementia



Alzheimer's Disease is the most common cause of dementia in Ireland and account for 66% of all cases. Alzheimer's Disease causes a progressive build-up of abnormal clumps of protein that causes damage to the nerve cells in the brain, so the brain is unable to work as it used to. It affects memory and other mental abilities. It generally affects short-term memory first. Alzheimer's ultimately affects all parts of the brain but each person is affected differently as it progresses, this is due to the nature and extent and which part of the brain is damaged. Because each part of the brain has different functions, the effect of where the damage occurs will therefore affect the types of symptoms the person will experience.

The second most common form of dementia is **Vascular dementia** (which is secondary to cardiac disease) can occur suddenly or gradually. Occurring when blood supply to the brain reduces because of narrowing or blockages in blood vessels, resulting in brain cells damage. The most common type of vascular dementia is caused by a narrowing of the small blood vessels in the brain, or by a series of small or mini strokes, or a combination of the two. Mini strokes are called 'transient ischaemic attacks' (TIA's). Each time the person has one of these TIAs, the person's dementia may get worse quite suddenly, and then not change again unless there is another incidence of a mini stroke. People with Vascular dementia often have difficulty concentrating and communicating.



In **Lewy Bodies Dementia**, abnormal clumps of protein build up over time in the brain. These protein deposits disrupt nerve cell connections in the brain and cause changes to a person's movement, thinking, behaviour and alertness. The person's memory and other mental abilities are affected, like in Alzheimer's disease. Symptoms progress gradually over several years. Sometimes these effects vary from day to day. People often have some physical problems too, such as rigidity and stiffness, difficulty starting movements, slowness of movement or tremors/weakness of the arms or legs, clumsiness or a tendency to falls. The person may also experience visual hallucinations, (seeing things that are not there).



Fronto-temporal lobal Dementia (also known as Picks disease) affects the front section of the brain, and / or the temporal lobes (over the ears). If the frontal lobes are affected, the person will have increasing difficulty with motivation, planning and organising, controlling emotions and maintaining socially appropriate behaviour. If the temporal lobes are affected the person will have difficulty with speaking and/or understanding language. This manifests quite differently than other forms of dementia, for example a person's memory may be fine but dementia will affects their personality and behaviours and their language skills quite dramatically.

Sometimes people with **Parkinson's disease** may develop dementia which affects their memory and ability to carry out everyday activities.

Other forms of dementia include alcohol-related dementia Korsakoff's syndrome or sometimes from an infection Creutzfeldt-Jakob disease.

Currently there is no cure for dementia; there are some medications that can reduce or alleviate symptoms. There is a lot that can be done to help the person living with dementia and their family, through support, social inclusion and activity.

The best way of all to care for someone living with dementia is to stay interested in them as a person and to let them know that they are loved.



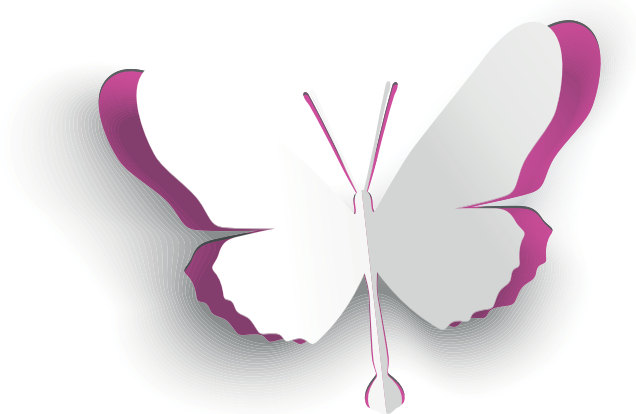
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The Dementia Care Matters Butterfly Model of Care;

Saint Joseph's Shankill is a Dementia Care Matters; Butterfly Home; that means we focus how we care on people's feelings and emotions, and ensuring that each person knows they are needed loved and still matter to us. The Butterfly Model challenges us to 'live in' or 'go to' the world of the person living with dementia rather than expecting them to conform to ours.

Each positive moment is important to a person living with dementia, as they carry those positive feelings into the next moment. You can use many of the ideas of creating positive moments at home as you are caring too.



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How to create positive moments in your home

 SMILE!	 Offer a cushion or a rug – make someone comfortable
 Say hello – greet someone by name	 Hold hands
 Give a hug or kiss	 Offer a sweet, biscuit, treat
 Shake hands/salute ‘Give me five’ – hands clap	 Blow bubbles
 Tell a joke	 Chink glasses of drink together and say ‘Cheers’
 Recite a poem	 Discuss daily news
 Give a compliment/notice appearance	 Open curtains and discuss view/weather
 Talk about the weather	 Share a bit of gossip or personal news from your own life
 Do a little dance	 Share a photograph
 Wink or wave or do a thumbs up sign	 Do ‘stone, paper, scissors’, ‘one potato, two potato...’, ‘pat-a-cake’
 Share some fruit – e.g. open a Satsuma and give half to another person	 Ask someone’s opinion or advice
 Talk about accessories – a bag, a scarf, earrings	 Look at fish or brush or stroke a pet
 Wear something funny	 Open a musical box or turn on an electronic moving or singing toy
 Put on a hat	 Walk/skip/dance arm in arm
 Smell a cream, a soap, some perfume	 Turn lights on/off
 Give a hand massage	 Brush hair
 Put on some lipstick	 Act ‘daft’ – silly face, trip up etc.
 Offer a flower to touch or smell	 Say ‘Bless you’ when someone sneezes
 Pick up an object to look at and touch	 Read from a book or magazine





Memory Box

The Memory Box contains items to remind a person living with dementia of their past such as their work, hobbies, interests. All of the people living in Saint Joseph's have a Memory Box. This is also something that you can create at home for your loved one living with dementia.

How do I use the memory box

- Pick a quiet place and limit other distractions
- Make sure the person can see the Memory Box
- Take items from the Memory Box to talk to the person about them
- Maximise the use of non-verbal communication such as tone of voice, expressions, eye contact, use of touch.

References

www.dementiacarematters.com

www.fightdementia.org.au/about-dementia/resources/help-sheets

www.understandtogether.ie/



Thank you for attending today.

Make sure to keep in touch with the people you met on the course.
You can note their names and numbers below:

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____
7. _____
8. _____
9. _____
10. _____



We would like to acknowledge the support of the Community Foundation of Ireland, the Bewley Foundation and Dun Laoghaire Rathdown County Council for their assistance in our Community Development Programme. Special thanks to all the course contributors and to Harp of Studio HB for the design work.



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