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link to Reader's Digest article [1]

brain [2] elderly [3] mental health [4]



In the powerful television drama, Elizabeth Is Missing, the main character Maud, who lives with dementia and a long-buried secret, experiences the chaotic resurfacing of memories as her sister's body is found. Meanwhile, retired doctor Jennifer Bute sees very different "glorious opportunities" amid the difficulties of her dementia.

Feeling unmoored

Maud is described as a proud woman "unmoored"; Jennifer feels "adrift", unable to anchor herself in time, place or person because of memory loss. Jennifer talks of "time travelling" in dementia [5], when people perceive themselves as living in a time in their past: one man was found clutching a knife in a care home kitchen, thinking he was back working as a chef. Losing track of time [6] can be an early warning sign of dementia; day and night clocks [7] and day of the week clocks can help.

Becoming disorientated by places and people is problematic for Jennifer. Train stations and hospitals are bewildering and most places can feel like unchartered territory. Friends are forgotten and seem like strangers and even one's own reflection can cause confusion. Jennifer recalls a woman becoming very cross when she saw in a mirror her husband kissing an older lady on the forehead, because she didn't recognise the lady as herself.

A brain unlocked

Some memories are locked away and seemingly forgotten, stored in the deep recesses of the healthy human mind. In dementia [8] they may rise unbidden creating havoc in the form of frightening hallucinations.

Jennifer has seen ambulances reversing into her upstairs bedroom and has been surrounded by swarms of bees in her visual hallucinations. Just as frightening are those involving the senses of sound and smell: she may be all alone yet hear the clatter of an old-fashioned typewriter or a baby's cry, whilst bizarrely smelling burning (tending to ignore it at her peril).

Memories re-emerge at random in dementia, and they can be mixed together in very odd ways. Unchained memories can be very unsettling, especially if other people come across as uncaring through a lack of understanding.

An unforgiving journey

When author Terry Pratchett [9] was diagnosed with dementia [10], he said, “I’m slipping away a bit at a time and all I can do is watch it happen.” Dementia is the long goodbye as a little piece of the person is stolen away week by week and month by month. The “real person” remains though, and Jennifer makes it her mission to “reach” them.

As difficult as the memory loss is the “emotional unzipping” that can happen in dementia. Jennifer describes the distress of no longer being able to control her emotions. Meltdowns can happen when she is tired or because of sensory overload. Another symptom is “sundowning [11]”, when agitation, aggression or confusion increase in the late afternoon or early evening, at dusk. It may be due to disturbances in the body clock, tiredness or medications; it’s also possible that the person is recreating their past, replaying their part in what was once their busy time of day.

Unexpected opportunities

Despite the “tough times and heartbreak” of dementia, it can also serve to highlight life lessons and home truths that every human needs to learn and listen to. That people need people soon becomes apparent, with social networks being incredibly important. Jennifer has seen a little kindness making an enormous difference [12] and her “memory groups” are places of joy, laughter, and even, sometimes, places where memories are recovered and people restored to themselves for a while.

Dementia gives the opportunity to ask what, in the end, really matters. Love and relationships are key with Professor Thomas Kitwood [13], pioneer in dementia care, summing it up when he said, “There is only one all-encompassing need—for love.” This is as true in dementia as in everyday life. When facts are forgotten, feelings remain—and love really lingers.

Sir William Thomson, Lord Kelvin, 19th-century physicist and engineer, said that, “When you are face to face with a difficulty, you are up against a discovery.” If a diagnosis of dementia helps you to rediscover love, or even redefine your idea of love [14] (challenging though it may be), as you become the helper for another, then it can be a glorious opportunity.

MEDICAL JOURNALISTS' ASSOCIATION

Source URL:https://www.helencowan.co.uk/what-its-live-dementia

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