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Awareness: The perception of dementia in the UK

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A recent YouGov survey commissioned by Alzheimer's Research UK in 2015 revealed that, when asked what they think dementia is and who it affects, just 23% of British adults specifically mentioned brain disease or degeneration... This left a huge majority believing something else to be going on. Research was carried out with families affected by dementia and the public to get a better grasp on how dementia is perceived. If we don't understand in detail the level and depth of public awareness of dementia, we won't be able to communicate effectively with people or help to educate and address misconceptions. Across the groups – regardless of their make-up – north, south, east, and west – a consistent observation was made that was certainly food for thought. The main groups questioned didn't recognise that dementia was caused by diseases – like Alzheimer's – in the brain. They didn't think about Alzheimer's in the same way they thought about cancer. To be reductive, they didn't think Alzheimer's was a "physical disease". The obvious follow-on question to ask was "what is it then?" A variety of answers were offered here: a part of ageing, just getting old, crossed wires, forgetfulness, but evidently people don't feel these symptoms are disease-driven. This misunderstanding around the physicality of the diseases that cause dementia – Alzheimer's is most common – If we can help people understand that we are dealing with aggressive and physical diseases, and not "craziness" or natural decline, it might help emancipate people to seek and talk about a diagnosis. There should not be shame in having these diseases, in the same way we don't shame people with cancer or heart disease. The terminology used around dementia doesn't help us. Dementia is often referred to as a disease in itself, which isn't quite right. We need simple language and easy analogies to enable us to understand what is going on. A point where we get the "aha" moment and realise that it's something we can learn to understand and manage. If I can briefly mention the Contented Dementia Trust- run by the fabulous Penny Garner. She paints a picture of the memory of someone with and without symptoms of Dementia by describing a photograph album. There is no mention of Hippocampus! Every single person who I have presented this analogy to has understood it completely and they themselves feel empowered at having basic understanding of the symptoms displayed. It doesn't need to be a scientific understanding. Make it real and make it life like and relatable- Once people get it – their minds by default open up to listen. The mood changes. A large percentage of the UK population living with Dementia are from socially disadvantaged backgrounds. They also represent a large portion of the cost to the Social and NHS services. These explanations would and have led to a better understanding for them. Another statistic that occasionally appears in the press is that dementia is "the most feared health condition" - sounds like a 911 warning! particularly in the over 55s. So, we have a situation where there is a lot of anxiety around dementia, but perhaps not a strong grasp of what is actually going on in the condition.

Biography

Lena Chauhan is the Co- Founder of Rise IQ, which involves Creating Solutions for Mental Health. Prior to setting up RiseIQ, she was the Co-founder of a Health-tech start-up. She is trained as a medical navigator to help empower patients and introduced the service to financial institutions. Her mission is to create awareness about Dementia.

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