


Research
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**Dementia: The Ageing
Brain and the Role of
Participatory Arts**
Key Stage 4 Psychology
Resource 4

2019



Resource Four Overview



Topic	Approaching Dementia More Positively: Theories and ways of thinking about people with dementia
GCSE Modules	Approaches to psychology, Humanistic psychology.
Objectives	<p>By the end of this resource, you should be able to:</p> <ul style="list-style-type: none">✓ Bust some myths about what it is like to live with dementia✓ Identify and compare useful humanistic theories and approaches for researching dementia, including a) the person-centred approach and b) positive psychology.✓ Better understand alternative ways to communicate and treat a person with dementia.
Instructions	<ol style="list-style-type: none">1. Read the data source2. Complete the activities3. Explore the further reading
Context	<p>To begin to understand dementia, it is important to firstly understand the brain and the structures that are affected by various dementia-related diseases, which have been covered in Resources 1, 2 and 3. Although we have briefly mentioned some of the symptoms which may affect different people with dementia, little has been discussed about what it actually feels like to live with dementia. There are many myths and unhelpful stereotypes and assumptions surrounding the topic of dementia in our society which we hope are starting to shift, thanks to greater awareness and information about dementia being made available. The following resource contains are a few myths about dementia and ways to improve how we speak about it and research it.</p>

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Data Source



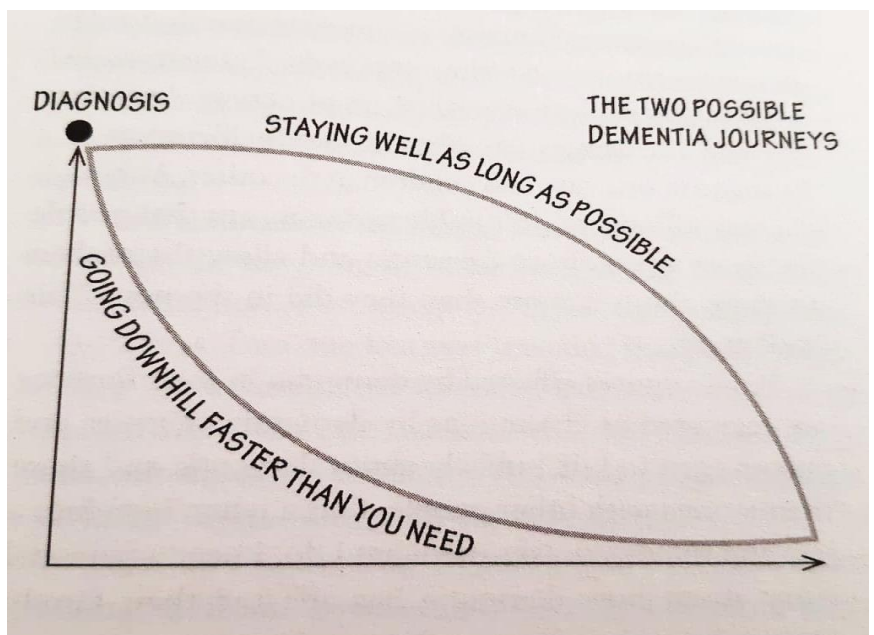
Section A

Myth-Busting



a) "A diagnosis of dementia means that life is over". Dementia is a very difficult diagnosis to receive, but this is an unhelpful attitude towards dementia which can lead to people 'giving up' on trying to live well with it. Meaningful lives are possible while living with dementia. People with dementia are very capable of continuing to live their lives as normally as possible, with the right support system around them. Instead of thinking "they are dying with dementia" we need to rephrase the sentence so that it reads "they are living with dementia and living well". Professor June Andrews illustrates this in a simple diagram in page 1 of her book:

Figure 14
The Two Possible
Dementia Journeys by
June Andrews



b) "People with dementia do not understand what is going on around them; they are like an empty shell". It is true that confusion is possible at any point in the dementia journey and people may experience difficulties in communicating – whether early or late stages of the disease progression. However, this doesn't mean that the person doesn't

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Data Source



understand you or the situations unfolding around them. Viewing them as an 'empty shell' dehumanises them and leads people to only focus on what they are losing, as opposed to what they are still capable of doing. Continue to treat the person with dementia with respect, describe their situation without negative phrases and find an alternative way to communicate with them if verbally is difficult, often using their different senses (e.g. cooking, music, dance, old photographs and objects).

c) "Dementia makes people aggressive and violent". This type of behaviour can happen occasionally, but certainly not all people become violent. Think about your own behaviour for a moment: think about a time when you were angry or feeling aggressive in the past. What made you angry? Was there a cause? What helped you calm down? Now think about someone with dementia: if they are showing some occasional aggression, some reasons for this could be frustration over their decreased ability or their worsening memory; confusion about where they are; seeing faces that seem unfamiliar and assuming they are intruders. With all these things taken into account, it is important to the environment comfortable and calming for people with dementia.

Section B

The Person-Centred Approach

The person-centred approach to dementia views the individual as playing a vital role in their care and treatment interventions, as well as reminding healthcare professionals that the individual has rights and needs which must be met. Tom Kitwood was a pioneer in dementia care and research, who developed models and approaches to dementia starting in the 1980s that focused on maintaining the personhood of somebody living with dementia. One such model is 'The Flower of Emotional Needs' (figure 15).

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Data Source



Figure 15

The Flower of Emotional Needs



When applying person-centred care in dementia, it is important to consider the following elements:

- 1) value the person with dementia, their family and their friends;
- 2) treat the person with dementia with dignity and as an individual;
- 3) attempt to empathise with the person with dementia, and consider their perspective; and lastly,
- 4) create a positive social environment and community.

A person-centred approach encourages carers, health professionals, researchers and members of the public to think about what the individual person needs to improve their well-being and adapt to their changing situation. Hence, the consideration of well-being is one of the greatest benefits of adopting a person-centred approach in health care and research, since it reintroduces the person back into a definition of what health is; this can significantly change

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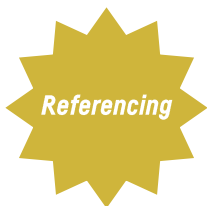
Data Source



behind the disease. This is in contrast to the biomedical model of health and medicine, which focuses more on the physical attributes of health and less on the subjective experience of an individual living with a particular illness or disease.

Section C

Positive Psychology Approach to Dementia



Another useful approach to use when working with or researching people with dementia is by using a positive psychology approach. The below definition of this approach is from 'The Oxford Handbook of Positive Psychology' by Lopez and Snyder:

"Positive psychology, the term, was first used in 1954 by Abraham Maslow in a book chapter where he noted that 'the science of psychology has been far more successful on the negative than on the positive side. It has revealed to us much more about man's shortcomings, his illnesses, his sins, but little about his potentialities, his virtues, his achievable aspirations, or his full psychological height...' (Maslow, 1954: 354). More than 40 years later, Martin Seligman reintroduced the term and proclaimed that... more attention needed to be paid to the good in people and in the world" (p.3).

Taking this perspective when considering people with dementia is very useful. Instead of looking at their shortcomings, their losses and their changes, it is helpful to consider their continued strengths, skills, interests, passions, and the ways that these things can be maintained. One way to measure this is by using Martin Seligman's PERMA model of wellbeing, which consider these five elements to be of importance to one's health, happiness and wellbeing: positive emotions, engagement, relationships, meaning and achievement.

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Data Source



Not many previous studies have applied the PERMA approach to dementia but this is something I am introducing in my own PhD research project. While observing people with dementia in my research project, I am considering the following: What types of emotions is the person expressing? Are they engaging with people or with any particular activities? Or are they very withdrawn? What are their relationships like? Are they making new friendships? Are they doing personal things in their daily lives that they enjoy? Do they still get the sense that they've achieved something today? Above all, are they focusing on what they can still do and not fixating on what they can't? While this approach is reductionist and may miss out on other factors that improve people's happiness and health (e.g. outdoor natural environments that are intrinsically therapeutic), it is a good starting point when considering what may improve someone's wellbeing.

Figure 16

Seligman's PERMA Model of Wellbeing



Resource Four Activities



Activities

1. What do each of the letters in Martin Seligman's PERMA model stand for? Write a few sentences on how each of the five parts of the model could be considered in dementia research.
2. What four things should you consider when attempting to make dementia care more person-friendly?
3. Outline two myths about dementia and explain why they are not true or accurate.
4. Briefly compare Martin Seligman's positive psychology PERMA model with Tom Kitwood's person-centred Flower of Emotional Needs. What overlaps or similarities do you see between their elements?
5. You have been asked to write some guidelines for new volunteers who will be working with people with dementia. Write a list of 10 things that volunteers should bear in mind when they are communicating with people with dementia. This list can be influenced by any material from the Resource 4's data source

Resource Four

Further Reading



Explore



Read

We have considered person-centred and positive psychology approaches in Resource 3. Below is a link to a journal paper by one of my PhD supervisors – Christine Milligan – and her colleague Carol Thomas. The paper is about how the UK society can and should adjust to dementia:

http://eprints.lancs.ac.uk/56355/1/society_adjust_dementia_summary.pdf

Read the following paper, which considers the PERMA model of wellbeing in relation to older adults and singing activities. Reference: Lee, J., Davidson, J. W., & Krause, A. E. (2016). Older people's motivations for participating in community singing in Australia. *International Journal of Community Music*, 9(2), 191–206. https://minerva-access.unimelb.edu.au/bitstream/handle/11343/194274/Lee%2CDavidson%26Krause2016_singers_PrePrint.pdf?sequence=1&isAllowed=y

Listen

A podcast on Soundcloud from the Alzheimer's Society called 'Source of Strength – Dementia together podcast June/July 2018'. This not only touches upon the experience of supportive family and friends, but also looks at the difficulties of the LGBT+ community who are affected by dementia.

Watch

'The Toddlers who took on Dementia' is a BBC programme where young toddlers were brought together with a group of older adults with dementia. Although no longer available to watch, you can find some clips in the following link or on YouTube:

http://eprints.lancs.ac.uk/56355/1/society_adjust_dementia_summary.pdf

Do

Visit the 'Positive Psychology Program' website, which offers further information on what the PERMA model by Martin Seligman is about.



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