

Long term condition information booklet

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MSc Public Health and Social Care in Practice

Community Care and Management of Long-Term Conditions

LCHS7003

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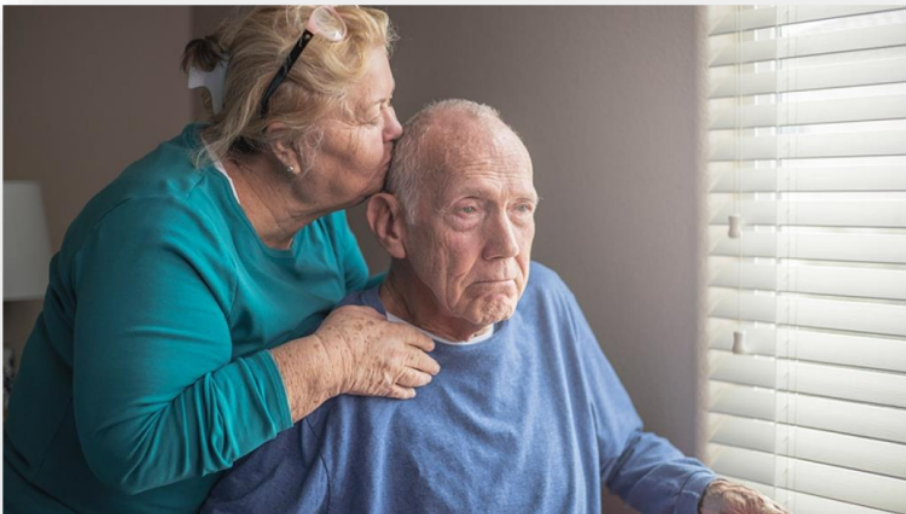
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Assignment 1: Information Booklet of Long-term Condition Management

Dementia

Information Booklet



(Gavin, 2021)

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What is Dementia?

²⁷ Dementia is an umbrella term used to describe numerous progressive diseases such as Alzheimer's, Vascular Dementia, and Lewy Bodies (Alzheimer's Association, 2019). These chronic diseases affect memory, cognitive abilities and behaviour. Additionally, they interfere considerably with a person's ability to carry out instrumental ³⁹ activities of daily living (IADL's) (⁴¹ Centers for Disease Control and Prevention, 2019). Dementia is described in the ICD-11 ⁶⁶ as the presence of severe impairment in two or more cognitive domains, which signifies a decrease from the person's prior level of functioning (World Health Organisation, 2020). It has also recently been referred to as Major Neurocognitive Disorder in the DSM-5 Criteria. This change in name is rooted in a global assumption that Dementia affects only older people and the aetiology is based upon cognitive decline, however this is not the case, as younger people are also susceptible to Dementia (Emmady and Tadi, 2022), and other risk factors must be considered, which will be discussed in the booklet.

Global Prevalence of Dementia

Dementia affects more than **55 million** individuals globally

Over **60%** of Dementia cases recorded globally occur in countries with a low or middle income

Every year, the prevalence of Dementia increases, as ⁶⁴ nearly **10 million** new cases are reported worldwide

(World Health Organization, 2023)

³⁰ Prevalence of Dementia in the UK

It is estimated that **944,000** people in the UK suffer from Dementia.

In our lifetime, **one in two** of us will be impacted by Dementia

1,000,000 people will have Dementia by the year 2030.

³³ (Alzheimer's Research UK, 2021)

Symptoms

Dementia is a neurodegenerative condition, meaning over time, nerve cells in the brain or peripheral nervous system become less functional and eventually die (NHS Inform, 2023). Therefore, the chronic condition is progressive and a patients symptoms exacerbate over time meaning symptoms range from mild to severe and can include the following:

Confusion, judgement lapses and loss of memory
Becoming disorientated or wandering in a familiar environment
Difficulties reading, writing and eventually speaking
Movement issues including loss of balanceLoss of balance and movement issues
Experiencing delusions, paranoia or hallucinations
IADL's take longer or conduct
Inability to care about the sentiment of other people
Inability to interpret conversations or express ideas resulting in repetition

(National Institute on Aging, 2021)

Aetiology and Risk Factors

The aetiology for Dementia is described as damage to the cells in the brain, whereby the damage inhibits brain cells from communicating with other cells (Mayo Clinic, 2021). Thinking, behaviour, and feelings are impacted due to the brain's communication deficit (Alzheimer's Association, 2019). The dominant risk factor for Dementia is older age, however, other non-modifiable risk factors exist, such as ethnicity, gender and genetics (National Institute on Aging, 2019). Modifiable risk factors that public health initiatives should focus on include:

- Comorbidity including diabetes, high blood pressure, or obesity
- Risky behaviour choices such as high alcohol intake, or smoking
- Poor physical health including lack of exercise, and high intake of saturated and trans fat
- Lack of exercise
- Low educational attainment

(Dementia UK, 2022)



(Very Well Mind, 2020)



(Online First Aid, 2021)

The Impact of Dementia

Dementia significantly affects ⁶⁹ the life of the person suffering with Dementia. Friends and family members who take on the role of carer or guardian are also greatly impacted, as they must now provide a new attention, and energy to ensure the persons safety and wellbeing. Most Dementia's have a gradual beginning, are progressive, and are irreversible (Dementia Australia, 2022), however the progression timeline varies from one patient to another, which results in uncertainty for both the person with Dementia (PWD) and those around them.

Physical Implication

The cognitive deficit can Interfere with a person's IADL's which enables people to live independently, such as the preparation and cooking of food, management of finances, cleaning including laundry, and transportation (Guo and Sapra, 2020). Eventually this can inhibit a person to carry out personal actions ⁵⁷ of daily living (PADL's) such as dressing, bathing and eating, thus requiring the arrangement of daily home specialist care, or specialist nurse care within a designated care facility (Dementia Care Notes, 2010).

Psychological Implication

Dementia is referred to as one of the most feared diseases among the global population, and this fear often leads to delayed screening and diagnosis (Watson et al., 2023). Following a diagnosis, communications take place with specialists regarding their unequivocal demise, with the advice to organise their assets, including appointing power of guardianship. This causes PWD's to experience negative psychological affects which is termed by Swaffer (2014) as prescribed disengagement. The person must now prepare for the loss of their own capacity and consider advanced care planning under laws and regulations such as The Mental Capacity Act (2005) which can be frightening.

Moreover, the notion of giving up your past life directly opposes many theories of ageing such as ⁴⁶ the Continuity Theory, which suggests that older individuals attempt to maintain their internal and external structures, using methods that relate to their prior experiences, and social environment (Atchley, 1989). When an individual is diagnosed with Dementia, they are unable to continue engaging in the same behaviours, relationships, and activities that they did in their earlier years, which is psychologically challenging.

Social Implication

A PWD's forced removal of independence and decrease in thinking abilities, profoundly affects their ability to socialise with family, and those involved in care provision in the following ways:

Forgetting people's names and eventually not recognising the person and acknowledging your relationship with them
Becoming more irritable and less patient due to cognitive impairment resulting in a strain on relationships
The shift in roles as an adult child or partner may become your carer can be difficult to accept
Sex and intimacy levels are affected

(NHS Choices, 2022)

PWD's experience isolation from society, and societal activities that they would have participated in daily, due to the lack of a Social Model of Care approach embedded in society. Unlike The Medical Model, The Social Model of Care depicts Dementia as an impairment that can be supported by society through suitable adaptations and societal education. Appropriate interventions can improve a PWD's quality of life (QOL), allowing them to live more closely to how they previously did prior to their diagnosis, be encouraged to make decisions, have optimal control, and have enhanced engagement in activities (Derbyshire Gov, 2014).

A PWD is faced with challenges in every day social activities such as shopping. Alzheimer's Society report that PWD's experiences whilst navigating retail settings is challenging, and simple store adaptations such as ensuring all staff wear named badges and accompany a PWD to items they are trying to locate, as well as educational Dementia training such as training security personnel on issues related to theft and mental competence, as well as training cashiers on how to empower a PWD experiencing difficulty with money recognition, can improve accessibility and help reduce social isolation (Dementia Friendly Retail Guide, 2018)

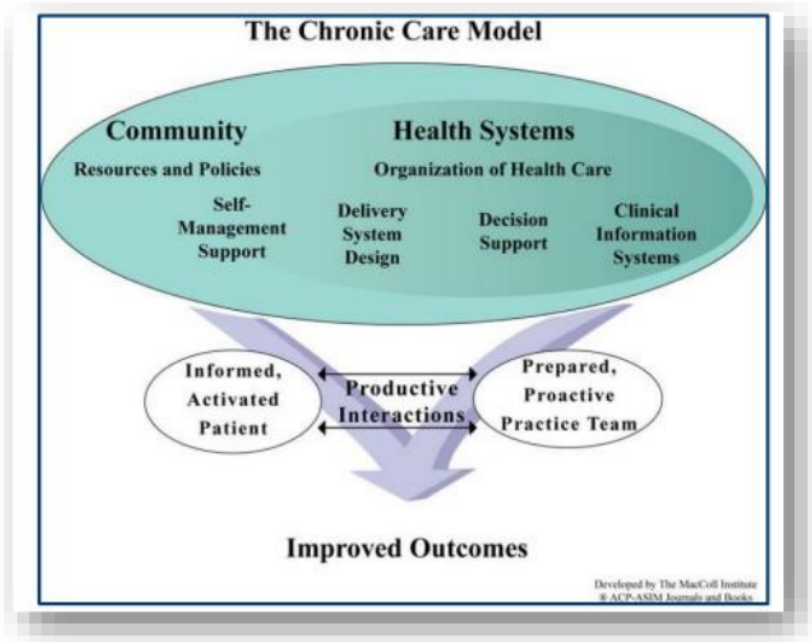


Theoretical Perspectives and Models for Improved Outcomes for Patients Affected by Long-term Conditions

Patients with complex morbidity, including Dementia account for a large share of healthcare spending, furthermore unmet social needs may exasperate their health care needs (Soley-Bori et al., 2020). Theoretical perspectives and models for improved outcomes help to provide guidance for practitioners that examines the whole picture of a person's health needs, including improving patient safety, ensuring continuity of care, effective management of their condition both medically and socially, and ensuring patient self-activation (University of Southern California, 2021).

International

An example of a model used globally is The Chronic Care Model, produced by Wagner in 1998, which aims to shift chronic illness patients' everyday treatment from acute and reactive to 'proactive, planned, and population-based' (Garland-Baird and Fraser, 2018).



The model can help to improve outcomes for patients with Dementia by presenting health care solutions for managing this rising burden, focusing on the following six elements:

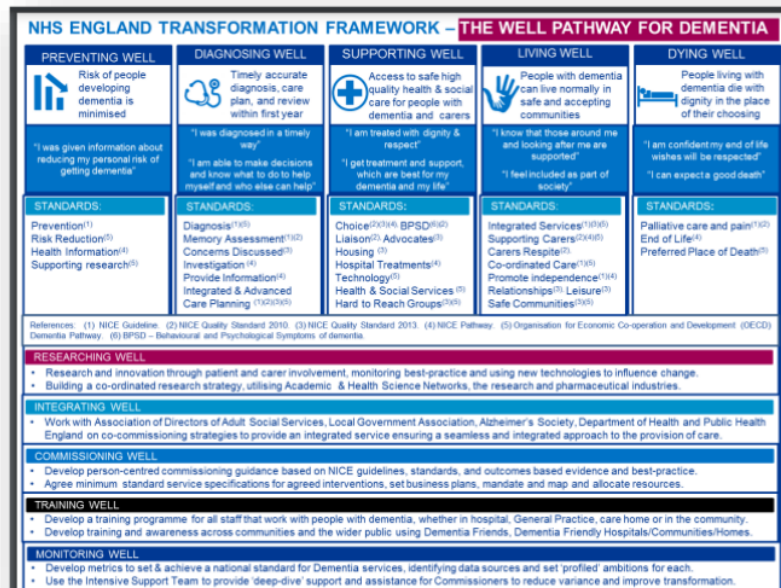
The Community	The Health System	Self-Management Support
Delivery System Design	Decision Support	Clinical Information Systems

The Chronic Care Model places emphasis on patient activation, working together with a prepared proactive coordinated health and social care team who have meaningful interactions, effective resources, and governing policies to ensure consistency in patient outcomes and best practice (Center for Accelerating Care Transformation, 2021). This model is fundamental to Dementia care guidelines in order to improve the quality of care. Due to the unambiguous disease trajectory, including symptoms such as loss of capacity, factors such as decision support, community based support to promote independence for as long as possible, and Dementia informed healthcare staff are pivotal in maintaining a good QOL for patients and their designated carers.

National

The UK is experiencing an ageing population, with the number of Dementia cases predicted to rise exponentially over the coming years (Centre for Ageing Better, 2022). The NHS have developed a transformation framework and pathway for Dementia, called 'The Well Pathway for Dementia' (NHS, 2016). This pathway seeks to streamline and standardise care procedures in order to improve organisational effectiveness and maximise patient outcomes (Lawal et al., 2016).

A key element of The Well Pathway for Dementia is the delivery of high-quality, National Institute for Health and Care Excellence (NICE) evidence-based recommendations in each phase of the Well Pathway. There is a focus on improved patient outcomes in the following domains: Preventing Well, Diagnosing Well, Supporting Well, Living Well, and Dying Well. Additionally, benchmarks for internal practices are incorporated to assist in the adherence to the NICE standards which include Researching Well, Commissioning Well, Integrating Well, and Monitoring Well.



(NHS, 2016)

Despite the clarity the Well Pathway model aims to provide, some researchers have questioned the suitability of a 'pathway' for a disease like Dementia, with unpredictable progression of symptoms, and the need for complex health and social care. Although the idea of bringing certainty to the Dementia journey using a 'pathway' is understandable, patients and carers, when completing elements such as advanced care planning struggle to foresee a realistic timeline for the PWD. Furthermore, PWD's who often suffer with multimorbidity are subject to further confusion from being seen under several pathways (Samsi and Manthorpe, 2014).

Local and National Political Health and Social Care Agendas

A UK health agenda is a crucial publication that summarises specific health issues that government, along with NICE, the NHS, national organisations and health care professionals are paying attention to within a specific time frame. The aim is to improve patient outcomes and bring about beneficial change to society (Shiffman, 2006).

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Prime Minister's Challenge on Dementia 2020 Implementation Plan

This plan was released under the Conservative and Liberal Democrat coalition government in 2015, and outlines over 50 commitments which the government hopes to achieve by 2020 within Dementia care, with the aim to be the best country in the world for Dementia care and support for PWD's, their family and carers. As well as the leading country for Dementia and other neurodegenerative illnesses research' (Department of Health, 2015).

These commitments included:

- **Investment of over £300 million into dementia research and innovation**
- **More Dementia friendly communities**
- **More targeted inspection of Dementia care in hospitals**

(GOV UK, 2016)

A review was conducted in 2018 to determine if these plans have been met. This provided a summary of the challenges stakeholders faced, its current state, and what was planned for the agendas remaining time. "Overall, respondents felt that we are on track," the government said in a statement, with specific mention of a £344 million Dementia research spend, which surpassed their target (Department of Health and Social Care, 2019).

However, national flagship charities advocating for Dementia such as Alzheimer's Society have conducted investigations such as 'Dementia – The True Cost: Fixing the Care Crisis' which have determined the following:

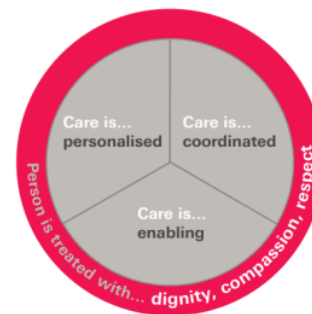
- **PWD and their families are faced with devastating care and support costs compared to the costs associated with other medical conditions**
- **Accessing necessary care is a struggle**
- **Care and support are described as of a poor quality once diagnosed with Dementia**

(Alzheimer's Society, 2018)

Improvement of Person-Centred Care Approaches

Person-Centred Care and Dementia

Person-centred care is achieved when a person's physical, psychological, and social requirements are met (Kitwood, 1997). The central goal of person-centred Dementia care is to maintain personhood through the deterioration of mental abilities. This can be achieved by empathy with the individual, seeking to learn about their history, their interests and values to understand their needs (Buron, 2008). A diagram illustrating the components of person-centred care can be seen below.



(The Health Foundation, 2016)

As well as treating their religious, cultural, or spiritual needs with respect, delving deeper into a person's interests, morals, and values provides PWD's with the opportunity to have relationships and conversations with other people, and ensures that they have the chance to take part in activities that they enjoy (Alzheimer's Society, 2019). Overall, this results in fewer primary, secondary, and tertiary care visits for unplanned health and social care needs. This can help to reduce the UK's health care costs for people with Dementia, which is currently £3.8 billion, and social care costs exceeding this threefold at £10.2 billion per annum (Wittenberg et al., 2019).

Social Prescribing and Personalised Tailored Activities

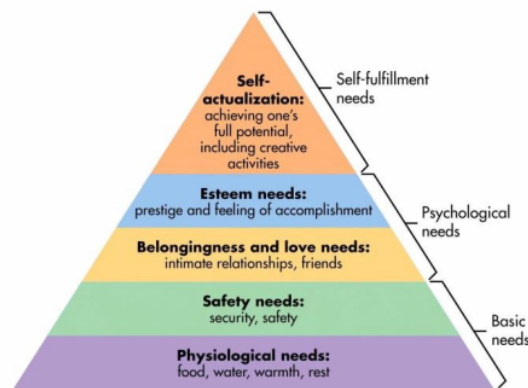
Social prescribing is an all age, national approach that has proven itself to be an integral element of delivering personalised care. It is person-centred as it connects individuals with chronic health conditions, those who suffer with poor mental health, or people experience loneliness to local non-clinical activities, groups or services that address their practical, social, and emotional requirements (Buck and Ewbank, 2020). A link worker is utilised, who takes a holistic approach through reference to the NHS Social Prescribing Model (see below) to effectively connect people to the most suitable services.



(NHS England, 2017)

This initiative serves as a meaningful activity for PWD's by providing social connectedness, mental stimulation and physical activity. However, the type of activity relevant to a PWD is determined by the stage of Dementia the person has. A study by Roland and Chappell (2015) whereby carers were asked about their thoughts regarding meaningful activities, reported that the feeling of connection and happiness for the PWD when participating in activities, regardless of the cognitive ability or care dependency, makes it beneficial and valuable. Moreover, the Activity theory states that elderly people who continue to engage in community-based activities or groups experience improved psychological and physical well-being compared to those who withdraw from society (Fernández-Mayoralas et al., 2015).

Furthermore, it enables PWD's to retain their ability to self-actualise by partaking in creative activities and hold themselves in good esteem by accomplishing task set in activities or personal goals. It also provides PWD's with belongingness. This correlates directly with Maslow's Hierarchy of Needs, which attains that humans require certain physiological and psychological needs. For a PWD to solely have their basic needs met will not provide a good QOL (Jackson et al., 2014). It is determined that social prescribing helps to fulfil these needs for a PWD and result in improved patient outcomes.



(Maslow, 2013)

Contrastingly, studies including randomised controlled trials and controlled clinical trials of PWD's experiencing personally tailored activities demonstrated that individually designed exercises may not have much of an impact on overall restlessness, hostility, uncooperative attitude including verbal and non-verbal behaviour outside of the activity (Renom et al., 2013). Therefore, further research is needed to determine which personalised activities at which stage of a Dementia journey works best to provide benefit to the patient outside of the intervention.

Technology for Self-Management

Technology has significant promise to enhance both the care given to those who have ⁶⁷ Dementia and the quality of life for the family members who are caring for them (Xie et al., 2020). They can seamlessly and subtly manage and monitor symptoms or health changes fostering independence for longer, and personalising the care or intervention needed based upon the individual, rather than a blanket approach for PWD's. These types of technology include:

- **Robotics:** Alerting of safety risks personal to their daily behaviours
- **Sensors and home testing:** Monitoring of health vitals in the comfort of their home
- **Artificial Intelligence:** Tackling loneliness through AI led conversations, and alerting potential health risks due to changes such as elevated temperatures
- **Tracking and Monitoring:** Providing carers with the ability to locate the PWD, and removes fear of risks to their safety

(Alzheimer's Society, 2019)

Importantly, legal and ethical issues of AI must be considered in the implementation of the above technology to improve person centred care. These considerations include gaining consent, privacy and data protection, fairness of algorithms, safety and regulatory standards, as well as not removing the importance of human touch (Gerke, Minssen and Cohen, 2020).

⁶⁵ End of Life Care

⁴³ Advance Care Planning is a crucial element to ensure a PWD's wishes can be carried out in their last months, weeks and days of life. Thus, when this is completed, plans can be made to ensure direct carers as well as health teams such as palliative care and hospices can aid in ensuring QOL for the patient and carers at this time (National Institute on Aging, 2019). PWD's ⁴³ who are approaching the end of life, are subject to anticipatory healthcare planning which is referred to as advance care planning. This process is completed at the beginning of their Dementia journey, in preparation for a loss of capacity resulting in the inability to make decisions regarding their care preferences. Advanced care planning must include ⁷¹ the person, and their family or carers, whilst utilising 'the principles of best-interest decision-making' (NICE, 2018).

Dementia patients in the end of life can experience high levels of pain. Recognition of pain is important to ensure person centred care at this time, however this can be difficult for healthcare workers who must rely on verbal and non-verbal cues from the patient when deciding the level of pain management to provide (McGuire et al., 2016). It is recommended that continuous professional development training in this area is imperative for all nurses, health workers and specialists involved in end-of-life Dementia care, to fulfil a person-centred care approach, and adhere to the advanced care plans that have been predetermined by the patient (SCIE, 2015).

Conclusion

This Dementia information booklet provides an insight into the management of Dementia for both the patients and caregivers. The global Chronic Care Model and The Dementia well Pathway were examined to determine their effectiveness in approaching the improvement of Dementia care within the UK. The Prime Ministers agenda to become the leading country for Dementia care and research provided clear aims and objectives, however studies from national organisations such as Alzheimer's society identified distinct shortfalls which should be addressed. The focus on person centred care, predominantly using technology such as AI, social prescribing, meaningful activities and personalised end of life care can help to ensure improved outcomes for PWD's in the UK.

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