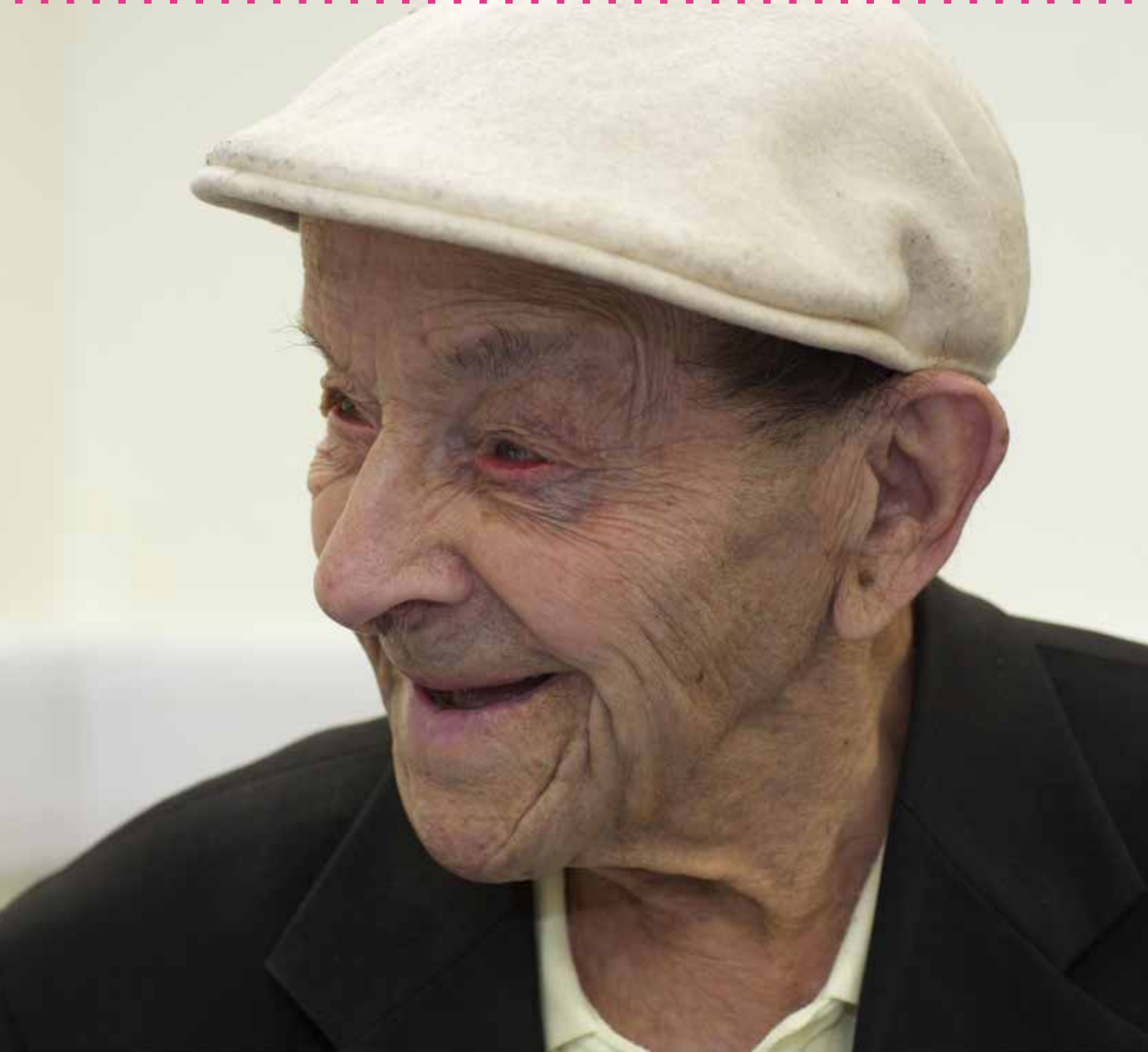
Transition to Care Home Nursing

Section B - Working in the Care Home with Nursing Setting

Chapter 5 - Dementia Care

A resource in the QNI's 'Transition' series, designed for registered nurses with an interest in working in a care home with nursing and for those who are already in this area of practice, who would like an update on current practice and approaches.



Section B - Working in the Care Home Setting

Chapter 5 - Dementia Care

Completing this chapter will enable you to:

- Develop your understanding of the prevalence of dementia and current guidelines and policies to improve dementia care in England and Wales
- Define what dementia is, symptoms and some of the treatments options available
- Understand your role as a registered nurse in a Care Home when providing high quality care for people with dementia.

Introduction

Dementia is one of the biggest challenges faced by an ageing population in the UK today, and some people with dementia will spend time in a care home either for respite or permanently. A brief overview will focus on symptoms and types of dementia and the treatment options available. There will be scenarios for individual and/or team reflection and discussion.

Here are some Dementia related facts:

- Every three seconds someone in the world develops dementia and it is the leading cause of disability and dependency as people age. There are approximately 700,000 people in England with dementia and with our aging population this figure is projected to double in the next 30 years.

- Dementia is insidious, does not discriminate and claims more lives than heart disease, cancer or any other serious illness. The disease costs the UK economy £23 billion a year. By 2040 the costs are likely to treble[1].

- 12% of deaths in 2016 (62,948) in England and Wales were as a result of dementia. This highlights how widespread the condition actually is and why the development of a cure or effective treatment is so important

- According to figures from the Office for National Statistics (ONS), women are more likely to die from dementia than men as they live longer so have a greater chance of developing it. In 2016, there were 41,747 female deaths, compared to the 21,201 male deaths[2].

- Over-65s are thought to be more at risk of dementia, because of increased blood pressure and the way the immune system changes as it ages. Death rates from the condition have more than doubled in the last five years and, as other illnesses have received better treatments, advances in medical care for dementia has remained largely unchanged.

A recent update by the Alzheimer's Society estimates there are 42,325 people under the age of 65 years with early-onset dementia in the UK, although other estimates are higher. This makes up between 5 and 8% of the total population and more men are affected than women. People with Down's Syndrome and other learning disabilities tend to develop dementia at a younger age due to their genetic make-up[3].

- There are approximately 25,000 older black and ethnic minorities (BME) with dementia in the UK and sometimes there is a delay in their families seeking support, due to cultural beliefs and stigma. Language barriers can also pose additional problems, both for spoken and on-line information[4].

Figure 5.1 Factors related to care homes and dementia:

There are approximately 421,100 people in Care Homes in the UK (Laing and Buisson, 2017).
Over 42% of Care Homes are registered as providers of specialist dementia care.
More than 300,000 people with dementia live in Care Homes most with high dependency, challenging and end-of-life care needs.
Between 70-80% of people living in a Care Home will have a dementia, but not all of them will have a formal diagnosis.

Government policies to improve dementia care support and research in England, Wales and Northern Ireland probably started in 2001 with the National Service Framework for Older People as a response to the 2000 Audit Commission's report entitled 'Forget me Not'. The policy responses are shown in Figure 5.2 overleaf.

Figure 5.2 Government policies to improve dementia care support

2006	National Institute for Clinical Excellence & Social Care Institute for Excellence (2006). Dementia: supporting people with dementia and their carers, Clinical Practice Guidelines London, NICE. http://www.scie.org.uk
2009	The National Dementia Strategy – Living well with dementia –key themes: • Raising awareness of dementia and removing stigma • Improving diagnosis rates • Good quality early diagnosis and intervention for all. • Increase in the range of services • Improved quality of care in general hospitals. • Living well with dementia in Care Homes. • Reduced use of antipsychotic medication.
2010	Dementia quality standard 1 - NICE guidance on how services should be commissioned and co-ordinated across the whole dementia pathway
2012	The Prime Ministers Challenge – three key areas • Creating dementia friendly communities • Driving improvements in health and care • Better research
2013-2017	Northern Ireland Executive's Dementia Signature Programme – raising awareness, information and support for people living with dementia- including Dementia Navigators in each of the five Trusts and Dementia Champions throughout NI.
2014	Dementia Friends and Dementia- Friendly communities – an initiative to recruit one million 'Dementia Friends' who are able to recognise symptoms and support people with dementia
2015	The Prime Ministers Challenge on Dementia 2020 – focussed on boosting research • To be best country in the world for dementia care and support for people with dementia • The Dementia Research Institute - the best place in the world to undertake research into dementia and neurodegenerative diseases • The Dementia Discovery Fund – the Secretary of State for Health announced a £100 million pound funding at the World Health Organisation's First Ministerial Conference on Global Action Against dementia
2016	• Welsh Government – published report ' that dementia is people's biggest health worry in Wales' • Making a Difference in Dementia- Nursing Vision and Strategy (refreshed edition) Building on the work started in 2013- see references/further reading
2017	Theresa May announced a 'dementia tax' government initiative that she swiftly did a 'u turn' on once she realised that this was extremely unpopular with the voting public

> “ Dementia is insidious, does not discriminate and claims more lives than heart disease, cancer or any other serious illness.

What is Dementia?

Dementia is an umbrella term used to categorise a collection of symptoms caused by chemical and structural changes in the brain which eventually affects functioning such as; memory, understanding, language, judgement and thinking. The changes are progressive and normally affect people over 65. Over time they can become severe enough to interfere with daily life and impact on someone's well-being or behaviour and in some cases leading to admission to a care home.

Symptoms of Dementia

The symptoms of dementia usually occur in three domains:

1. **Functional changes** including difficulties with activities of normal daily living such as personal care, driving, using money, cooking a meal or crossing a road.

2. **Cognitive changes** that may affect speech, language, ability to recall events or remember conversations, ability to understand instruction, getting day and night muddled or becoming confused about where they are.

3. **Behavioural and psychological symptoms in dementia (BPSD)**: These are changes in personality and behaviours that may lead to agitation, anxiety and aggression and can be challenging to both the person and their carers

Types of Dementia

Although there are many types of dementia, Alzheimer's disease, vascular dementia, mixed dementia, Lewy Body, Dementia in Parkinson's disease and Frontotemporal dementia are generally the most well-known.

Alzheimer's Disease (AD)

Alzheimer's disease is the most common type of dementia and damage in the brain may have started 10 to 20 years before any problems are evident. Tangles begin to develop deep in the brain in an area called the entorhinal cortex and plaques form in other areas. As more plaques and tangles develop healthy neurons begin to be affected and lose their ability to function and communicate with each other. This process then spreads to a structure in the temporal lobe called the hippocampus (because it looks like a seahorse), which is important in forming memories. There is no straightforward test for Alzheimer's disease and diagnosis is usually made by excluding other causes which present with similar symptoms.

Vascular Dementia

Vascular dementia is the second most common type and is a degenerative disease that leads to a progressive decline in memory and cognitive abilities because of poor blood circulation to the small vessels in the brain. This can be due to the blood supply carrying oxygen and nutrients being interrupted by a blocked or diseased vascular system. Commonly, it is caused by a series of tiny strokes that often go completely unnoticed and cause damage to the area associated with memory, learning and language. Sometimes these strokes are referred to as TIAs (Transient Ischemic Attacks), which result in temporary, partial blockages of blood supply and impairment in consciousness or sight. Symptoms of Vascular dementia are similar to AD.

Mixed Dementia

Mixed dementia is when symptoms characteristic of more than one type of dementia exist together. The most common form of mixed dementia is Alzheimer's disease and vascular dementia, but in some cases more than one other dementia may be involved. Studies have suggested that mixed dementia may be under diagnosed especially Alzheimer's and vascular dementia as often the risk factors and symptoms are the same.

Lewy Body Dementia (LBD):

Its name comes from the presence of 'Lewy Bodies' or abnormal lumps of proteins which develop inside dying nerve cells. The Lewy Body contains a protein; 'alpha-synuclein' that is linked to Parkinson's disease and other disorders. In the early stages, DLB can mimic Alzheimer's disease but the condition can progress differently from AD, with hallucinations, fluctuations in cognition, falls or changes in mobility, Parkinsonism and variation in personality. There can also be extreme sensitivity to antipsychotic medications. LBD seems to be twice as common in men as women, whereas AD is more common in women.

Parkinson's dementia (PD)

It is known that around 80% of people with Parkinson's will develop dementia. Symptoms are similar to LBD but if the Parkinson's has been established for some time then it is known as Parkinson's Dementia and if the dementia developed before or around the same time the Parkinsonism (movement disorder) it is called LBD.

Frontotemporal dementia (FTD)

This is one of the more rare forms of dementia and covers a number of conditions including Pick's disease. The symptoms can be quite varied, although primarily due to damage in the frontal and temporal areas of the brain. It tends to present in younger age groups and is relatively more common in those under 65. In the early stages it can be a difficult condition to diagnose because the changes can be quite subtle. People may notice changes in personality and behaviour and, early on, there may be only minor memory problems.

Pseudo-Dementia

This is a term used to describe conditions that can affect memory but are not a dementia, the key being they are treatable and reversible whereas dementia is not. Depression is often mistaken for dementia as is anxiety, stress and certain medical conditions such as fibro-myalgia,

diabetes and the menopause to name a few. Delirium can be mistaken for dementia and affects around 14% of care home residents (Dean 2017).

How is Dementia Treated?

It is important to remember there is no cure for dementia and the focus of treatment centres on enabling the person with dementia to live well with the condition.

Drug treatments

There is a group of drugs called cognitive enhancers that can improve some of the symptoms by giving the appearance of slowing down the progression of the condition. They are not suitable for everyone due to side effects and contra-indications and work for about 60% of people. They can help maintain thinking, memory, language skills and activities of daily living and help with certain behavioural problems, but the underlying disease is unchanged.

Non-Drug Treatments and Support

There are a wide range of non-drug treatment options for people with dementia and they can be quite effective in the earlier stages when the person still retains the cognitive plasticity to benefit from the intervention. These include counselling, cognitive behavioural therapy (CBT) and Cognitive Stimulation Therapy (CST). As the disease progresses interventions such as music and reminiscence therapy can play an important part, however, this needs to be done sensitively if at all if the person is Lesbian, Gay, Bisexual or Transgender (LGBT). A controversial therapy used in a growing number of care homes is the use of dolls which is said to reduce anxiety and distress.

Research

Research into cures for dementia has continued to grow over the past few years and now with the 'Join Dementia research' (JDR) project, anyone including healthy participants can volunteer to take part.
www.joindementiaresearch.nihr.ac.uk

Nursing people with Dementia in a Care Home

Often people who have dementia are looked after by their families for as long as possible before being admitted into a care home. This means they can be at a later stage in the disease and require more skilful interventions. People with dementia in a care home have the same rights as everybody else to high quality nursing care from knowledgeable adept staff. However, challenges may become apparent such as confusion, disorientation and distress about where they are or why they are living with other people they do not know. A skilled care home nurse needs to balance unique individual care as well as consider the welfare of the other residents. Adopting an interpersonal, social and person-centred model of care, such as advocated by the late Tom Kitwood, will promote a positive and respectful approach to each resident, (Kitwood 1997).

These are some of the ways this can be achieved:

- **Building and maintaining a relationship with the person and their family.** It is really important to get an understanding of the patient's life history and some insight of how they were before they developed dementia. Take the time to listen and show interest in their lives and what makes them happy.

- **Understanding the unique experiences of a person living with dementia.** In addition to having an excellent understanding of the pathologies involved in dementia, one of the most important requirements for the role of the care home nurse is a high level of assessment skills, not just of paper-based tests, but also in observation of the patient and their surroundings. Facilitating regular reviews of clinical care, such as

> “ One of the effects of dementia is that the person can feel like they are losing control, which is why they can be resistant to accepting professional help.

medication and therapeutic interventions, are also within the scope of the care home nurse. Providing suitable intervention to prevent a crisis will help reduce the need for antipsychotic drugs or the need for hospital admission due to infection.

- **Responding to behavioural changes.** Behavioural change can be due to many factors and a proficient nurse should be aware of how these changes developed. Was it sudden suggesting infection, pain, a drug reaction or even a change in routine, or more gradual as a result of the progression of dementia? Is it continuous or only at certain times of the day? Is there a pattern to it? Could it be due to hunger or thirst a change in temperature or a dislike to another resident or staff member? What is the person doing; are they agitated, shouting, moaning, crying, pacing, fidgeting, hallucinating or unusually withdrawn? Understanding the cause is vital to helping the resident so a good history and physical examination are important to rule out any underlying physical reasons. Skilled communication to ease agitation and avoid escalation include distraction, limiting stimuli such as background noise, reassurance and calm positive statements and if possible moving the person to a more restful environment (Turkington and Mitchell 2010).

- **Respecting the person and their family and treating them with dignity and compassion, taking account of their culture.** One of the effects of dementia is that the person can feel like they are losing control, which is why they can be resistant to accepting professional help. Sometimes, moving to a Care Home environment can accelerate the feeling of losing control. Ensuring that the person is professionally cared for in an environment where they feel comfortable and not threatened plus enabling them to make their own decisions and maintain familiar routines can have very positive outcomes.

Admiral Nurses

Where the complexities of care are high, a specialist nurse maybe best placed to provide support and advice. Established by Dementia UK in 1994, the role of the Admiral Nurse offers specialist assessment skills as well as providing information and practical support on different aspect of care. The Care Home model of Admiral Nursing is evolving slowly and provides a more practice development function. Admiral Nurses are not available in all areas and may require specific referral criteria. There is a helpline: 0800 888 6678 were you can get advice and support.

Innovations and Activities

Like non-drug treatments, there are many different activities for the care of people with dementia. As with everybody, people with dementia may respond better to one intervention than another. Innovations range from art therapy, handling objects, storytelling, reminiscing and singing. Listening to music can assist with agitation as can pet therapy. There are also projects around intergenerational activity between young people and people living with dementia. All are aimed at improving communication, well-being and helping with recall of pleasant memories.

Assistive Technology

The use of Assistive Technology is gaining popularity in care homes and includes any aid that can assist the frailest most vulnerable members of our society to live safely either at home or in a Care Home environment. Gadgets such as motion sensors, virtual door and exit sensors help to keep people safe especially if they are frail and prone to falls. More information is available here: https://www.icarehealth.co.uk/blog/assistive-technology-improve-dementia-care/

Life Story Work

Our life experiences shape us as individuals and this helps others to understand who we are as a person. People with dementia sometimes need help to communicate significant aspects of their identity like their background, interests, who and what is important to them.

Life Story work is an activity in which the person with dementia is supported by staff and family members to gather and review their past life events and build a personal biography. It is used to help the person understand their experiences and how they have coped with events in their life. Again it can be a sensitive issue for someone who is Lesbian, Gay, Bisexual or Transgender.

Activity

Make a list of the types of activities available in your care home for people with dementia and consider how these activities assist in making people feel included in the home.

Lesbian, Gay, Bisexual or Trans Gender

Dementia is challenging for everyone, and everyone's situation will affect what living with dementia is like for them. However, being LGBT and having dementia can present extra difficulties and it is something that you do not hear talked about as much. If you are caring for a lesbian, gay, bisexual or trans person who has dementia in a care home, this booklet describes how you can help them live well with the disease. https://www.alzheimers.org.uk/download/downloads/id/3629/lgbt_living_with_dementia.pdf

Advance Care Planning and End of Life Care

Ideally everybody living in a Care Home should have an Advance Care and End of Life Care plan but currently this is not the case. Like Life Story work this can be an important way to involve the individual (if they are able), family and carers in one of the most important aspects of care providing peace of mind for the future (O'Kelly et al 2015).

Quotes from experienced nurses working in care homes

'It is caring for people whose brains are so damaged by disease their dementia renders them incapable of taking responsibility for their hygiene, personal care and daily lives.'

'It is caring for people whose judgement is so diminished they cannot take responsibility for their actions and who as a result engage in unacceptable risks.'

'When people with dementia know they need us, they need us least; when they need us most, they know they do not need us at all.'

Reflection trigger point – what would you do if…?

These reflection triggers are for you with your mentor and other appropriate team members to debate possible solutions. They could be used as a basis for a discussion, revalidation reflection or even a teaching session. We are aware that the solutions to these triggers may vary from Care Home to Care Home according to local policy and procedure. We are also aware that there may be no 'right or wrong' answers to how certain situations might be tackled and therefore it will be for you as a qualified nurse to apply your problem solving within the parameters of your professional practice.

1. Caroline has been living in the Care Home for the last fifteen years and has dementia. In the last month, she has been diagnosed with end stage cancer of the pancreas with secondary spread. You have observed deterioration in Caroline both mentally and physically. Discuss how you would address and meet Caroline's care needs at the end of her life

2. Maximillian has early onset Dementia and has lived in the Care Home for the last twelve years. Max's short-term memory is particularly failing and he keeps forgetting whether he has had a drink and to eat his meals. At his last routine weigh in he had lost seven pounds in weight. How can you work towards Max getting sufficient nutritional and fluid intake on a daily basis to maintain his weight?

3. You are working with a resident in your home that is becoming increasingly more aggressive and violent towards male staff members in particular. They seem to take a long time to 'calm down' and you notice that other patients are finding it difficult to be around her. How might you address this level of aggression?

4. You notice that two of the residents have become quite close and enjoy each other's company. They often sit holding hands which causes distress when their partners come to visit. How can you sensitively approach and resolve this situation?

Summary

The chapter has raised some awareness of the prevalence and importance of dementia in the Care Home setting and the significant role that the nurse plays when caring for people with dementia. The complexity of this kind of care can at times be overwhelming and it's important to have regular supervision as well as seeking support and advice from colleagues and other health and social care professionals in this aspect of care.

> “ Being assertive does not always mean you get what you want, but it can help you achieve a compromise.

Further Resources

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O'Kelly, A. Fullick, W. Richards, G. (2015) Out of the closet, into a difficult place in later life. Journal of Dementia Care, 23, (3), p.p. 22-24 May/June

- Managing behavioural and psychological symptoms of dementia https://www.alz.org/documents_custom/hcp_MD_BPSD.pdf
- Parkinsons https://www.parkinsons.org.uk/information-and-support/dementia
- Frontotemporal dementia support www.ftdsg.org
- Guidance for using the Life Story Book template http://www.dementiauk.org/wp-content/uploads/2017/03/Lifestory-.compressed.pdf
- Advance Care Planning and End of Life Care ww.mariecurie.org.uk/globalassets/media/documents/commissioning-our-services/past-initiatives/end-of-life-care-and-dementia/end-of-life-project-report.pdf

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3. https://www.alzheimers.org.uk/download/downloads/id/1766/factsheet_what_is_young-onset_dementia.pdf

4. https://www.scie.org.uk/dementia/living-with-dementia/bme/

Notes on the chapter