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Dementia friendly dentistry for the periodontal patient Part 2: Ethical treatment planning and management

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Abstract

This is the second of two articles, which provide a guide to aid the clinical management of people living with dementia who present with periodontitis in dental practice. Guidance is provided to encourage optimal treatment planning and periodontal care for patients with dementia. Best practice in relation to UK statutory legislation, which governs the rights of those with impaired capacity, is also covered. Although the articles centre on periodontal care, much of the content is equally applicable to the wider general dental care for the dementia patient.

Key points

- Provides a guide to periodontal treatment planning for patients who have dementia.
- Describes appropriate preventive advice for dementia patients.
- Indicates realistic dental treatment aspirations based on dementia severity.
- Highlights pertinent legislative requirements that are associated with the capacity for consent and safeguarding vulnerable adults.

Introduction

It has long been recognised that oral hygiene becomes increasingly difficult as the symptoms of dementia advance¹. As cognition deteriorates, the risk of developing dental caries and periodontal disease increases¹⁻⁵. Furthermore, for a proportion of susceptible individuals, periodontitis is implicated in the causation and/or the neurodegeneration of Alzheimer's disease⁶⁻¹⁰. The rate of cognitive decline has been found to be greater in those who have periodontitis, compared to those who do not¹⁰. Although further studies are needed to corroborate this, the available evidence clearly indicates that good quality periodontal care for those with dementia is paramount to their wellbeing. The potentially detrimental disease cycle and linked pathogenesis between periodontitis and dementia could also impact on both the behavioural and tissue response to periodontal treatment. Thus, achieving periodontal stability for those who have co-existent dementia is likely to be challenging.

The rise in dementia diagnosis and prevalence¹¹ combined with greater carer awareness of oral health needs, means that dentists in general practice are more likely, than ever before, to be caring for an increased number of patients who have both dementia and periodontal disease. The care of this patient group presents a number of challenges, these need to be recognised and accommodated when planning and conducting dental treatment.

Periodontal risk, prognostic & treatment planning implications of dementia

Dementia can increase a patient's risk of developing periodontitis and other primary dental diseases^{1 12}. This is due to several contributing factors including:

- Dementia stage and associated functional impairment.

- Limitations in the ability and amount of carer involvement during preventive routines.
- Dry mouth, as the result of medications used in the management of dementia, dehydration and co-existent medical conditions.
- Limitations in ability to co-operate with dental treatment and comply with preventive routines.
- Degree to which a non-nutritious cariogenic diet is used to manage medication and behavioural needs.
- Limitations to accessing dental expertise, which often requires carer co-operation.

A thorough dental assessment is therefore indicated as early in the dementia disease process as possible, to enable appropriate treatment planning with the goal of providing high quality, low maintenance dentistry to reduce the risk of future dental morbidity. Outstanding treatment needs and the control of any active disease should be completed in as short a period as possible after dementia diagnosis.

In addition to the overall risk assessment it is advisable to determine the prognosis for each tooth and the dentition as a whole. Regardless of the periodontal prognostic scheme used, due to the increased risk of periodontal deterioration associated with dementia, the criteria chosen should be downgraded by a factor of 1, as suggested by McGowan and colleagues for other systemic conditions¹³. For example, for the purposes of making long-term treatment planning decisions, if the tooth would otherwise have a doubtful prognosis, as the severity of dementia increases the prognosis is likely to be more accurately be described as poor.

Whether teeth are symptomatic or asymptomatic, extractions are advisable for the patient with mild dementia to avoid future dental morbidity for the following periodontal reasons:

- Grade III mobile teeth, with careful consideration of grade II mobile teeth in relation to the patients declining oral hygiene capabilities and level of carer involvement in oral hygiene
- Combined perio-endo lesions that do not respond to treatment
- Repeated periodontal abscesses or suppuration despite treatment
- Teeth judged to have poor prognosis after prognostic assessment e.g. 80% bone loss

Other teeth that will require careful consideration are those with fremitus that cannot be alleviated, molars with furcation involvements and deep periodontal pockets, and periodontally compromised teeth supporting fixed and removable prostheses. Where possible, complicated implant superstructures that hinder plaque control will be best simplified to aid maintenance, and in cases of peri-implantitis that is not amenable to hygiene phase and debridement therapy, implant removal should be considered before the patient reaches severe dementia. This is particularly pertinent for dementia patients who have slowly progressing dementia with few co-morbidities and a relatively long-life expectancy. The aim of all periodontal treatment planning must be to minimise the risk of future pain and acute infection occurring in severe dementia, when consent and behavioural management are commonly complex, and if left untreated would be likely to negatively impact on the patient's health and quality of life.

Tooth replacement requires careful consideration for patients with dementia. If molar teeth are missing, yet sufficient inter-occlusal contacts remain to enable a shortened dental arch¹⁴ this option is likely to be more tolerable for the dementia patient than providing a prosthesis, particularly where the patient has not worn one previously. Where transition to dentures is functionally necessary, this is best completed as early

in the dementia process as necessary, as the patient's ability to adapt to prostheses is likely to be inversely proportional to the dementia severity.

While in the early stages of dementia aesthetic alterations can be beneficial for the patient and boost their self-esteem, it is important that any changes instigated do not increase the complexity of future maintenance and oral hygiene. Family members and carers can often be more concerned than the patient in relation to dental aesthetic issues. It can be worth reminding them that care must be in the patient's best interests and if the patient can no longer appreciate the aesthetic improvement there is little sense in undergoing treatment.

The patient's ability to co-operate with dental treatment will in part be a function of the dementia stage and will be affected by previous life experiences. If the patient was a regular dental attender who enjoyed visits to the dentist, they will be far more likely to cope with dental treatment well into the moderate stages of dementia. Whereas, co-operation for dental treatment may be lost early in the disease process for those who have only attended the dentist when in pain or who have had unpleasant past dental experiences¹⁵.

A general guide explaining the implications of each dementia stage is shown in Table 1. The duration that the patient spends in each stage will be dependent on the age at onset, other co-existent medical conditions and dementia related factors e.g. rate of progression. Generally, the slower the rate of neurodegeneration the greater the risk of dental morbidity. The information provided in Table 1 illustrates the general deterioration experience by those who have dementia¹⁶. The course of dementia is most predictable and protracted for those with Alzheimer's disease. Table 1 is not intended to be prescriptive for all patients, as the rate and order of clinical symptoms will vary from person to person. Compliance with dental treatment can be extremely variable, difficult to predict and is not always related to dementia stage¹⁷.

The dental compliance and capability index can be used to help predict dental co-operation (Table 2). This can be assessed in a rapid and dentally specific manner using an index based on the answers to 5 questions, which are scored out of 10¹⁷. Scores of 0-3 indicate that there will be minimal adjustment to the treatment plan required. Scores 4-7 indicate that palliative care is indicated, and for scores of 8-10 only emergency dental care will be possible.

Where the patient cannot co-operate for dental care yet would benefit from dental management to resolve pain and/or infection, sedation or general anaesthesia (GA) may be required. Care must only be provided if the patient is likely to benefit from it. The risk/benefit of completing dental treatment under general anaesthesia, must be considered jointly by the dentist and anaesthetist, by balancing morbidity and mortality risks for each individual. This is particularly pertinent for the patient with dementia because of the possible neurotoxic effects of the agents used to induce GA¹⁸⁻²⁰. If GA is planned, it will be important to remove all likely sources of pain and infection, to negate the need for repeated GA. Where extractions are required, primary wound closure²¹ will reduce the risk of post-operative aspiration of blood, which poses a significant risk for those with dementia.

Tailored preventive advice

People with dementia have a high risk of developing caries and periodontal disease^{22 23} therefore, a thorough preventive dental regimen is paramount. This routine should be instigated as soon as possible after diagnosis and modified appropriately as the patient's health and self-care abilities deteriorate. If it is to be successful it will require co-operation from the patient, their carers and the dental team. In this context preventive dental advice should not be specific to periodontal disease, rather it should aim to reduce the likelihood of all oral disease.

The implications of dementia stage on oral hygiene are described in Table 1. Patients with mild dementia are likely to need prompting to remind them to brush their teeth, gradually they will begin to require supervision and increasing support when brushing their teeth. As patients begin to lose their oral hygiene capability, they become unaware that they may have missed complete areas of the mouth that had previously been cleaned well and they will need the support of the dental team and carers to help clean effectively. Even with supervision there will become a point (usually during stage 6 of the GDS scale shown in Table 1) when patients will have lost the ability to clean their teeth, so oral hygiene needs to become the responsibility of their carer(s). This can become challenging for carers as they will similarly be adapting to increased needs across the spectrum of activities of daily living (Table 1), so it is important that the dental team is as supportive as possible at this time, recognising small improvements and positive changes. The carers burden will be lighter when shared, so it can be useful to explain what is required in terms of oral hygiene to any relatives, friends and carers who are likely to be involved in the patient's care. Memory aids, such as instructional cards with short written descriptions and pictures are helpful and these can be laminated and placed by the sink that is used for oral hygiene in the patient's home or care environment.

Carers need to be aware that mechanical removal of plaque is most effective, and that any advised pastes, gels and mouthwash chemical plaque control agents will be far less effective if used without mechanical plaque removal. Changes to routines can be difficult for those suffering from dementia and are best initiated in the early stages of the disease process. Some dementia patients who have not used electric toothbrushes (ETB) previously may not tolerate them due to the increased sounds and vibrations associated with their use. However, this was not found to be the case for the majority of patients participating in a randomised controlled trial conducted in Norwegian care homes²⁴, which found that ETB were a useful aid for carers who provide help with oral hygiene. They also concluded that when patients completed their own oral hygiene the quality of plaque control advice was more important than the type of brush used (manual or electric), which has been corroborated by a subsequent study²⁵.

Practical hands on advice for patients and carers using a facial mirror is good practice. This is best done after plaque disclosure so everyone can visualise problem areas. Plaque disclosure should be used to provide supportive advice rather than to chastise the patient and their carer. Most carers find that the most effective position for providing oral hygiene is to stand behind a seated patient in a chair with head support. In this manner, an electric or manual toothbrush can be used effectively when used to brush lingual, palatal, buccal, and labial tooth surfaces in a structured sequence. For those susceptible to periodontal disease the interproximal surfaces can be cleaned using interproximal brushes. Many carers will not have experience of using these in their own mouths, so will need specific guidance on appropriate sizing, technique and importance of using these aids. If carers struggle to provide oral hygiene care due to a lack of patient co-operation, the VERA approach to communication²⁶ (Part 1, Table 5) can be used to help

calm the patient and investigate the reason why they are behaving in that manner. Carers should be advised not to be disheartened by a negative response and encouraged to continue to attempt to provide oral hygiene. Aggression is usually a reaction to events or circumstances, rather than a symptom of dementia, therefore if a patient responds in an aggressive manner to oral hygiene intervention it is worth exploring the reason for this²⁷. Co-operation may be possible either with someone else or at a different time of day. If the patient has previously been co-operative, a lack of co-operation persisting for over two weeks, may suggest dental pain should be considered, and a dental opinion sought.

Due to dementia patients' high risk of developing dental caries, 5000 ppm sodium fluoride is advisable. Where the mucosa is particularly friable (due to hyposalivation, mucositis and candidiasis, commonly as the result of polypharmacy) sodium lauryl sulphate (SLS) can increase the discomfort associated with these mucosal changes, thus use of a SLS-free toothpaste may be advisable (e.g. Sensodyne® daily care original or Oralieve® ultra-mild) as these reduce the pain and discomfort of those with recurrent aphthous stomatitis²⁸. Carers involved in providing oral hygiene assistance to those with dementia must also be aware of the friable nature of the oral mucosa among elders with polypharmacy. Chlorhexidine mouthwash (0.2%) can be a useful adjunct, and as dysphagia becomes more of a risk 1% chlorhexidine gel can be applied as an alternative by carers. For the patient who is either allergic or unable to tolerate chlorhexidine, essential oil mouthwashes provide a suitable alternative²⁹. Caesin phosphopeptide - amorphous calcium phosphate (CPP-ACP marketed as tooth mousse®) and xylitol can also prove beneficial for remineralising early carious lesions³⁰. The importance of dietary modifications to reduce the frequency of refined sugar should not be overlooked, however sugar snacking can be particularly embedded among those with dementia and their carers'. Eating disturbances are common among those with dementia³¹ and the advice of a nutritionist is an important adjunct to overall wellbeing.

Periodontal treatment for those with dementia

The mantra for all dental and oral treatment for dementia patients is 'high quality, low maintenance'³². Where dementia is mild, hygiene phase periodontal treatment should continue, with the aim of stabilising the periodontium in as short a period as possible. When periodontal debridement is planned, dependent on patient co-operation, consider treating smaller areas i.e. instead of treating the whole or half of the mouth, a quadrant or sextant approach, over a series of appointments, ideally in short succession may be more easily tolerated.

Good aspiration is essential when using ultrasonic instruments as many patients with dementia have dysphagia with increased likelihood of aspiration and the potential sequelae of pulmonary infection. This risk of dysphagia increases with dementia severity and its management with antipsychotic drugs³³. Patients in the moderate stages of dementia, who have not been used to ultrasonic scalers, may become frightened by their noise, sensation and water spray. If this occurs the VERA framework (described in Part 1 of this series) can be instilled to respond appropriately, if the patient can be sufficiently reassured it may be possible to continue using the ultrasonic scaler. If this is not possible, hand scalers provide a suitable alternative. Co-operation is likely to be variable, so if it is not sufficient to enable treatment during a single appointment it can be worth further attempts on alternative days and times. The reduced attention span

of most patients with dementia mean short appointments are often better tolerated than long, particularly as the dementia progresses.

Exposed root surfaces that have circumferential dental caries at the gingival margin are an all too common occurrence as dementia progresses. These lesions can be treated atraumatically by the application of silver fluorides followed by stannous fluoride applications with or without restoration³⁴. Where the caries has extended subgingivally in a patient with limited co-operation, this technique can often avoid the need for gingivectomy and haemostatic agents³⁴.

Increasing numbers of people living with dementia are likely to have had dental implants placed earlier in life. For those who already have dental implants, even without the complications of dementia, 22% are likely to develop peri-implantitis. Thus, dementia patients who have dental implants will need to be carefully managed on a 3-monthly basis³⁵. Periodontal surgery and implant placement is generally not advisable for the dementia patient. The exception to this would be periodontal surgery, completed in the early stages of mild dementia, where the outcome is believed to predictably and significantly reduce the patient's risk of further periodontal destruction, even with diminishing future plaque control. For most cases, diminishing plaque control will be likely to favour destruction over stability, even if the initial outcome is favourable, therefore the long-term prognosis for the tooth must be considered from the outset.

Supportive long-term care plans

Further reviews should be scheduled at appropriate intervals according to NICE³⁶ and SDCEP³⁷ guidance. As most patients who suffer from dementia will have a high risk of developing further primary dental disease the most appropriate recall interval for the most patients is likely to be 3 months, to enable altered routines suitable for the patient's changing needs and early detection of dental disease. During these it is important that patients and carers are made to feel comfortable, without embarrassment about additional dental needs, as this has been identified as a barrier to seeking dental care for those with dementia³⁸.

As the patients' cognitive ability diminishes, and with it, their recollection of previous dental treatment and maintenance routines they would be likely to benefit from a dental passport. Like a dementia passport, this will contain information regarding previous dental treatment and realistic oral hygiene routines to maintain it. This can be particularly useful where dental implants or complex work has been completed, as carers can find caring for these daunting. It will provide information to aid new and temporary carers, along with contact information for the dental team if carers have concerns. An example of a dental passport can be seen in Figure 1.

Appropriate consent

The legislation that governs decision making for those who may lack the capacity to consent is the '*Mental Capacity Act 2005*'³⁹ for England and Wales, and the '*Adults with Incapacity (Scotland) Act 2000*'⁴⁰ in Scotland. In Northern Ireland it is the '*Mental Capacity Act (Northern Ireland) 2016*'⁴¹ which is due to be

fully implemented in 2020. Together these documents provide a statutory legal framework to protect and empower those who lack the capacity to provide informed consent, in the United Kingdom.

There are five basic principles of the Mental Capacity Act (MCA):

1. Presumption of capacity, unless proven otherwise.
2. Support to enable individuals to make their own decisions, this may be in the form of additional explanations, time and additional support aids e.g. diagrams.
3. Individuals, who have capacity to consent, retain the right to make decisions that others may consider are unwise or eccentric.
4. Anything done for, or on behalf of a person who lacks capacity must be done in their best interests.
5. Where intervention is required for a person who lacks capacity, the least restrictive (minimal) option should be chosen.

Not everyone with dementia will lack the capacity to consent, and the point at which an individual loses this capacity will vary from person to person, so will need to be assessed by the dentist at each appointment. When assessing an individual's capacity to consent it is important to ensure that:

- The discussion takes place when the patient feels comfortable, at a time of day when their cognition is best.
- The patient has been given all the relevant information on each treatment option in a manner that they can understand.
- The patient has access to a relative, friend or carer to mull the decision over if they wish.
- The patient has sufficient time to make the decision (which is often longer than would be expected for someone without dementia)⁴².

Loss of capacity can be partial, temporary, or variable. For example, the patient may have enough understanding to have the capacity to consent to radiographs, but insufficient to consent to multiple prophylactic tooth extractions under general anaesthesia. Capacity to consent will be lost if a person:

- Cannot understand the relevant information (despite all practicable measures being taken to assist them),
- Cannot retain pertinent information relating to the decision,
- Cannot appreciate the relevance of the decision for them, or
- Cannot communicate the decision (either using verbal or non-verbal means).

Where the dentist is unsure of a patient's capacity to consent, they can consult with the patient's GP, neurologist or clinical psychologist.

Advance decisions made whilst the patient had the capacity to consent must be upheld. Agreement to treat can be gained on behalf of the patient, from a person whom the patient previously awarded legal lasting power of attorney. It is therefore essential to know whether the person who accompanies the patient to their dental appointments has been granted legal power of attorney (or welfare attorney/guardian in Scotland). Only in Scotland can a Section 47 certificate, completed by an appropriately trained doctor or dentist, provide authority to treat. Although where treatment is either serious, irreversible or controversial it would require court approval. If no-one has been awarded lasting power of attorney, in the best interests of the patient prior to treatment, it will be important to consult with anyone previously named by the

patient as someone to be consulted, anyone involved in caring for the person (not normally paid carers), close relatives or friends and/or any deputy awarded by the court of protection to make decisions for the person. Where no-one is available to act on behalf of the patient an Independent Mental Capacity Advocate must be consulted, although not normally involved in periodontal decision making, they would be expected to be involved in complex decisions such as: the use of sedation or GA, the management of oral cancer or the management of peri-implant conditions and infections. A number of detailed texts provide further information relating to these matters⁴²⁻⁴⁵.

What if the patient with dementia declines oral care?

Whilst it is a person's right to refuse care, it can also be considered neglectful not to provide care for a person who clearly needs it. It is important to investigate why the patient is refusing care²⁷. In the dental context this may be because:

- The patient is fearful of treatment
- The patient has oral pain which they believe will be exacerbated by treatment
- The patient feels embarrassed about their oral condition
- The patient does not understand what is being asked
- The patient is mistrustful of dental professionals
- The patient wishes to show a sense of control, particularly if they feel they are being ordered to do something
- The patient is misinterpreting the situation or environment e.g. believing the surface of dental chair is wet or unclean, so refusing to sit on it
- Of behavioural or psychological effects of dementia
- The patient does not want to have the treatment

Once the reason for refusal has been determined, it will be possible to work on resolving it. For example, if the patient is refusing dental care because they do not understand what is being said, it may help to provide clear explanations delivered at a pace the patients can comprehend.

Safeguarding responsibilities for the dental team

Those who are living with dementia are some of the most vulnerable people living in our society and we have a duty to safeguard them from harm⁴⁶. Sadly reports show that abuse of those with dementia is commonplace⁴⁷. All clinical members of the dental team are well-placed to recognise and report abuse and/or neglect of vulnerable adults. Abuse can be physical, domestic, sexual, psychological, financial, discriminatory or organisational. Neglect includes ignoring medical & dental needs and not enabling access to medical & dental care or prescribed medications. Unfortunately, as the dementia advances self-neglect becomes inevitable, and where suitable social care is not in place, this is also a reason to report concerns. Triggering an alert or reporting a concern will be broadly similar in all areas of the UK, yet the exact procedure varies in the different countries and counties of the United Kingdom due to legislative differences.

Four pieces of legislation govern safeguarding vulnerable adults in the UK. The 'Care Act 2014'⁴⁸ governs the procedures of safeguarding vulnerable adults in England. In Scotland it is the 'Adult Support and Protection (Scotland) Act 2007'⁴⁹. In Wales it is the 'Social Services and Wellbeing (Wales) Act 2014'⁵⁰, and in Northern Ireland it is the 'Adult safeguarding operational procedures'⁵¹. Concerns regarding the abuse of vulnerable adults should be reported to the local Safeguarding Adults Board in England or the local Adult protection Board in Scotland. In Wales a variety of terms are used to describe the safeguarding and adult protection arrangements, these are listed by the older peoples commissioner for Wales⁵². In Northern Ireland suspected abuse can be reported to the local health and social care trust adult protection gateway or to the police service of Northern Ireland (PSNI). A comprehensive list of all the appropriate boards in the UK is also available⁵³.

Unusual mucosal and gingival traumatic ulceration can be the result of reduced perception, sensory and motor abilities and caused by the patient themselves in the late moderate stages of dementia, although it could also be indicative of abuse or neglect. If in doubt regarding whether to raise a concern, attempt to seek further information using subtle enquiry. If you remain uncertain it is important to share the information you have with other health and social care providers and the local authority to protect the patient. Raising an alert does not in itself trigger a safeguarding investigation, the decision of whether, or not an investigation is warranted is made by a representative of the local safeguarding of vulnerable adults' board.

Conclusion

There is a clear need for the provision of good quality periodontal and restorative dental care for those who are living with dementia. Dental involvement in memory multidisciplinary care teams will help to minimise the risk of dental morbidity in those who develop severe dementia. This is important as a deterioration in the cognitive and functional symptoms of dementia critically increase the complexity and cost of providing dental care. Realistic treatment planning to lower dental morbidity due to periodontal causes is fundamental to delivering optimal dental treatment for this patient group, whose ability to provide oral hygiene and receive dental care diminishes as the severity of their condition progresses. To ensure optimal standards of dental care it will often need to be co-ordinated between medical colleagues and social care systems.

The need for improved oral health for vulnerable older people, including those living with dementia in the UK is recognised, and a guide for commissioning services written to aid local authorities⁵⁴. Improving the quality of dental care that can be provided for those who have dementia requires awareness and training for staff. Those who provide dental care for dementia patients need to be aware of the impact dementia will have on the oral environment, the patients diminishing ability to co-operate with treatment, and specific matters relating to consent and safeguarding legislation. Unique communication strategies to empower and engage patients and their carers during this treatment are also paramount. Online training⁵⁵ and clinical guidelines for dementia-friendly dentistry^{57 58} provide useful sources of information for all members of the dental team. Staff must also feel empowered and adequately resourced to make changes that will enable them to deliver patient centred dementia friendly care⁵⁹. In the dental context this translates to more chairside and administrative time, with resultant financial implications.

References

1. Cicciu M, Matacena G, Signorino F, et al. Relationship between oral health and its impact on the quality life of Alzheimer's disease patients: a supportive care trial. *Int J Clin Exp Med* 2013; **6**: 766-72.
2. Bramanti E, Bramanti A, Matacena G, et al. Clinical evaluation of the oral health status in vascular-type dementia patients. A case-control study. *Minerva Stomatol* 2015; **64**: 167-75.
3. Warren J J, Chalmers JM, Levy SM, et al. Oral health of persons with and without dementia attending a geriatric clinic. *Spec Care Dentist* 1997; **17**(2):47-53.
4. Avlund K, Holm-Pedersen P, Morse D E, et al. Tooth loss and caries prevalence in very old Swedish people: the relationship to cognitive function and functional ability. *Gerodontology* 2004; **21**: 17-26.
5. Henry RG, Wekstein DR. Providing dental care for patients diagnosed with Alzheimer's disease. *Dent Clin North Am* 1997; **41**: 915-43.
6. Cerajewska T L, Davies M, West N X. Periodontitis: a potential risk factor for Alzheimer's disease. *Br Dent J* 2015; **218**: 29-34.
7. Cerajewska T L, West N X. Could periodontitis play a role in the pathogenesis of Alzheimer's disease. *Perio Insight - Eur Fed Periodontol* 2019; **9**: 1-4.
8. Teixeira FB, Saito MT, Matheus FC, et al. Periodontitis and Alzheimer's Disease: A Possible Comorbidity between Oral Chronic Inflammatory Condition and Neuroinflammation. *Front Aging Neurosci* 2017; **9**: 327.
9. Harding A, Robinson S, Crean S, et al. Can Better Management of Periodontal Disease Delay the Onset and Progression of Alzheimer's Disease? *J Alzheimers Dis* 2017; **58**: 337-48.
10. Ide M, Harris M, Stevens A, et al. Periodontitis and Cognitive Decline in Alzheimer's Disease. *PLoS One* 2016; **11**: e0151081.
11. Prince M, Ali G C, Guerchet M, et al. Recent global trends in the prevalence and incidence of dementia, and survival with dementia. *Alz Res Ther* 2016; **8**: 23.
12. Delwel S, Binnekade T T, Perez R, et al. Oral hygiene and oral health in older people with dementia: a comprehensive review with focus on oral soft tissues. *Clin Oral Investig* 2018; **22**: 93-108.
13. McGowan T, McGowan K, Ivanovski S. A Novel Evidence-Based Periodontal Prognosis Model. *J Evid Based Dent Pract* 2017; **17**: 350-60.
14. Kayser AF. Shortened dental arches and oral function. *J Oral Rehab* 1981; **8**: 457-62.
15. Dougall A, Fiske J. Access to special care dentistry, part 9. Special care dentistry services for older people. *Br Dent J* 2008; **205**: 421-34.
16. Reisberg B, Ferris SH, de Leon MJ, et al. The Global Deterioration Scale for assessment of primary degenerative dementia. *Am J Psychiatry* 1982; **139**: 1136-9.
17. Niessen LC, Jones JA, Zocchi M, et al. Dental care for the patient with Alzheimer's disease. *J Am Dent Assoc* 1985; **110**: 207-9.
18. Baranov D, Bickler PE, Crosby GJ, et al. Consensus statement: First International Workshop on Anesthetics and Alzheimer's disease. *Anesth Analg* 2009; **108**: 1627-30.
19. Jevtovic-Todorovic V. General Anesthetics and Neurotoxicity: How Much Do We Know? *Anesthesiol Clin* 2016; **34**: 439-51.
20. Seitz DP, Shah PS, Herrmann N, et al. Exposure to general anesthesia and risk of Alzheimer's disease: a systematic review and meta-analysis. *BMC Geriatr* 2011; **11**: 83.
21. Wachtel H, Fickl S, Zuhre O, et al. The double-sling suture: a modified technique for primary wound closure. *Eur J Esthet Dent* 2006; **1**: 314-24.
22. Ship JA, Puckett SA. Longitudinal study on oral health in subjects with Alzheimer's disease. *J Am Geriatr Soc* 1994; **42**: 57-63.
23. Jones JA, Lavalley N, Alman J, et al. Caries incidence in patients with dementia. *Gerodontology* 1993; **10**: 76-82.
24. Fjeld KG, Mowe M, Eide H, et al. Effect of electric toothbrush on residents' oral hygiene: a randomized clinical trial in nursing homes. *Eur J Oral Sci* 2014; **122**: 142-8.
25. Zenthofer A, Meyer-Kuhling I, Hufeland AL, et al. Carers' education improves oral health of older people suffering from dementia - results of an intervention study. *Clin Interv Aging* 2016; **11**: 1755-62.
26. Blackhall A, Hawkes D, Hingley D, et al. VERA framework: communicating with people who have dementia. *Nurs Stand* 2011; **26**: 35-9.
27. Social Care Institute for Excellence. Behavioural challenges when supporting a patient with dementia. Available at <https://www.scie.org.uk/dementia/living-with-dementia/difficult-situations/> (accessed April 2019).

28. Shim Y J, Choi J H, Ahn H J, et al. Effect of sodium lauryl sulfate on recurrent aphthous stomatitis: a randomized controlled clinical trial. *Oral Dis* 2012; **18**: 655-60.
29. Van Leeuwen M P, Slot D E, Van der Weijden G A. Essential oils compared to chlorhexidine with respect to plaque and parameters of gingival inflammation: a systematic review. *J Periodontol* 2011; **82**: 174-94.
30. Walls AW, Meurman JH. Approaches to caries prevention and therapy in the elderly. *Adv Dent Res* 2012; **24**: 36-40.
31. Kai K, Hashimoto M, Amano K, et al. Relationship between eating disturbance and dementia severity in patients with Alzheimer's disease. *PLoS One* 2015; **10**: e0133666.
32. Fiske J, Frenkel H, Griffiths J, et al. Guidelines for the development of local standards of oral health care for people with dementia. *Gerodontology* 2006; **23**: S5-S32.
33. Friedlander A H, Norman D C, Mahler M E, et al. Alzheimer's disease: psychopathology, medical management and dental implications. *J Am Dent Assoc* 2006; **137**: 1240-51.
34. Lewis A, Wallace J, Deutsch A, et al. Improving the oral health of frail and functionally dependent elderly. *Aust Dent J* 2015; **60**: S95-105.
35. Tonetti M S, Chapple I L, Jepsen S, et al. Primary and secondary prevention of periodontal and peri-implant diseases: Introduction to, and objectives of the 11th European Workshop on Periodontology consensus conference. *J Clin Periodontol* 2015; **42**: S1-4.
36. National Institute for Health and Care Excellence. Dental checks: intervals between oral health reviews. 2004. Available at <https://www.nice.org.uk/guidance/CG19> (accessed September 2018).
37. Scottish Dental Clinical effectiveness programme. Oral health assessment and review. 2011. Available at <http://www.sdcep.org.uk/published-guidance/oral-health-assessment/> (accessed September 2018).
38. Hilton C, Simons B. Dental surgery attendance amongst patients with moderately advanced dementia attending a day unit: a survey of carers' views. *Br Dent J* 2003; **195**: 39-40 .
39. United Kingdom Government. Mental Capacity Act 2005. London: The stationary office. Available at <http://www.legislation.gov.uk/ukpga/2005/9/contents> (accessed September 2018).
40. Scottish Government. Adults with incapacity (Scotland) Act 2000. Available at <http://www.legislation.gov.uk/asp/2000/4/contents> (accessed September 2018).
41. Northern Irish Assembly. Mental capacity Act (Northern Ireland) 2016. Available at <http://www.legislation.gov.uk/nia/2016/18/contents> (accessed September 2018).
42. Dougall A, Fiske J. Access to special care dentistry, part 3. Consent and capacity. *Br Dent J* 2008;205(2):71-81.
43. General Medical Council. Consent: Patients and Doctors making decisions together. <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/consent>. (accessed September 2018).
44. Dental Protection. 2015 Consent: Scotland. Available at [https://www.dentalprotection.org/docs/librariesprovider4/dental-advice-booklets/consent-\(scotland\).pdf?sfvrsn=2](https://www.dentalprotection.org/docs/librariesprovider4/dental-advice-booklets/consent-(scotland).pdf?sfvrsn=2) (accessed September 2018).
45. Dental Protection. Consent: UK excluding Scotland. 2015. Available at https://www.dentalprotection.org/docs/librariesprovider4/dental-advice-booklets/dental-advice-booklet-consent-uk-excl-scot.pdf?sfvrsn=f0a45aac_36 (accessed September 2018).
46. General Dental Council. Standards for the dental team. In: General Dental Council, ed. London, 2018. Available at <https://standards.gdc-uk.org/> (accessed May 2019)
47. Cooper C, Selwood A, Blanchard M, et al. Abuse of people with dementia by family carers: representative cross sectional survey. *BMJ* 2009; **338**: b155.
48. Department of Health. Care Act 2014. 2014. Available at <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>. (accessed September 2018).
49. Scottish Government. Adult Support and Protection (Scotland) Act 2007. Available at <http://www.legislation.gov.uk/asp/2007/10/contents> (accessed September 2018).
50. National Assembly for Wales. Social Services and Wellbeing (Wales) Act 2014. Available at <https://www.legislation.gov.uk/anaw/2014/4/contents> (accessed September 2018).
51. Northern Ireland Adult Safeguarding Partnership. Adult safeguarding operational procedures: adults at risk of harm and adults in need of protection. 2016. Available at <http://www.hscboard.hscni.net/download/PUBLICATIONS/safeguard-vulnerable-adults/niasp-publications/Adult-Safeguarding-Operational-Procedures.pdf> (accessed September 2018). .
52. Older peoples commissioner for Wales. Adult protection contacts in Wales. 2016. Accessible at http://www.olderpeoplewales.com/en/adult_protection/adult-protection-in-wales/adult-protection-contacts.aspx (accessed September 2018).

53. Child Protection Company. Local safeguarding adults boards. 2018.
<https://www.childprotectioncompany.com/CPC/local-safeguarding-adults-boards> (accessed 22 September 2018).
54. Public Health England. Commissioning better oral health for vulnerable older adults. 2018. Available at
<https://www.gov.uk/government/publications/commissioning-better-oral-health-for-vulnerable-older-people> (accessed May 19).
55. British Medical Journal. Management of dementia in primary care. 2012. Available at
<https://learning.bmj.com/learning/module-intro/.html?moduleId=10032231> (accessed September 2018).
56. Guy's and St. Thomas' NHS Foundation Trust. Barbara's Story. British Medical Journal. 2012. Management of dementia in primary care. <https://www.guysandstthomas.nhs.uk/education-and-training/staff-training/barbaras-story.aspx> (accessed September 2018).
57. National Health Service England Cheshire and Merseyside Health and Care Partnership. Dementia Friendly Dentistry: advice and guidance for the primary dental care team. 2016. Available at
<https://healthwatchwirral.co.uk/wp-content/uploads/2016/07/Dementia-Friendly-Dentistry-Book-May-SOV.pdf> (accessed March 2019)
58. Faculty of General Dental Practice. Dementia-friendly dentistry: good practice guidelines. 2017. London, UK. Available at <https://www.fgdp.org.uk/guidance-standards/dementia-friendly-dentistry> (accessed November 2018).
59. Handley M, Bunn F, Goodman C. Dementia-friendly interventions to improve the care of people living with dementia admitted to hospitals: a realist review. *BMJ open* 2017; **7**: e015257.

Please note that references on this list relate to the references throughout the manuscript and the separate table documents.

Table 1. The degenerative stages of dementia and their implications for periodontal treatment planning ^{16, 17}

STAGE	IMPAIRMENT	SYMPTOMS	DURATION	PERIODONTAL CARE
1	No Cognitive Impairment (NCI)	Free from cognitive, functional, behavioural & emotional decline.	3-5 decades of adult life	As for healthy adults.
2	Subjective Cognitive Impairment (SCI)	Self- awareness that name & object placement recall has declined or difficulty in finding correct words when speaking. Not noticeable to intimates or professionals. Also termed normal aged forgetfulness.	Approx. 15 years	As for healthy adults.
3	Mild Cognitive Impairment (MCI)	Subtle deficits in cognitive function that are noticeable to others e.g. repetition of questions, inability or difficulty in learning new skills	2-7 years	Treatment to minimize risks of future morbidity Reduced ability to master new oral hygiene routines. May forget appointments. Cognition worse during stressful procedures. Plan for future when not able to care for dentition. Avoid procedures that increase maintenance.
4	Mild dementia	Inability to manage complex activities of daily life. Short-term memory loss. Can remain reasonably independent but needs help. Less emotionally responsive & withdrawn.	2 years mean duration	Treatment to minimize risks of future morbidity Capable of continuing oral hygiene if established, possibly unaware of loss of capability. Treatment to aid minimal future maintenance, extract teeth with poor prognosis, finish complex care, reduce complexity of implant supported prostheses. May require carer involvement for treatment planning / decision-making.
5	Moderate dementia	Inability to function independently or complete basic activities of daily living. Increasingly vulnerable to predators. Behaviour problems: anger and paranoia common.	1.5 years mean duration	Palliative care Significant deterioration in oral hygiene. Capacity to consent unlikely. Primary dental care if behaviour amenable, more likely if the patient has been a regular dental attender.
6	Moderately Severe Dementia	(a) Inability to dress (b) Personal hygiene (c) Need support during toilet visits (d) Urinary incontinence (e) Faecal incontinence, severe memory loss, inability to recognise family, speech difficult.	2-3 years mean duration	Palliative / Emergency care dependent on patient's ability to co-operate In 6b all ability for oral hygiene lost. Carers need to instill a suitable daily oral hygiene routine. Capacity to consent highly unlikely; treatment in the best interests of the patient with appropriate assent.
7	Severe Dementia	(a) Speech limited-6 words. (b) Speech - a single word (c) Loss of ambulation (d) Inability to sit up (e) Unable to smile (f) Unable to hold head up. Re-emergence of primitive reflexes.	Each sub-stage 1-1.5 years.	Only emergency dental care Commonly provided under general anaesthesia following a decision made in the best interests of the patient with assent where possible.

Table 2. Dental compliance and capability index for the patient with dementia¹⁷

Question	Score
Can the patient adequately clean their teeth/dentures?	Yes = 0 Some assistance needed = 1 Completely dependent on assistance = 2
Can the patient communicate their principal dental concern?	Yes = 0 Partially = 1 No = 2
Can the patient follow simple instruction? E.g. sit in chair, open mouth.	Yes = 0 Sometimes = 1 No = 2
Can the patient hold a radiographic holder in position for long enough to achieve a diagnostic image?	Yes = 0 Sometimes = 1 Never = 2
Is the patient assaultive? E.g. bites, hits.	No = 0 Sometimes = 1 Always = 2

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Figure 1. Example Dental Passport in trifold leaflet format

PURPOSE

This dental passport has been prepared by the dental team for our patient who is living with dementia. It provides detailed information for carers to help them to look after their daily oral health needs. Each of the completed fields specifically relates to the person named on the cover. The information included may also help other dental and medical professionals as they provide care.

Contact Details for the Dental Team:

Anything else you need to know:

My name is:

I like to be known as:

DENTAL PASSPORT

I am living with dementia, help me look after my teeth & gums

Before I was diagnosed with dementia, I visited the dentist:

- ☐ Regularly
- ☐ Occasionally
- ☐ If I had pain

Completed on:

I am **ALLERGIC** to:

I often respond negatively to:

Oral Care Instructions:

If I get anxious, aggressive or don't want my teeth to be brushed, it may help if you:

I like to **RELAX** by:

The areas of my mouth that need to be brushed first are:

The dentist recommends that I use:

- ☐ A powered electric / manual toothbrush
- ☐ Toothpaste
- ☐ Mouthwash
- ☐ Interdental cleaning aids
- ☐ Other

Please note:

- ☐ I have a particularly dry mouth
- ☐ My gums / tongue / inside of my cheeks are extremely sensitive

I was diagnosed with dementia on:

The type of dementia I have is:

My oral hygiene ability is:

- ☐ Independent
- ☐ I need help to:
- ☐ Dependent please clean my teeth for me 2x daily

I tend to co-operate with oral hygiene care:

- ☐ Always
- ☐ Mostly
- ☐ Sometimes
- ☐ Rarely

☐ I wear **DENTURES**

Please look after them by:

☐ I have **DENTAL IMPLANTS**

They are located:

Please look after them by:

My oral hygiene is important because I have a HIGH RISK of developing &/or worsening:

- ☐ Tooth decay
- ☐ Gum disease
- ☐ Other

The dental treatment I have received throughout my life has included: