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Original Article

Oral health of people with dementia

1 Introduction

As more people survive into old age, there is a growing emphasis on older people's general health care (National Service Framework for Older People[1]) and on improving health in old age (Better Health in Old Age[2]). The British Dental Association (BDA) policy document 'Oral Healthcare in Older People: 2020 Vision'[3] set the scene for increased challenges in dental service provision for this sector of the population. In 2004, the Chief Dental Officer for England built on this by commissioning a strategic review of how the challenges of the oral health of older people can be met[4].

To address standards of care for people with dementia, the National Institute for Clinical Excellence is developing a dementia guideline that is due for publication in 2007. As the number of older people increases and the incidence of dementia rises, more dental teams will encounter the oral care problems of people with this disorder. Future trends predict that people will keep their natural teeth for longer and that older cohorts (55 years plus) will be more demanding of dental care than previously[5]. People with dementia experience the same oral health problems as the general population. However, their oral health can be compromised by the nature of dementia – including the severity of cognitive impairment, social functioning and behavioural aspects; compliance with dental care; ability of individuals and carers to undertake oral hygiene procedures; and the ability of individuals to undertake daily living activities.

The experience of the dental team in providing oral care for people with dementia and the extent to which dental professionals understand the nature of dementia, influences the quality of oral health care provided. The capability of carers to recognise and report oral health problems, thereby initiating oral care, is of paramount importance. Education and training, plus the use of oral risk assessment tools, are essential to ensure optimal oral health for this group of people.

2 Aim

These guidelines have been developed to assist in the development of local standards for, and the provision of, oral health care for people with dementia who may no longer have, or will reach a stage when they no longer have, the ability to:

- Voice their needs for oral health care and treatment
- Carry out daily oral hygiene to a level that prevents dental disease
- Make informed choice, and
- Give valid consent for treatment.

3 Guiding principles

The guiding principles set out here are borrowed from the British Society for Disability and Oral Health's guidelines for 'Principles on Intervention for People Unable to Comply with Routine Dental Care'[6]. Whilst it is recognised that some people with dementia, particularly in the early stage of the disease process, are able to comply, the ethos of the following principles still applies.

- It is assumed that those people providing care share common values, a commitment to adherence to accepted clinical and professional standards, and, above all, operate within the interests of the service user.
- All individuals have a right to equal standards of health and care.
- All individuals have a right to autonomy, as far as possible, in relation to decisions made about them.
- Good oral health has positive benefits for health, dignity and self-esteem, social integration and general nutrition. The impact of poor oral health can be profound.

4 The dementias

Dementia is a progressive, neurodegenerative disease that effects the ability to perform daily living activities. It has been described as a variety of syndromes rather than a sign, a symptom or a disease[7]. There are a number of types of both reversible and irreversible dementia.

4.1 *The reversible or treatable dementias*

These have been described[7] as being due to:

D drugs e.g. alcohol
E emotions and depression
M metabolic factors e.g. pernicious anaemia
E endocrine conditions e.g. hypo- and hyperthyroidism
N nutritional deficiencies e.g. folic acid deficiency
T tumours and trauma of the brain
I infections e.g. TB, syphilis, human immunodeficiency virus (HIV)
A arteriosclerosis of cerebral vessels

4.2 *The irreversible dementias*

According to Ettinger[7] and, Ritchie and Lovestone[8], these include:

- *Alzheimer's disease* which accounts for 50–60% of diagnosed dementias
- *Vascular disease/stroke* which accounts for 20% of cases and is due to brain tissue damage as a result of hypoxia or infarct
- *Lewy body disease, frontal lobe dementia and Pick's disease* which all lead to the destruction of brain cells
- *Parkinson's disease* which is associated with an increased incidence of dementia
- *Huntington's disease* which involves mental deterioration in its later stage
- *Diseases such as acquired immunodeficiency syndrome (AIDS) and Creutzfeldt Jakob Disease* (CJD) which account for a very small proportion of cases
- *Brain tumours and other causes of intra-cerebral pressure* which can cause symptoms of dementia

5 Alzheimer's disease

Most of the dental literature that relates to dementia is specific to Alzheimer's disease (AD). This is probably because AD is one of the most protracted forms of dementia and, thus, oral health is likely to be an issue at some stage during its process. The clinical features, symptoms and the principles that would be used in providing oral health care for people with AD and other types of dementia are similar, although the time scale of the dementia process may be different and in some cases accelerated; for example, CJD related dementia. *For these reasons the bulk of this document refers to AD, however, the guidance can be equally well applied to any type of dementia.*

Alzheimer's disease is the most common cause of dementia and is responsible for just over half of the 720 000 cases in the UK. The female to male ratio is 2:1[9]. The cultural incidence varies. It is low in people of African and Asian origin, and in China, Japan and the Russian Federation vascular dementia is more common than AD[8].

5.1 *Aetiology*

The immediate cause is the loss of neurones. Brain cells are destroyed disrupting transmitters that carry messages in the brain, particularly those responsible for storing memories. The aetiology of AD is uncertain, although, a number of risk factors are recognised.

They include:

- *Age* – the risk of developing AD increases with age from one in 1000 below the age of 65, to five to 10 in 100 over the age of 65, and one in five by the age of 80 years
- *Inherited family risk* – some families have a strong family link with dementia but many other people inherit a gene which makes the disease slightly more likely
- *Brain damage* – severe head injury with loss of consciousness, or repeated head injury throughout life
- *Down's syndrome* – approximately 60% of people with Down's syndrome (DS) who survive into their 50s develop AD because of their chromosomal defect. In DS, neuropathological changes typical of AD usually develop by the fifth decade of life; and 75% of individuals with DS over the age of 60 show clinical signs and symptoms of AD. Most commonly, these are changes in personality (46%), apathy (36%) and loss of conversational skills (36%). However, a complete medical assessment should be carried out to eliminate any treatable disorders with similar symptoms such as thyroid disease or depression[10].
- *Herpes simplex* – the virus is considered to have a possible complicated link with genetic and chemical factors[8].

5.2 *Onset of Alzheimer's disease*

Alzheimer's disease may be either early onset type or late onset type[8]. The latter is more common.

Early onset In the UK, approximately 170 000 people below the age of 65 have AD. Onset can be as early as 35 years of age. AD in younger people often progresses more rapidly. A number of rare genetic faults make AD more likely at a young age. People with a strong family history may seek genetic

counselling. However, if identified as having inherited the associated faulty gene nothing can currently be done to prevent the development of AD.

Late onset A gene is also associated with late onset AD. The *apolipoprotein E gene (ApoE)* is carried by everyone. However it comes in three forms – *ApoE2*, *ApoE3* and *ApoE4*. *ApoE2* seems to protect against AD, while *ApoE4* makes AD more likely. If an individual inherits one *ApoE4* gene, there is an increased chance of AD. If an individual inherits *ApoE4* from both parents (approximately two in 100 people), there is a much greater chance of developing AD by the age of 80.

5.3 *Clinical features and symptoms*

Clinical features characterising AD are memory loss, language deterioration, impaired visuo-spatial skills, poor judgment, indifferent attitude, but preserved motor function. AD is a progressive disease, appearing first as memory decline and, over several years, destroying cognition, personality and ability to function (see Table 1). Confusion and restlessness may also occur. The type, severity, sequence and progression of mental changes vary widely. Usually, AD is a slow disease, starting with mild memory problems and ending with severe brain damage. Whilst, the course the disease takes varies on an individual basis, the average life expectancy from diagnosis is 8–10 years. The disease can last for as many as 20 years and the commonest cause of death is infection.

Its onset is insidious, but progressive over time. In the early stages, a person in their familiar home environment may be able to pass off the symptoms as forgetfulness. With time (6 months or more) a pattern of problems emerges and, as AD progresses, the individual may:

- Experience short-term memory loss and routinely forget recent events, appointments, names and faces
- Have difficulty in understanding what is said
- Become confused by routine procedures such as handling money, driving a car or using a washing machine
- Become increasingly disorientated in time, place and, eventually, person
- Undergo personality changes becoming agitated, irritable and sometimes verbally abusive or becoming apathetic and non-responsive
- Experience delusions, illusions and/or hallucinations

In the advanced stages of AD people may also adopt unsettling behaviour (such as, getting up in the middle of the night and/or wandering off from home and becoming lost) or inappropriate behaviour (such as, undressing in public). Finally, the personality disintegrates and the person becomes totally dependent on others for daily living activities such as getting up, washing, dressing, feeding, etc. Relatives have described this experience as 'like living with a stranger' and 'a living bereavement' that is to say the person they knew and loved has died but the body is still there[9].

5.4 *Diagnosis*

Diagnosis usually occurs over a period of time and is made on a differential diagnosis of ruling out other types of dementia (both reversible and irreversible), recording symptoms over time and the results of cognitive/memory tests. Confirmation of diagnosis can only be made at postmortem when the specific pathology of senile plaques and neurofibrillary tangles are identified in the brain[8,9].

5.5 *Management*

Modern management is aimed at maintaining quality of life. There is no cure for AD but its management has improved. Drugs, which slow down the rate of mental decline, are being developed. The first of these drugs to be licensed in the UK was donepzil (Aricept) in 1997. Donepezil and galantamine (Reminyl) are cholinesterase inhibitors and act by enhancing cognitive function in patients with AD. Clinical trials have shown the traditional remedy Ginkgo biloba to improve cognitive function in AD and to be well tolerated by patients[11].

Drugs can be used to help to control the depression, agitation and challenging behaviour associated with AD. Antipsychotics, such as risperidone, (Risperdal) and olanzapine (Zyprexa) and antiepiletics e.g. carbamazepine (Tegretol) may improve behavioural symptoms. However, pharmacologic interventions only appear to be modestly effective and trials to licence the drugs were performed in patients with mild-moderate dementia who had few co-existing conditions[8]. As yet it is unclear how long these drugs can help for and the newer drugs are not yet widely available.

Memory aids and familiar routines are helpful in maintaining as normal a life for as long as possible. As AD progresses the individual will need more support and eventually is likely to need close supervision and, ultimately, nursing care.

6 Oral health

General health and comfort are closely linked with oral health in the terminal stages of progressive neurogenic disease (PND). Poor oral health can impact on diet and nutrition, oral and general comfort, cognition, behaviour change, quality of life and life expectancy[12–14]. Aspiration pneumonia risk is significantly increased by oral factors such as decayed teeth, periodontal disease and the presence of various decay-causing organisms in saliva[15]. Good oral health can improve the quality of life and prolong it by reducing the likelihood of aspiration pneumonia.

It is well recognised that oral health is likely to decline as AD progresses. The impact of the disorder, especially in the latter stages, leads to poor oral hygiene with an increase in periodontal disease, higher levels of decay (both coronal and cervical) and a greater incidence of other dental problems. These include difficulty wearing dentures, the inability to comply with oral care and the inability to carry out oral hygiene procedures[16–21]. Poor oral care and an increase in oral disease can lead to changes in eating habits that may be because of a non-functional dentition, pain and discomfort or ill fitting dentures; as well as affecting self-esteem because of compromised aesthetics[22].

6.1 *Key influential factors*

Factors influencing oral health, the ability to self care, routine access to, and provision of, oral care include:

- The severity and stage of the dementia
- The individual's level of cognitive impairment and physical disability
- Lack of personal perception of oral health care problems
- Previous dental history, including oral health care and dental attendance
- Ability to receive oral hygiene care from carers and/or the dental team
- Impact of medication on the oral cavity, especially xerostomia (dry mouth)
- Motivation and behaviour
- Capacity to consent to oral health care
- Knowledge of, and attitudes towards, oral care of health and social care workers and carers
- Lack of information on how to access dental services
- Dental team's attitudes to, and awareness of, ageing and dementia
- Lack of training and understanding by dental professionals in oral health care and strategic, long-term, treatment planning for people with dementia
- Dental personnel unwilling or unable to provide appropriate care
- Site of oral care provision, e.g. dental surgery, day centre, at home

6.2 *Evidence of oral health problems*

Because of the difficulty in carrying out longitudinal studies on people with dementia, to date there is very little published research to support the subjective views of the dental professionals that oral health is often affected.

6.2.1 *Oral hygiene*

People with dementia have poorer oral hygiene than the general population, the consequences of which lead to an increase in oral disease[17,18]. The loss of cognitive and motor skills as dementia progresses reduces the ability to self-care, including carrying out oral hygiene procedures[20,23]. Reliance on carers who may not have the motivation, knowledge, skills or training necessary to carry out oral care (especially if an individual has challenging behaviour) can have an adverse impact on oral hygiene. Chalmers *et al.*[21] found that high carer burden and oral hygiene difficulties had a negative bearing on both oral care and caries increment. Additionally, they reported[90], that people with dementia already had a compromised oral health status when admitted to long-term care homes. The high plaque levels on natural teeth were of particular concern.

6.2.2 *Periodontal (gum) disease*

There is clear evidence that gingivitis is more prevalent in people with dementia. This is due to cognitive impairment, motor restlessness and apraxia. Increased periodontal disease is not surprising as adequate plaque control and oral care require both cognitive and motor skills. Although studies by Ship[17,18] found that people with dementia had significantly higher plaque scores, an increased proportion of gingival bleeding sites and more calculus than the matched control group, there was no statistical difference in periodontal health between the control and dementia group. Warren *et al.*[23] and Chalmers *et al.*[21] demonstrated that poor gingival health increased with the severity of dementia.

6.2.3 *Dental caries (decay)*

The majority of studies concerning the prevalence of caries for people with dementia include

non-medicated individuals in the early to moderate stage of the disease process. Thus, it is likely that they underestimate the eventual progression of oral disease and impairment of those individuals who are on medication for their illness. In a recent longitudinal study, Chalmers *et al.*[21] compared dentate people with dementia living in the community with a matched control group without dementia and found that both coronal (crown) and cervical (root) caries increments were significantly higher in the group with dementia. The research concluded that sex (male), dementia severity, high carer burden, oral hygiene difficulties, use of neuroleptic medication (causing dry mouth) and previous caries experience were all risk factors for dental decay.

Warren *et al.*[23] reported that the more severe the dementia the more likely it was that there would be oral health problems, including an increased prevalence of dental caries. Whilst a number of researchers have described decreased salivary flow rates, poorer oral hygiene and increased caries (both coronal and cervical) as consistently higher in people with dementia than in control groups, they have been unable to demonstrate any clear statistical difference between the groups and the authors made recommendations for further studies[18,19,24]. The results of such research could be attributable to the exclusion of people with advanced AD who are unable to give informed consent; and the challenges of gaining co-operation of, and compliance from, this group of people when they are included. Those individuals least able to co-operate and comply are the people who are most likely to be at risk of increased oral disease. Indeed, all research in this area has concluded that it is the severity of cognitive impairment rather than the diagnosis of dementia that is a factor in the caries experience[18,19,21,23,24]. Avlund *et al.*[25] demonstrated that in a Swedish population, aged 80 years and over, both coronal and cervical caries increases as cognitive function decreases. Additionally, people with poor cognitive function have a four times higher risk of not using dental services regularly. Rejnefelt *et al.*[26] point out that people with dementia living in care homes have more oral health problems than individuals without dementia. Whilst, Adam and Preston[27] conclude that moderate to severe dementia may have a deleterious effect on the oral health of individuals in care homes.

6.2.4 *Medication, saliva and oral mucosa*

The commonest medications used in AD (see 5.5 Management) have the potential to cause xerostomia (dry mouth) and its complications of plaque accumulation, periodontal disease, denture wearing problems and dental caries. If medications are syrup-based the potential for the development of rampant caries is increased. It is prudent to advise the use of sugar free medications where possible. Frequent dental review and use of chlorhexidene and fluoride help in the prevention and/or control of caries development. As AD progresses the individual is less able to remember, and less able to carry out, daily living activities such as tooth brushing and will need support in this task. Also, the individual becomes less able to express their needs or wishes, and to understand and explain dental symptoms such as pain[7].

People with dementia may be given a variety of drugs to treat problems such as anxiety, depression, psychosis, insomnia and other systemic illnesses prevalent in the older age group as well as medication that may slow the dementia process. The medications used to help with mood control and to attempt to slow cognitive impairment include anticholinesterases, antidepressants, antipsychotics and anxiolytics. All these drugs can have xerostomic side-effects[28]. Chalmers *et al.*[21] found that the use of neuroleptic medication increases a person's susceptibility to caries. The drugs used can also cause glossitis (anticholinesterases) and mucositis (antipsychotics), as well as gingival hyperplasia, oral ulceration, erythema multiforme and loss of taste (anticonvulsants)[7,20,29].

Ship *et al.*[17] found that submandibular gland salivary flow rate was significantly reduced in people with early AD although parotid flow rates were the same as for the control group. Adequate salivary flow is a requirement for good oral health. It assists in the prevention of abrasions (especially for those people wearing dentures), and its qualities of buffering and washing help to reduce the potential for caries. There may be increased plaque accumulation and gingival inflammation in people with a dry mouth that can be painful leading to less inclination to brush the gums and, consequently, poorer oral hygiene[30,31]. Ship[18] found no difference in mucosal pathology (including candidiasis) although the group with dementia tended to have dry and cracked lips. Despite no significant difference in the prevalence of Candida, 50% of people with dementia had denture induced stomatitis.

People with dementia may not be able to complain of a dry mouth so it is prudent, where possible, to include an evaluation for xerostomia in the overall oral health risk assessment. The effect of a dry mouth has serious consequences for a cognitively impaired older person who may be unaware of, or unable to, articulate their difficulties[17,18,30,31].

Paradoxically, despite reduced salivary flow, drooling (or siallorrhea) can be a problem in people with AD. It is defined by Brodsky[32] as 'abnormal spillage of saliva from the mouth on to the lips, chin and clothing'. It tends to occur because of dysphagia (difficulty swallowing) coupled with a head down posture. It can be exacerbated by oral pain and discomfort. According to Kilpatrick *et al.*[33], profuse drooling can cause perioral maceration, skin chapping and infection, antisocial odour, requirement for frequent change of clothing, lowered self-esteem and depression. Management strategies for controlling drooling include behavioural and oral motor techniques to remind or teach the person to swallow; drugs to reduce salivation (which can exacerbate oral health problems even further); and surgery to reduce the amount of saliva or to re-route the saliva to by-pass the oral cavity[33]. In the later stages of AD, the pharmacological approach may be the most effective. Because of side-effects such as dry mouth, behavioural changes and hot flushes, anticholinergic drugs (such as transdermal scopolamine) tend to be used intermittently; for example, prior to social outings. It is not possible to predict the degree of dry mouth that will be achieved and it is important to monitor this so that one problem (i.e. drooling) is not substituted for others (e.g. dry mouth, caries, difficulty eating).

7 Oral health assessment

In a health care setting, assessment is described as the gathering of information and formulation of judgments regarding a person's health, situation, needs and wishes which should guide further health action. An effective oral health assessment identifies risk factors for present and future oral health care and includes negative factors that impact on oral health. It is not a diagnostic tool unless it also includes a comprehensive oral examination as part of a holistic assessment. Where it is intended for use with a specific client group, it should incorporate the known risk factors for oral health for that client group. There is no universal response to risk factors and there will be individual variations. However, some risks will be deemed to be acceptable as an essential component of treatment, e.g. the side-effects of long-term medication or high calorie, sucrose containing, food supplements to maintain nutritional status.

An oral health risk assessment is essential for those conditions where impairment or disability impact on oral health. In dementia it is relevant to focus on:

- The four Cs
  - Communication
  - Competence
  - Consent
  - Compliance
- The oral side-effects of medication
- Dietary changes required to maintain nutritional health[7]

These factors must be viewed in the context of dementia as a progressive degenerative condition with individual variation in the rate of progression of the illness and be related to all aspects of oral health.

An assessment of the individual's ability for self-care in oral hygiene and cooperation for treatment is essential at the point of diagnosis and throughout the progression of dementia in order to formulate appropriate oral care plans, preventive strategies and treatment options. Assessment should be repeated at agreed intervals when there are changes in the progression of the illness, in medication and/or diet. However an oral risk assessment is of limited benefit if it is not accompanied by mechanisms to provide the individual and/or carers with appropriate advice and prevention, and to facilitate regular contact with appropriate dental services. Re-assessment is essential prior to considering any form of dental treatment.

7.1 *Types of oral health risk assessment*

According to Griffiths & Boyle[34], there are three broad groups of assessment systems. These are based on:

- Intra-oral examination
- Observation or assessment of the individual's behaviour
- Client perception of need

An intra-oral assessment is designed to monitor changes in oral tissues. It can be simple, as in screening; or complex, as in a full clinical examination. As many factors may influence the individual's oral health, directly or indirectly, assessments that are based on observed or reported behaviour may be more effective than those based on clinical examination, for individuals who are less able to be compliant. This type of assessment can also draw upon the knowledge of carers and health care professionals with little or no training implications. Assessment of the individual's perception of felt or expressed need and subjective value of oral health is valuable during the early stage of dementia, before cognitive impairment interferes with communication. Most assessment systems include a combination of these three approaches.

A number of assessment systems have been described for people with progressive illness[7,34–36]. Griffiths and Boyle[34] list the key areas that give an indication of oral health status and point towards objectives for care as:

- Existing signs and symptoms of oro-dental disease
- Current mouth care practices
- Preventive behaviour
- Patterns of dental attendance
- Systemic disease
- Side-effects of medication
- Key stressors for oral health
- Level of carer intervention for oral care

These provide the basis for an assessment tool that weights the different risk factors, quantifies risk status and can subsequently provide guidance on the degree and type of intervention that the individual may require. Appendix 1 provides an example of a simple oral health risk assessment form. However, the assessment of a patient with dementia may require a more detailed analysis of cognitive impairment, behaviour and potential co-operation or compliance; and an analysis of the potential benefits to the individual in relation to the identified risks[7,35].

7.2 *Undertaking the assessment*

Oral risk assessment is mainly carried out by dentists as part of an individual assessment. The BDA policy document 'Oral Health Care for Older People: 20:20 Vision' recommends that a free oral health risk assessment is available to people from the age of 60[3]. This occurs in Wales for people over the age of 65 years and is planned in Scotland from 2006. It is also recommended that such an assessment is accompanied by a strategic long-term oral health care plan that provides information on how to reach and maintain oral health[4]. The BDA document also recommends greater use of Dental Care Professionals (DCPs) (formerly Professions Complimentary to Dentistry, PCDs), such as hygienists, who have been appropriately trained in carrying out oral health risk assessments.

In the case of progressive conditions such as dementia, an oral health risk assessment should be carried out at the point of diagnosis. There is an urgent need for other health professionals to incorporate oral assessment into standard health assessments. The introduction of annual general medical practitioner (GP) surveillance for people over the age of 75 provided an opportunity to identify and screen for oral problems. Implementation of the Single Assessment Process (SAP)[1] and the Unified Assessment Process (UAP)[37] provide an opportunity to include a basic oral health risk assessment into a comprehensive and holistic assessment process. The EASY-Care assessment system developed for over 75 health checks is being used in some areas as the basis for SAP and UAP. It includes questions on chewing ability and personal oral care[38,39]. Simon's Nursing Assessment for elderly mentally ill people covers most aspects of nursing care (including dietary intake) but does not include an assessment of oral problems that might impact on dietary intake[40]. Rather than introduce new assessment systems, it would be expedient to expand the questions on oral and dental problems as described in the British Society for Disability and Oral Health guidelines for people with a physical disability[41] and people with mental health problems[42–47] which are accessible at http://www.bsdh.org.uk. An example of how this might be carried out is found in Appendix 2.

As the onset of dementia can occur in younger age groups, it would be pertinent to include an oral health risk assessment within the initial psychiatric assessment by general medical practitioners, at Community Memory Clinics and at the initial assessment of other conditions that may give rise to dementia. The Cardiff Health Check for people with learning disabilities includes basic questions about dental problems and dental attendance[48,49]. This assessment is of particular relevance for people with DS as they have a higher incidence of AD at a relatively early age.

There is increasing awareness in the nursing profession of the need for oral assessment. Oral health assessment based on subjective and behavioural indicators are reported to be successful in identifying need on admission to residential or continuing care facilities[50,51] or contact with day services. Intra-oral assessment requires training and there are difficulties translating theory into practice, in establishing agreed standards and providing the necessary training[14]. However, Lin *et al.*[36] describe a successful education programme that equipped nurses and health care assistants to carry out an oral health assessment based on a brief intra-oral examination. They concluded that with appropriate training, health care assistants are as capable as qualified nurses in assessing oral status. Chalmers and Pearson[53] state that expert opinion indicates that oral assessment screening of care home residents by staff and a dentist would be ideal at admission and regularly thereafter. However, they go on to say[54] that delineation is needed between a comprehensive dental examination conducted by a qualified dentist and a dental assessment screening by a carer, nurse,

allied health professional or medical practitioner. They suggest that dental examinations should be supplemented with oral health assessments and screenings by trained nurses and carers to monitor residents' oral health, evaluate oral hygiene care interventions, act as a trigger to call in a dentist when required, assist with individualised oral hygiene care planning and assist with triaging and prioritising residents' dental needs.

7.3 *Assessment for dental treatment*

The decision making process in planning oral health care for people with dementia and/or other cognitive impairments presents challenges to the dental team who are primarily trained to cure oral disease. Treatment planning must take account of the stage of the illness and the level of cognitive impairment. Consultation with members of the multi-disciplinary psychiatric team, relatives and carers is essential to obtain an accurate assessment of cognitive impairment. The Mini Mental State Examination[55] is a brief, quantitative measure of cognitive status in adults (http://www.minimental.com). It can be used to screen for cognitive impairment at a given point in time, to follow the course of cognitive impairment over time and to document individual responses to treatment. The scoring system provides a classification of the degree and severity of cognitive impairment.

Ettinger[7] recommends that, before assessing the oral/dental status and formulating an individualised treatment plan, a comprehensive patient assessment is carried out including:

- Level of cognitive impairment
- Assessment of daily living activities
- Level of social functioning.

Niessen *et al.*[35] describe an Index of Dental Management based on an assessment of observed behaviour and ability. Adverse or aggressive behaviour is an essential component of this assessment. The dental index score provides useful guidance on treatment planning approaches (see Table 2). Kayser-Jones *et al.*[56] suggest strategies for

Table 1 Summary of the stages and characteristics of Alzheimer's disease

Stage	*Clinical phase/clinical characteristics*
Normal	No more than occasional forgetfulness
Forgetfulness	Subjective forgetfulness; normal physical examination
Early confusion	Difficulty at work, in speech, when travelling in unfamiliar areas; detectable by family; subtle memory deficit on examination
Late confusion	Decreased ability to travel, count, remember current events
Early dementia	Needs assistance in choosing clothes; disorientation as to time or place; decreased recall of names of grandchildren
Middle dementia	Needs supervision for eating and toileting; may be incontinent; disorientated as to time, place and, possibly, person
Late dementia	Severe speech loss; incontinence and motor stiffness.

Source: Reisberg[89]

Table 2 Index of Dental Management to assess ability to co-operate for dental treatment

Can patient brush teeth or clean dentures?	Yes	(0)	Needs some assistance	(1)	Needs complete assistance (2)
Can patient verbalise chief complaint?	Yes	(0)	To limited degree	(1)	No (2)
Can patient follow simple instructions? e.g. sit in chair	Yes	(0)	Occasionally complies	(1)	Cannot follow instructions (2)
Can patient hold radiograph in mouth with film holder?	Yes	(0)	Sometimes	(1)	Never (2)
Is patient assaultive (bites/hits)?	No	(0)	Sometimes	(1)	Always (2)
Total score	0		5		10

Source: Niessen[35].

Scoring system: 0–3, mild disease (no change in treatment); 4–7, moderate disease (modify treatment plan); 8–10, severe disease (emergency treatment only).

conducting dental examinations among cognitively impaired nursing home residents that permit examiners to conduct the examinations successfully, including developing rapport with the residents, providing a quiet environment and enlisting the help of the primary caregiver. The importance of interdisciplinary collaboration among health professionals, especially dentists and nurses, is also stressed.

Ettinger[7] offers an algorithmic approach to decision making and treatment planning for patients with cognitive impairment that provides clinical guidance (see Appendix 3). However it must be based on common law, the current legal framework and best practice within that country[6]. Although the assessment and subsequent decision making process may be predominantly based on subjective opinion, it should not be dismissed as an aid to the clinician in developing treatment options that are individualised, realistic and based on wide reaching consultation with family, carers and the multi-disciplinary team.

8 Oral health care planning

Ideally a dentist should be part of the multidisciplinary care team for people with progressive neurogenic disorder from diagnosis, so that oral care can be planned throughout the disease process and does not become crisis management in the final phase of the condition. The implications of AD for oral care and dental treatment as the individual becomes increasingly cognitively impaired are that they become less able to:

- Express their needs or wishes and to explain what they want
- Understand and explain dental symptoms such as pain
- Take part in the decision making process about treatment
- Give informed consent
- Tolerate dental interventions
- Perform daily living activities such as oral hygiene
- Understand that oral hygiene needs to be carried out[7,57]

8.1 *Expression of oral symptoms*

Once a person is unable to interpret or vocalise pain or discomfort they become reliant on another person to recognise, interpret and report behaviour change, which may indicate dental problems; and to initiate oral care. Changes in behaviour, which can be indicative of oral pain include:

- Refusal to eat (particularly hard or cold foods)
- Constant pulling at the face
- Increased drooling
- Leaving previously worn dentures out of the mouth
- Increased restlessness
- Moaning or shouting
- Disturbed sleep
- Refusal to co-operate with normal daily activities, such as grooming, washing and tooth brushing
- Self-injurious behaviour
- Aggressive behaviour towards carers[7,57]

Gordon[58] and Ettinger[7] highlighted the dilemma in decision making for the cognitively impaired dental patient as how to determine:

- When a dental condition requires intervention
- How to know if cognition is impaired to the point that pain perception is so altered that the patient neither perceives pain nor is able to describe it
- How to predict which seemingly asymptomatic oral conditions will become symptomatic in the absence of treatment (see Case scenario 1)

There is a dearth of studies regarding the effects of oral problems, dental pain and behavioural problems in people with dementia. Lapeer[59] looked at the research associated with the impact on pain sensation for people with dementia and found it confusing and sparse. He felt that an existing oral problem may be expressed in a change in behaviour or be identified by clinical examination; and urged the dental profession to treat, rather than ignore, any oral health problems. People in the late stage of AD are often unable to communicate dental symptoms of pain and dysfunction[60]. Henry and Wekstein[20], and Ettinger[7] reported that dental pain in people with dementia often manifests itself in a sudden worsening of behaviour, moaning or shouting, refusal to do tasks or eat certain foods and increased restlessness and impaired sleep, thus, a history of baseline behaviour is essential in identifying oral pain.

Friedlander and Jarvik[61] reported personal findings that there was an increase in minor injuries for people with dementia because of falls, judgmental errors, misperception of environmental dangers and poor motor skills. Intra-orally, they found oral ulceration because of injuries from cutlery and foreign objects. However, none of these findings has been substantiated by further published research.

In terms of people with dementia presenting with oral and or facial trauma, the question of non-accidental injury must be considered[62]. Local guidelines for dealing with suspected abuse in

Case scenario 1: Mrs B

Mrs B was an 87-year-old women who had recently moved into a residential home where she was visited by her family only occasionally. She was physically fit and mobile but in the moderate stage of AD with impaired cognition and little, or no, obvious means of communication.

The visiting dentist was asked to examine her as the care staff had noticed that she had a large number of extensively decayed, broken down teeth and bad breath. The dentist could only gain a cursory look in Mrs B's mouth as she would not co-operate – pushing hands and dental mirror away and screaming. Apparently this was her usual behaviour when being washed, dressed and fed. The dentist could see no obvious signs of acute dental infection but came under increasing pressure from the staff to arrange for Mrs B to have her teeth extracted as her halitosis was making it increasingly difficult for them to assist Mrs B in activities of daily living.

After a best interests meeting, gaining professional consent and the anaesthetist's go ahead that Mrs B was fit enough to have a day-case general anaesthetic, her teeth were extracted. When next seen by the dentist Mrs B's whole demeanour had changed. Staff reported that she was co-operative for washing and dressing. She now had a healthy appetite and was often heard singing.

Clearly Mrs B had been in a deal of dentally related pain for some time. She had no means of communicating to the staff that she had toothache and the staff had no means of interpreting her aggressive behaviour.

vulnerable adults should be accessible to, and followed by, the dental team. Although there is no evidence to support the role of dental disease in precipitating non-accidental injury, the possibility that it may be the direct result of challenging behaviour that is due to dental pain should not be underestimated.

8.2 *Capacity to consent*

Although the person may be cognitively impaired or 'locked in' and unable to express themselves, it is important that (s)he is informed, and whenever possible, consulted in choices and the decision making process. It is not always possible to know how much, if anything, the person with dementia understands. It is good practice to explain, in simple terms, what is being done and why; and to afford the individual the opportunity to make, or take part in, the appropriate choices. It may be possible to judge from the person's reaction, facial expression and body language how much is understood. Whilst too many choices can be confusing for the individual, choice can be offered (and information gathered) by phrasing questions so that they only need a 'yes' or 'no' response or by using appropriate communication aids such as word or picture boards.

In situations where communication is questionable and where the individual is not considered to have the capacity to give informed consent, it is prudent to involve family and/or carers in the decision making process. In some residential settings a 'best interests meeting' will be held, involving all parties, to decide whether the proposed dental treatment is in the best interests of the individual. Even when agreement is gained from relatives and carers, professional consent (that is two independent health care professionals agree that the treatment is in the best interests of the patient) should be sought in instances where proposed dental treatment is radical or irreversible. The BSDH guidelines 'Principles of Intervention for People Unable to Comply with Routine Dental Care'[6] have been developed 'to assist in the provision of oral health care for people whom it is judged do not have the capacity to consent and/or whose behaviour requires further support to facilitate the safe delivery of oral and dental care'. They provide sound advice with the emphasis on a proactive approach to care rather than just a reactive approach to managing aggression and disruptive behaviour.

The UK Mental Capacity Act will be implemented in 2007. It aims to protect people with learning disabilities and mental health conditions, such as AD. It will provide clear guidelines for carers and professionals about who can take decisions in which situations. The Act states that everyone should be treated as able to take their own decisions until it is shown that they are unable to do so. It aims to enable people to make their own decisions for as long as they are able and a person's ability to make a decision will be established at the time that a decision needs to be made. Additionally, there will be a new criminal offence of neglect or ill-treatment of a person that lacks capacity.

Whatever the circumstances, the legal situation regarding consent must be adhered to. Additionally, the individual's rights must be respected and guidance on physical intervention appreciated[6]

8.3 *Oral health care planning*

This is an essential part of ensuring oral health and comfort. Every long-term care resident and hospital patient with AD should have an oral health care assessment and plan as part of their general health/nursing care plan on admission[63,64]. Oral health should be monitored at regular intervals and reviewed according to the individual's requirements.

An oral health assessment by health professionals provides a mechanism for opportunistic identification of people who have oral and dental problems, require attention from the dental team and/or require help with daily oral hygiene. Appendix 2 provides an example of an oral health assessment tool that can be used or adapted for use with people who have AD. The oral health assessment acts as the indicator for referral for appropriate oral health care where long-term strategic planning for both dental treatment and oral health care can be initiated. The current National Institute for Clinical Excellence (NICE)[64] guidance on dental recall intervals facilitates individual risk assessment and appropriately tailored review intervals.

8.4 *General principles for oral health care*

The following guidelines are useful: when considering strategic, long-term, oral care planning for people with AD:

- Instigate appropriate preventive measures to minimise dental disease as soon as possible
- Undertake dental intervention in the early stages of the condition to manage outstanding dental treatment needs
- Ensure dentures are named; cleaned professionally on a regular basis; and renewed using a duplication technique when their replacement is necessary
- Instigate regular review tailored to the individual's needs to maintain the oral status quo, avoid pain and minimise further interventions
- Ensure that fear, stress and embarrassment for the carer and the person with AD are minimised by adopting an 'open-door' approach and providing back-up and support[57]

A carer advice sheet is available at http://www.alzheimers.org.uk

On a day-to-day basis, the following guidelines are useful when providing oral care for people who have AD:

- Recognition that some people have good days and bad days. If possible, dental care is better postponed to a good day and to the individual's best time of day.
- Short attention spans mean the ability to co-operate is decreased and dental appointments should be kept within the individual's capacity to cope.
- Short-term memory loss means communication can become difficult and tedious. Clear short instructions repeated in the same words are useful. For example, 'sit down' or 'sit here' is much more likely to elicit the desired reaction than is the invitation to 'please have a seat' or 'would you like to sit down'. The person with AD is likely to ask the same questions repeatedly, it is unhelpful to say 'I have just told you…' as this only adds to their sense of confusion. It is best to repeat the answer in the same words. Smiling and use of appropriate touch are useful, reassuring gestures. Resist the temptation to speak more loudly as this will not aid understanding.
- Emotional lability causes swings from laughing to crying within a short space of time. This is not as a result of dental treatment. It is a symptom of AD. Warning dental staff about the possibility of such mood swings makes it less distressing for them and easier to cope with. Rather than focussing on the mood swing, distraction is a useful coping strategy.

8.5 *The role of carers*

The carer has a role in maintaining daily oral hygiene and in initiating dental treatment, whether it be routine or emergency care.

Whilst it is important to maintain a person's independence for as long as possible by encouraging them to carry out daily living tasks, it is equally important that a balance is struck between maintaining independence and maintaining adequate oral health. In the early stage of AD, the individual remains capable of carrying out adequate oral hygiene. However, they may need to be reminded to carry out the task; given the brush and toothpaste and told what to do with it; and/or supervised whilst cleaning their teeth. As manual dexterity decreases, electric toothbrushes or toothbrush handle adaptations may help to maintain independence. As AD progresses and the individual loses interest in personal hygiene, or loses the ability to care for personal hygiene, a carer

needs to take over this task. The carer needs instruction and support from the dental team on how to approach the task (see Appendix 4). Ghezzi *et al.*[65] recommended that family members must be trained in regular oral and denture hygiene procedures.

If the individual is without a carer to look after their oral hygiene needs, he/she can develop severe halitosis, which is socially unacceptable. Also, increased plaque accumulation can cause rapid deterioration of the periodontal condition in susceptible people and/or dental caries, leading to tooth loss.

Alzheimer's disease is distressing for the individual [particularly in the early stage when (s)he is aware that something is wrong] and for the carer (throughout the disease process). The book 'The 36 Hour Day – Caring at Home for Confused Elderly People' provides insight into how AD causes confusion and change in the lives of people with AD and their families and highlights the stresses that carers can experience[66]. These may include exhaustion, self-neglect and isolation as all their energies are put into looking after the person they care for. Emotional turmoil and depression are also common amongst carers. Relatives feel considerably reassured if the dentist is aware of the problems of AD and understands the nature of the disease. Whittle *et al.*[67] found that whilst carers believe dental care is important for people with AD, they doubt the dentist's expertise and ability to cope and did not initiate dental treatment. They considered this to be the greatest barrier to dental care for people with AD. Locally, this issue can be addressed by interested dentists becoming involved with carers' support groups.

Nolan[68] found that one of the major sources of carer stress relates to a lack of support and recognition from professional carers – including health professionals. Specific issues mentioned by carers included poor attitudes and a failure to supply promised help. To foster relationships, which encourage carers to contact the dental profession, it is essential to establish their worries, concerns and needs, as well as, to respond to them. An emphatic approach, good questioning skills and active listening will help to achieve this goal.

The model of good practice for oral health care for care home residents proposed in the strategic review of meeting the oral health challenges of older people[4] addresses the roles and responsibilities of care home owners and staff. The model includes:

- Oral health assessment incorporated into basic entry assessment
- Standards for routine oral and denture hygiene linked to the National Minimum Care Standards
- Structured modular training for care givers to assist with and/or to provide daily oral hygiene
- Healthy eating policy in place
- Arrangements for access to emergency and routine dental services
- Regular dental screenings or check-ups arranged for residents in accordance with NICE guideline time-intervals

9 Dental treatment

9.1 *Tolerating oral and/or dental interventions*

Compliance for oral health care procedures and dental care does not necessarily decline with advancing dementia. Even people with very advanced dementia can retain the capability of tooth brushing if handed a toothbrush. In care homes, the individual's self-care skills can be overlooked so that nurses and carers may overcompensate leading to unnecessary dependence. The use of oral risk assessment tools can assist in avoiding this situation.

The ability to comply with oral hygiene procedures and dental care is often influenced by past dental behaviour and experiences[69]. Nordenram *et al.*[70] and Lester *et al.*[71] confirmed that poor co-operation of people in the late stage of dementia was not necessarily because of the nature of the illness but because of past negative dental experiences. Where possible, information on past dental care and previous attitudes towards oral care should be sought from relatives and carers. This information can be useful in predicting the behaviour and willingness to receive dental care for people who are unable to consent to care. The ability to co-operate for dental treatment assessment, described in Table 2, can be a helpful guide where other information is lacking[35]. Additionally, knowledge of the policies regarding physical restraint within care homes is important so that appropriate oral health care advice can be given that fits the ethos of that particular home.

Both the progression of AD and the effect it has on personality vary enormously. Dental management can be quite easy when dealing with a 'happily confused', co-operative individual or even a passively, compliant person. It can be very difficult and sometimes impossible, when faced with someone who becomes distressed when interfered with in any way (e.g. washing, dressing, hair-brushing or tooth cleaning) or when a person is verbally and/or physically aggressive. Determining

the individual's level of social functioning and whether he/she is physically or verbally abusive helps to determine the treatment modality suitable for delivery of dental care[7].

Some people with dementia who have had regular dental treatment throughout their lives seem to remember what they are expected to do in the dental surgery. They have little difficulty co-operating with simple procedures until the late stage of the disease. Familiar surroundings, routines and people are reassuring if a person is confused, and aid co-operation.

9.2 *Treatment planning*

The dental treatment that can be provided for the individual with dementia is based on the dentist's clinical judgement. Ettinger has illustrated this process as a decision tree (see Appendix 3) with the outcome being reached in conjunction with the patient and their family or carers[7].

The important areas that Ettinger highlights for consideration in this process are:

- The patient's level of independence, co-operation, cognitive state and physical impairment
- The presence of dental problems and whether they are symptomatic or asymptomatic
- The individual's ability to give informed consent

Once these questions have been answered a realistic management plan tailored to the individual's needs and capabilities can be constructed. All management plans should be based on the principal that the person should benefit from treatment. The treatment philosophy should be based on the primary responsibility of the dentist to eliminate pain, control infection and prevent new disease.

The average life-span of people with AD is 8–10 years from diagnosis with a range of 3–20 years[7]. As the disease is progressive, knowing when the AD was diagnosed helps to determine approximately where the individual is in the disease process and to predict their ability to carry out oral self-care and to accept dental treatment.

9.2.1 *In the early stage*

At this stage (the first 0–4 years) most restorative and rehabilitative care is possible. Treatment should be planned anticipating the person's decline in cooperation and ability for self-care. Key teeth can be identified (e.g. canines, molars, occluding pairs) and restored to function. Restorative treatment should be high quality and low maintenance. Any advanced restorative treatment should only be planned in the knowledge that, when the individual can no longer provide oral self-care, a care-giver is prepared to take on this role. Rigorous preventive measures (both home- and surgery-based) should be put in place at this stage so that they become routine for both the individual and their carer.

9.2.2 *In the moderate stage*

At this stage (2–8 years) the focus of oral care changes from restorative and rehabilitative to maintenance and prevention. During this stage the person is often relatively physically healthy but has lost cognitive skills. Some people are verbally and/or physically abusive at this stage making treatment difficult. Sedation or general anaesthesia may be necessary for treatment. The decision will be based on the individual's ability to co-operate, dental treatment needs, general health and social support. Rigorous prevention should be continued and more frequent recall visits and support for carers employed, as appropriate.

9.2.3 *In the late stage*

At this stage of the disease (6–10 years) the person is severely cognitively impaired and often physically frail or disabled. They may be unco-operative but no longer abusive or violent. Treatment at this stage focuses on prevention, maintaining oral comfort and emergency treatment.

As dementia progresses, dental interventions should be kept as non-invasive as possible e.g. using Carisolv for caries removal, atraumatic restorative techniques (ART) such as glass ionomer cement restorations, regular application of chlorhexidene varnish to control root caries[72], etc. This helps to build rapport and co-operation. If treatment beyond the individual's coping capacity is required two questions need to be asked. The first asks:

- Is the treatment necessary?

If the answer to this question is yes, then the second question to ask is:

- How can it best be carried out?

The treatment planning then has to take account of the treatment modalities available, such as a combination of oral or intranasal sedation with intravenous sedation, or general anaesthesia. The benefit from treatment has to be weighed up and at least balanced with the difficulties of providing it in terms of co-operation, consent, restraint, etc.

9.3 *Denture requirements*

In a study of people with early dementia, Whittle *et al.*[16] found that a higher proportion were edentulous and the dentures worn were significantly older, than in a matched population without

dementia. Also, the denture cleanliness was poorer in the group who had cognitive impairment. The Adult Dental Health Survey (1998) reported that 13% of the population were edentulous and this was predicted to fall to 5% in 2018[5]. However, there will still continue to be a large number of people requiring prosthodontic care in old age, for both partial and complete dentures.

9.3.1 *Denture wearing*

Shimazaki *et al.*[73] have suggested that people with poor oral health status especially those people who are edentate and without replacement dentures, are more likely to have deterioration in systemic health.

Denture wearing success (particularly of complete dentures) depends, to a large extent, on the wearer's ability to control the dentures with their oral musculature. It also relies on the presence of an adequate amount and quality of saliva. The impact of dementia can affect a person's ability to wear dentures. The movement disorders such as tardive dyskinesia, muscle spasms, muscle in-coordination, rigid facial muscles, sucking reflex, reduced salivary function, postural hyper-salivation and poor muscle control that can occur in dementia conspire to jeopardise denture retention and control, leading to loose dentures[70]. For some individuals this will mean they are not able to cope with dentures, whilst others will require the use of a denture fixative/adhesive to increase denture retention and denture-wearing confidence. Experienced denture-wearers can be skilful in controlling poor-fitting dentures with their lip, cheek and tongue muscles. As dementia progresses and muscle skills diminish, previously seemingly well-fitting dentures may appear to become loose. These should not be discarded as it may be possible to reline or re-base them. Also, they can contribute valuable information to the process of providing new dentures; such as the arch form, polished surface and contours.

9.3.2 *Denture loss*

Denture loss is common when people with dementia are in unfamiliar environments such as short-term respite stay in care homes. This can be heartbreaking for carers as it can be seen as the loss of the last vestige of normality. Now the person not only does not behave normally, but they no longer look normal. Replacing lost dentures can be challenging and sometimes impossible. If the person is without their dentures for any length of time, they can lose their denture wearing skills and their ability to adapt to new dentures. An additional problem can be that the individual no longer possesses the co-operation which is necessary to allow the provision of new dentures. Carers are often unaware of the co-operation, the technical skill and the muscle control required to result in 'successful' dentures. In these challenging situations, it is prudent to have a relative/carer sit in on the dental treatment visit. This allows them to see at first hand the problems involved with taking impressions etc. when a person cannot co-operate or resists treatment. Sometimes gentle restraint by the carer (e.g. hand-holding, distraction by encouraging attention through hand-stroking or talking) may be all that is needed. If this is insufficient a realistic solution can be discussed such as providing an upper denture only for the sake of appearance, or even an upper denture base with only anterior teeth set on it. Seeing the difficulties for themselves helps carers to come to terms with the situation.

Eventually, many people with dementia reach a stage where they can no longer tolerate dentures in their mouth although they have worn them without problems up to this point. Here, the dentist's responsibility is to ensure that the mouth is healthy, the dentures were not causing any damage and empathically explain the situation to the family/carers.

9.3.3 *Denture provision*

New complete dentures are provided in two circumstances. One, when dentures are lost and, two, when the person becomes edentulous. In both circumstances the person with dementia may have difficulty in coping with their new dentures, even if they have previously worn partial dentures successfully. They will need to be encouraged, by their carer, to persevere with the dentures. This is more likely to happen if the person is cared for at home by a family member than if they are in a care home. New dentures should be provided using conventional techniques. The use of training bases and the neutral zone technique are of limited value for people with dementia because of their decreased ability to understand and co-operate. It may be possible to use these techniques occasionally, for example, if the person is in the early stage of AD, has a compliant nature and has a supportive, full-time carer.

Replacement complete dentures should be constructed using a duplication technique, or at least taking account of key features of the old dentures such as the arch shape and tongue space, assuming past dentures have been worn successfully. It may be necessary to construct duplicate dentures and gradually modify them to test the bounds of

tolerance towards the desired result. Once this stage is reached the transitional dentures can be copied to provide the final set. If previous dentures were not useful, the replacement set should be provided using a conventional denture construction technique.

Partial dentures should be designed to provide a balance between simplicity, for ease of insertion and removal, and with adequate clasping and extension, to provide good retention to encourage denture wearing. Wherever possible the gingival margins and exposed root surfaces should be uncovered by the denture to minimise plaque accumulation and root caries risk.

If partial dentures have not been worn previously, the main consideration should be, whether they are really necessary. It may be possible and preferable, to fill one or two strategic gaps with adhesive bridges and/or to accept the shortened* or extremely shortened dental arch†[74]. These options lead to less plaque accumulation and reduced root caries risk compared with partial dentures. They also negate the tolerance or skill required for denture wearing.

9.3.4 *Denture marking*

All dentures belonging to people with dementia should be marked with their name. New dentures should be permanently marked during construction, by the technician[75]. Currently worn dentures can be temporarily marked using a simple technique that will last for 6–12 months (see Appendix 5). The denture should be checked periodically to ensure the name is still legible; and marking renewed as necessary. Naming dentures does not prevent denture losses. However, it does mean that when dentures are found they can be reunited with their owner.

9.3.5 *Denture and mouth hygiene*

Denture and mouth hygiene may need to be undertaken by a carer. Dentures should be cleaned in, or over, a bowl of tepid water so that, should they be dropped, the water will cushion their fall preventing breakage. They should be thoroughly brushed on all surfaces with a tooth or denture brush and liquid soap or toothpaste to remove food debris and plaque. In a care home or hospital setting, only one person's dentures should be cleaned at a time. This is in the interests of hygiene and to prevent any confusion of ownership.

When there are no natural teeth the mouth still requires gentle cleaning either with a soft toothbrush or a flannel wrapped round a finger. In progressive neurogenic disorders, it is important to ensure that stagnant food that has not been swallowed is removed from around the mouth. This can be done using a cloth or flannel wrapped around a finger to sweep the buccal (cheek) pouches for food. Its removal reduces the risk of aspiration and subsequent chest infection, as well as, preventing bad breath.

10 Delivery of dental care

10.1 *Dental attendance*

Kocaelli *et al.*[76] recommended that frequent recall visits are needed to maintain lifelong oral health. Older people have generally become much more conscientious about oral health care, with an increasing number of people in the 55 year plus age group attending for dental care[5]. In contrast, the Alzheimer's Society found that only 8% of respondents had seen a dentist in the previous year despite half of them reporting a dental problem[77]. This corroborates the earlier work of Whittle *et al.*[16], who reported that 76% of older people with a mental illness had not visited a dentist in the previous 6 months compared with 58% of a matched control sample.

Memory loss can affect an individual's ability to access regular dental care and lead to reliance on carers to facilitate oral health care. Hilton and Simons[69] reported that carers of people with dementia in a day unit in Britain were not facilitating access to dental care despite being aware of dental problems or the need for regular dental attendance.

10.2 *Access to dental services*

There are several concerns regarding access to oral health care for older people in general, and additional concerns for those people with dementia. As the disease progresses, short-term memory loss becomes more apparent and the ability to organise and remember dental visits is reduced. Carers and health professionals play a major role in facilitating access to dental care[1–4]. Ensuring that carer training for oral health care is in place is vital in this process. Procedures that identify people in need of dental care in the way of oral risk assessment tools must be part of the overall single assessment

*The shortened dental arch comprises second premolar to second premolar in both upper and lower jaws giving a functional dentition of 20 teeth.

†The extremely shortened dental arch comprises first premolar to first premolar in both upper and lower jaws giving a functional dentition of 16 teeth.

process and fail safe mechanisms for referral for dental care should be in place. The NSF for Older People in England has specifically recommended that the Salaried Dental Service is best placed for agreed working and referral arrangements with the specialist mental health service.

In the early stages of dementia, continuity of oral care with the usual dental team is to be encouraged, involving carers when the individual is no longer able to access dental care unaided. The environment within which a person with the more advanced stages of dementia receives dental care is of paramount importance. Although the individual may be ambulatory, domiciliary care lessens confusion by providing treatment in familiar surroundings.

Within the NHS dental remuneration system for general dental practitioners, there have been no financial incentives to provide dental treatment for people with disability and additional complex needs who are likely to be more time-consuming and testing to treat. This is particularly true of the provision of domiciliary care[78,79]. Consequently, the bulk of the service provision for people with anything other than early stage dementia has been restricted to a small but highly specialised sector of the salaried primary care dental service (the Community Dental Service) and a small group of dental practitioners who have developed a specialist interest. This situation puts limitations on the volume of care available.

10.3 *Delivery of dental services*

Many issues influence the decision about which site oral care can be most appropriately delivered to people with dementia. These factors include cost, manpower, availability of domiciliary equipment, availability and access to mobile dental units, geography of area, cultural and language issues, time of year, local ambulance/transport facilities, needs of the patient and carers, time considerations, risk management and experience of the dental team[78]. The evidence would suggest that those people in the later stages of dementia are better assessed initially in familiar surroundings to reduce anxiety and confusion and to increase compliance.

Familiar surroundings, routines and people are reassuring if a person is confused. For some people it may be sufficient to be accompanied into the dental surgery by a carer who remains in sight or holding a hand reassuringly throughout treatment. For others (although they may be ambulant and physically able to visit the dental surgery) the journey to the surgery, the strange environment and the unfamiliar faces of the dental team can exacerbate their confusion making treatment difficult or impossible. In these circumstances the advantages of a less confused and more co-operative individual may swing the balance in favour of a domiciliary visit. The disadvantages of domiciliary care are that it is costly, time consuming and has some limitations in treatment provision. However, the benefit for the individual patient can be vast as illustrated in Case Scenario 2.[42–47,78]

Domiciliary care requires a plethora of skills. Although in theory, any dentist should be able to provide this care, it may be best provided by staff who have appropriate training and skills in both domiciliary care and managing patients with complex medical conditions and challenging behaviour such as dementia.

Domiciliary care may be provided on various sites by using portable equipment or mobile dental units[78]. They include:

- The individual's home
- Care homes
- Sheltered housing
- Day care units (health and social care)
- Hospital environment

Current NHS changes provide a unique opportunity to begin to address the oral health needs and service provision for older people and people with dementia in a proactive manner. It is essential that bodies, such as Primary Care Trusts, who have the responsibility for commissioning oral health care to meet local needs specifically consider older people within their population. This involves taking a public health approach to examining demographic trends, assessing the oral health needs and demands of their local population and the current supply of care, along with exploring ways to facilitate access to quality care.

This knowledge will inform planning and commissioning of dental services. Assessing needs at a local level should include seeking the views of older people on how local services may be shaped to facilitate access to care. It should also include working with the voluntary, community and social sectors related to older people, to ensure that there is a patient led focus to care. Given the changing demography it will be important for health services to be monitored on an ongoing basis. Appendix 6 provides a checklist for commissioning bodies to use to facilitate their commissioning of oral health care for older people.

10.4 *Professional barriers*

Despite the fact that there have been a number of dental publications describing the oral care and

treatment planning for people with dementia, professional barriers to care remain[7,20,35,61,76,80,81]. Kiyak[81] demonstrated how dentists' negative views of ageing affected elderly people's use of dental services, access to dental services in general, and access to preventive and advanced restorative dental services in particular. Therefore, it was disappointing that Nordenram *et al.*[70] found that dentists had much lower expectations than nursing and family carers regarding the importance of various aspects of oral health in people who were cognitively impaired.

A negative attitude towards ageing, a lack of disability awareness, and a lack of understanding of the limitations of people with dementia and their affects on the individual, family and carers are amongst the professional barriers controlling access to care[20,81]. Additionally, there are issues such as having a clear understanding of the principles surrounding consent, the ability to address poor compliance with dental care and the ability to provide/access appropriate training for the dental team[82,83]. Without these values and skills, the ability of the dental health professional to determine, and deliver, the treatment level that balances cognitive and physical impairment with realistic treatment aims will be lacking, thus reducing access to appropriate care.

Access to appropriate undergraduate training and postgraduate specialisation in gerodontic and special care dentistry would begin to address the framework of awareness, knowledge and skills required to improve access to appropriate dental services[4,84].

10.5 *Carer barriers*

Very often people with severe dementia are unable to express their wishes or make rational decisions regarding their oral care. The perspective and treatment priorities of the individual's advocate and the dental team influence oral care planning. Nordenram *et al.*[70] surveyed the views of nursing personnel, carers and dentists regarding priorities for oral health care for people with dementia. Nursing staff felt that being able to eat was important, whereas, relatives were much more concerned about social behaviour and communication, including aesthetics, speech and fresh breath. All three groups of people were concerned about the importance of being free of oral pain and prevention of aspiration. Despite this situation, a number of studies have demonstrated carer reticence towards using dental services. Whittle *et al.*[67] reported that 96% of carers who took part in their study considered dental care to be important, but many of them remained reluctant to use dental services as they perceived the dental team to be ill equipped to deal with people with dementia. Moody[85] indicated that carers and relatives felt

Case scenario 2: Domiciliary care for someone with dementia

Mrs X, aged 84, was recently diagnosed with dementia. She is cared for at home by her 88-year-old husband. Mrs X has experienced memory problems for 18 months and is progressively less able to grasp the thread of a conversation or to carry out activities such as cooking or going outside by herself. Among the latest items she has 'mislaid' are her dentures. Mr X is upset by her diminished appearance and by the fact that she is now restricted in the foods she can eat.

Mr X took his wife to the dentist to have new dentures made. She became extremely agitated and aggressive in the unfamiliar surroundings and refused to sit in the dental chair. A subsequent visit was no more successful. The dentist suggested that domiciliary visits might be less traumatic for Mrs X as she would be in familiar surroundings and would feel safer and less confused.

At the first visit to her home, she accepted the presence of the dentist and the dental nurse. They explained and demonstrated the procedure they would carry out. Mrs X had an impression taken of her upper jaw without any problem. Then her mood changed and she refused to have anything else done. The dentist did not try to force the pace. He helped Mr X to calm his wife and praised her for doing well. When he returned the following week, he was able to regain Mrs X's trust and the rest of the course of treatment went smoothly. Mrs X accepted and wore, her new dentures without any problem. Smiling for the first time when her dentures were fitted, she said 'Don't I look nice?'. Mr X agreed and felt relieved that his wife's slow decline seemed in some degree to have been halted.

The successful outcome of Mrs X's dental treatment at home brought a real improvement in her quality of life that could not have been achieved in the dental surgery. The results justify the extra time that is required for the dental team to prepare the domiciliary equipment, travel to and from a person's home, establish rapport and gain the trust of the individual with dementia.

reassured when the dentist was fully aware of the nature of dementia. Hilton and Simons[69] found that carers of people with dementia were reluctant about taking them to visit a dentist for various reasons and indicated that the patient's past fear towards oral care was an important factor in their decision not to utilise dental services.

Consideration must be given to carers' attitudes towards the provision of oral hygiene. The reasons why carers dislike this role and find it difficult, are well documented[86]. However, access to information and training regarding daily oral hygiene can help to reduce these barriers[87]. Additionally, carers of people with dementia may not have the knowledge of how to access information or dental services. Awareness training and information dissemination are recommended in order to help to reduce these barriers to access.

11 Autonomy and respect

Each person with dementia is an individual with their own experiences of life, their own needs and feelings, and their own likes and dislikes. Although there are symptoms of dementia, which will be common to everyone, each person will be affected in different ways. A person with dementia often remembers the distant past more clearly than the recent past and the present. They are often happy to talk about their memories. Finding out something about their past and talking about it can be a useful way of gaining attention and building rapport.

It is important to treat the person as an adult, and with courtesy and respect, however advanced their dementia. The Alzheimer's Society[88] suggested that this can be done by:

- Being kind and reassuring without talking down or patronising
- Never talking across people with dementia or over their heads as if they are not there, for example when taking the medical history
- Including them in the conversation and not talking about them with a third party as if they were not present
- Avoiding scolding or criticising the person as this will make them feel small, for example when oral or denture hygiene is poor
- Looking for the meaning behind the words the individual uses even if they do not initially seem to make much sense. A relative or carer may help in their understanding
- Validating feelings rather than dismissing them
- Respecting privacy, for example seeing the individual in a private room on a domiciliary visit in a care home setting

12 Addressing the barriers

To address all the issues related to barriers to access to care for people with dementia requires a consolidated and organised plan. The elements of which must consider:

- Implementation of a single holistic assessment process
- Utilisation of oral risk assessment tools
- Development of team working and multi-agency working
- Implementation of national standards for oral health care within care homes
- Instigation of appropriate education and training for care workers and healthcare professionals
- Access to information about oral health care and dental service provision
- Access to oral hygiene equipment and maintenance of dignity in care settings
- Robust systems for referral to oral health care services
- Access to appropriate dental care
- Appropriate dental undergraduate training in Gerodontic and Special Care Dentistry
- Access to appropriate postgraduate, specialist training in Gerodontic and Special Care Dentistry
- Access to patient centred, realistic treatment planning and care
- Interventions to assist in the provision of dental care
- Support for the implementation and maintenance of aggressive preventive regimes
- Understanding, and safe address, of consent and restraint issues
- Appropriate dental team skill mix
- Appropriate site and modality of dental service provision
- Appropriate local commissioning of dental services for older people, in general, and for those with dementia, in particular

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14 Useful Websites

Alzheimer's Society	http://www.alzheimers.org.uk (last accessed 9 October 2006)
British Society for Disability and Oral Health	http://www.bsdh.org.uk (last accessed 9 October 2006)
British Society of Gerodontology	http://www.gerodontology.com (last accessed 5 November 2006)
Huntington's Disease Association	http://www.hda.org.uk (last accessed 9 October 2006)
Motor Neurone Disease Association	http://www.mndassociation.org (last accessed 9 October 2006)
Multiple Sclerosis Society	http://www.mssociety.org.uk (last accessed 9 October 2006)
Parkinson's Disease Society	http://www.parkinsons.org.uk (last accessed 9 October 2006)

15 Appendices

Appendix 1. Oral Health Risk Assessment (OHRA)

Oral health assessment by health professionals provides a mechanism for opportunistic identification of clients who have oral and/or dental problems, are not receiving regular dental care and/or are at risk of poor oral health. Subjective indicators include the ability to speak, smile or eat without pain or discomfort. This example of an Oral Health Assessment may be adapted to suit any client group or adapted for self assessment. It is recommended that risk assessments are used in collaboration with local dental services in order to facilitate access to an appropriate dental service.

1. Does the client have natural teeth?	☐ NO	☐ YES	☐ **Don't Know**
2. Does the client wear dentures?	☐ NO	☐ YES Specify ☐ Upper ☐ Lower	☐ **Don't Know**
a) If YES, are dentures labelled?	☐ YES	☐ **NO**	☐ **Don't Know**
b) If YES, how old are dentures?	☐ < 5 yrs	☐ **> 5 yrs**	☐ **Don't Know**
3. Does the client have any problems? Eg pain, discomfort, difficulty eating, decayed teeth, denture problems, ulcers, dry mouth, halitosis etc. **If YES, describe the problem.**	☐ NO	☐ **YES**	☐ **Don't Know**
4. Does the client smoke or have a past history of smoking?	☐ NO	☐ **YES**	☐ **Don't Know**
5. Is the client taking medication? **Check the British National Formulary for any oral side-effects**	☐ NO	☐ **YES**	☐ **Don't Know**
6. Is urgent dental treatment required?	☐ NO	☐ **YES**	☐ **Don't Know**
7. Date of last dental treatment?	☐ < 1 yr	☐ **>1 yr**	☐ **Don't Know**
8. Registered for dental care? If Yes, record name and address of dentist.	☐ YES	☐ **NO**	☐ **Don't Know**

Adapted from Griffiths, 1995

A response in a highlighted area signifies a need for further investigation or action

Appendix 2. Joint Assessment Nursing Education Tool (JANET)

Name: (Mr/ Mrs/ Miss/ Ms) **Address:** _____ _____ _____ _____ **DOB:** _____ **Hosp No:** _____ **Consultant** _____ **DOA:** _____ **Discharged:** _____	**Status:** Day ☐ Respite ☐ Acute ☐ Rehab ☐ Cont care ☐ Com care ☐ **Impairment:** Physical disability ☐ Cognitive ☐ Learning disability ☐ Mental health ☐ Communication ☐ Other ☐ **Mobility:** Ambulant ☐ Needs assistance ☐ Wheelchair user ☐ Confined to bed ☐

Care Plan

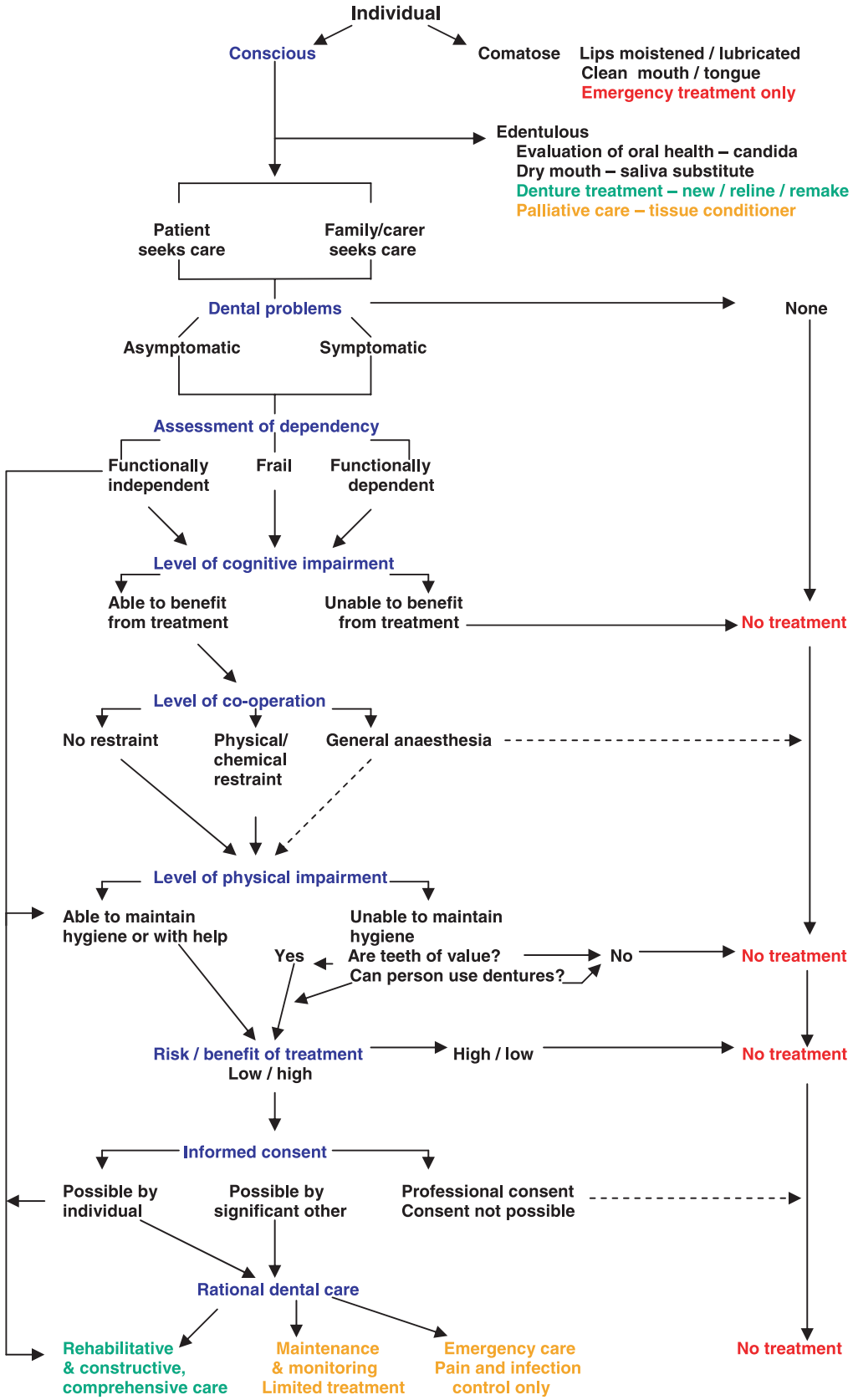
Natural Teeth: Yes ☐ No ☐ Uncertain ☐ Number if known: Appearance: Comments:	
Dentures: Yes ☐ No ☐ Uncertain ☐ Full upper ☐ Partial upper ☐ Full lower ☐ Partial lower ☐ Worn regularly Yes ☐ No ☐ Worn at night Yes ☐ No ☐ Labelled Yes ☐ No ☐ Denture hygiene Good ☐ Poor ☐ Appearance Broken ☐ Cracked ☐ Rough ☐ Stained ☐ Comments:	
Complaints: Yes ☐ No ☐ Uncertain ☐ Teeth ☐ Gums ☐ Denture ☐ Other ☐ Pain ☐ Bleeding gums ☐ Swelling ☐ Difficulty eating ☐ Halitosis ☐ Loose dentures ☐ Comments:	
Diet: Normal ☐ Soft ☐ NG or PEG ☐ Special diet ☐ Food supplement ☐ Comments:	
Habits / Lifestyle: e.g. diet, sweets, smoking, alcohol, drugs, Pica, etc. Comments:	

Stressors for oral health: Yes ☐ No ☐ Level of hydration ☐ Facial weakness ☐ Mouth breathing ☐ Facial paralysis ☐ Medical problems ☐ Cleft lip/palate ☐ Dysphagia ☐ Epilepsy ☐ Tracheotomy ☐ Risk of aspiration ☐ Challenging behaviour ☐ Comments:	
Regular medication: Yes ☐ No ☐ *Print drugs and record whether liquid, tablet injection or other* _____ _____ _____	
Dependence for oral / denture hygiene: Needs no help ☐ Needs some supervision ☐ Unable to carry out oral hygiene ☐ Needs more than 1 person to help ☐ Comments:	
Manual disability: Yes ☐ No ☐ Change in use of dominant hand Yes ☐ No ☐ Comments:	
Dental attendance: Last dental appointment was in the last year Yes ☐ No ☐ Uncertain ☐ If Yes, record name and address of dentist:	
Assessment completed by: _____ **Status:** _____ **Date:** _____	

Forward completed assessment form to the Dental Service

This section to be completed by the dental team **Signature:** _____ **Date:** _____ **Status:** _____

Appendix 3. Principles of Treatment



Appendix 4. Assisting the Individual with Tooth Brushing

- The technique will vary depending on the individual concerned
- Generally, the easiest method of assisting the individual with tooth brushing is:
  - to seat her/him on a dining style chair;
  - stand behind her/him with the head cradled against the carer's body by an arm to provide neck support and control over head movements;
  - gently pull back the cheek with the other hand to improve vision and access;
  - then brush the teeth using a damp small-headed, medium-textured toothbrush or cloth/flannel wrapped around a finger;
  - with a damp cloth/flannel wrapped around a finger, gently remove any food trapped in the cheek pouches or under the tongue
- If the individual can rinse their mouth, use a fluoride toothpaste
- If the individual can not rinse out, dampen the toothbrush in fluoride mouth rinse (use an alcohol free rinse to avoid discomfort) or in chlorhexidene mouthrinse. Alternatively, just use a damp brush
- If there is difficulty with co-operation in opening the mouth or biting onto the brush, finger-guards can be tried to prop open one side of the mouth while brushing the other
- In cases where the person with dementia finds it difficult to co-operate it may be necessary to have a third person to hold their hands
- Many people prefer to wear disposable 'examination' gloves whilst carrying out this task. They can be purchased from the chemists

Appendix 5. Denture Marking

Permanent marking

Ideally denture marking should be done during the construction of all new dentures. This can be done by embedding a very thin piece of paper or metal, bearing the denture owner's name, in the body of the denture. The name is placed in a part of the denture that is not visible during wear, see Fig. 1.

Figure 1 Permanent marking of a denture

Temporary marking

Dentures that have not been marked during manufacture can be temporarily marked with the owner's name. This will last in the order of 6–12 months before the marking needs to be renewed. Below is a simple method for doing this.

- Denture marking can be done using a proprietary denture marking kit or by using a piece of kitchen scourer, a pencil (or alcohol based pen) and clear nail varnish.
- It takes about 10 minutes and can be carried out by any member of the dental team, or by a carer, who has been trained how to do it.
- First, clean and dry the denture.
- Then, select an area towards the back of the denture on the side that faces the cheek (see Fig. 1) and use the scourer to remove the surface polish from a portion just large enough to take the person's name.
- Neatly print the person's initial and surname, paint with a thin coat of the varnish, and allow to dry before applying a second thin coat of varnish.
- Once this has dried, the denture can be returned to its owner.
- The denture should be checked periodically to ensure the name is still legible and renewed as necessary.

Appendix 6. A Checklist for use in Commissioning Oral Health Care for Older People

1 Needs and demands assessment of older people (especially vulnerable older people)
- (a) Demography: number of older people including those in care homes plus number and size of care homes
- (b) Epidemiological surveys of oral health
- (c) Screening programmes
- (d) Expressed need via uptake of current dental services
- (e) Views of local older people and carers through population surveys

2 Analysis and monitoring of dental service provision for older people
- (a) Volume of service uptake across services
- (b) Gap in service uptake
- (c) Views of older people and their carers
- (d) Waiting lists for specific services, e.g. domiciliary care
- (e) Information sharing across health and social services re-dental care

3 Care homes
- (a) Oral assessment for people entering care homes
- (b) Training and support for care home staff in oral hygiene maintenance
- (c) Regular oral screening of older people by a dentist
- (d) Access to care for people in care homes through a designated dentist commissioned to provide care and/or information on local services

4 Single assessment process
- (a) Oral health component of locally used tool
- (b) Training for health care staff on use of the local tool
- (c) Information on local services available to health and social care staff providing local services including advice on referrals and information on domiciliary care

5 Dental services and workforce
- (a) Care pathways for older people with complex, additional needs
- (b) Ensure the work force has an appropriate skills mix
- (c) Access to domiciliary equipment and/or referral
- (d) Support from DwSIs and Specialists for patients
- (e) Ongoing professional development support for GDPs and DwSIs from Specialists.
- (f) Transport arrangements
- (g) Information on costs

6 Guidelines available for use in commissioning of services
- (a) NICE dental recall intervals[64]
- (b) NICE Dementia Guideline – publication due 2007
- (c) BSDH Guidelines for oral health care for people in residential care, with physical disability, with learning disability, with mental illness, terminally ill, dementia[42– 47].

Source: National Working Groups for Older People, 2005