

Dementia Friendly Dentistry

Advice and guidance for the primary dental care team

Dementia Toolkit

First Edition | December 2017

Dementia Friendly Dentistry

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Foreword from the Local Dental Networks

Dear Colleagues

The changing dynamics of our UK population reveals that individuals are living longer. If current trends continue, the number of people with dementia in the UK is forecast to increase by 40% to over 1million by 2025.

Primary Care Dental teams will need to be prepared and competent to react to the needs of these patients, who are likely to also have complex dental and medical histories. There are many types of dementia, each of which can result in a decline in multiple areas of function; including memory and communication skills. These patients are likely to present with unique sets of factors that may compromise their oral health.

The Dementia Friendly Toolkit has been successfully implemented in Cheshire and Merseyside Primary Care Dental Practices. This toolkit has now been tailored for Greater Manchester Dental teams, to assist in providing appropriate support to patients and carers living with dementia. The main aim of the toolkit is to provide guidance to Dental practices on accurate prevention advice and help with appropriate treatment choices. The impact of good oral health will benefit in terms of self-esteem, dignity, social integration and nutrition. Aiding in the ability to eat, laugh and smile.

As the Chair of Greater Manchester Local Dental Network, I would like to thank the individuals and teams from Cheshire and Merseyside who have shared this document with us. The toolkit we hope will benefit our patients in the short and long term.

Mohsan Ahmad

Chair, Greater Manchester Local Dental Network

Foreword from the Local Dental Networks

Dear Colleagues

The number of people diagnosed with dementia is set to rise significantly over the next ten years and the impact of this condition on the lives of those affected and their carers is hugely significant. Many of us already have first-hand experience of family members or friends who have been affected, and have witnessed how the condition creates uncertainty and worry for those affected and their carers.

Dementia was identified as an early priority for the Greater Manchester devolution programme, with two key aims:

- to improve the lived experience of people with dementia and their carers
- to reduce pressure on the health and social care system

An important part of this is to ensure that primary care and community services are able to respond to the needs of people with dementia, and help them maintain their independence and have a full and active life for as long as possible. It is also important for primary care services to plan the clinical care they provide to best meet the needs of this group of patients as the condition progresses.

In seeking to make Greater Manchester the best place in the world to live for people with dementia, we welcome the opportunity to learn and share in examples of best practice. This 'dementia friendly toolkit' was originally developed in Cheshire & Merseyside, drawing on expertise from colleagues across the North West, as well as referencing much of the helpful material published by a number of national charities and dental organisations.

As a practical guide, I am sure that it will encourage and support primary dental care teams across Greater Manchester to consider how they can make their practices, clinics and services more orientated to the needs of people living with dementia, particularly during the earlier stages after diagnosis, and contribute to improving their quality of life.

Yours sincerely

Sarah Price

Executive Lead – Population Health and Commissioning
Greater Manchester Health and Social Care Partnership

SECTION 1

Introduction

Improving the lives of those living with dementia, their carers and their families is a national priority. The Prime Minister's Challenge launched in 2012 led to a programme of work which set about improving health and care for those affected by dementia, created the idea of dementia friendly communities and gave a boost to research.

Following on from the Prime Minister's Challenge, the NHS, Public Health England and Local Government all regard further research, increasing awareness and care for those living with dementia as a priority. Diagnosis rates and post diagnosis support to patients and carers have improved but there are still many people living with dementia who have not been diagnosed. Initiatives such as 'dementia friends' and 'dementia friendly communities', which are both supported in the UK by the Alzheimer's Society have led to increased awareness and understanding of dementia but there is more work to be done if those living with dementia, and their carers, are to feel understood and supported with the organisations and services they come into contact with on a daily basis.

In the UK there are currently 850,000 people living with dementia and it is currently predicted that this number will rise to just over one million by 2025.

Why develop a 'dementia friendly dentistry' toolkit?

The Alzheimer's Society report that for people living with dementia, the following tasks are important for them to be able to achieve either independently or with the support of a carer.

- being able to travel
- going to shops
- running errands
- visiting places of worship
- managing day-to-day tasks

Alongside visiting the doctor, local pharmacy and opticians, visiting the dentist is one of the key community based services which people living with dementia need to attend – either independently or with the support of a carer.

A survey of dental service provision for those living with dementia in part of the North West highlighted that patients were generally satisfied with the quality of dental treatment provided, although the amount of preventive care and advice offered was limited. (Public Health England 2014). Carers highlighted that sometimes the organisation of the practice made the experience of visiting the dentist difficult: for example noisy waiting rooms, appointments at difficult times of day and a lack of communication between the dental team members about the patient's needs, were commonly experienced. Pathways into more specialised dental care were not clear – and often involved significant travelling distances for patients and carers.

Dementia Friendly Dentistry

The following stories from carers attending a memory café illustrate some of the challenges which are encountered when accessing dental services.

"Dentists were something we found really tricky when my dad was alive. His own dentist did not understand his difficulties and it was impossible to get dad to sit and relax and trust the dentist even though he had been to him many times before. The other issue was the need to keep replacing false teeth which kept disappearing. The dentist was not convinced that he was losing them and not keen to replace. I remember contacting you guys for help and in the end dad was without teeth for last 6-8 months of his life as getting replacements was impossible. Sorry it's not a great story."

"All dentists should have some training around dementia - the best approach would be calm and may be in a room that is quiet with no background music and not tilting chairs too far back. Also a good idea would be if the dentist or dental nurse visited the person's home to chat with them for a short period so residents become familiar with their face weeks before an appointment so people don't feel afraid and see a familiar face they trust."



"Dad (85) had dentist appointment at 2pm, arrived 5 mins early and then waited for 20 mins to see the dentist, not easy to repeatedly explain. Told dental nurse who collected him that he has "dementia" and anything he was told would need to be explained to me.

I try to still give dad some privacy. He needed a numbing injection so was sent back to the waiting room while this took effect. Again difficult to explain. We waited another 20 minutes. Then he was seen, given a prescription for special toothpaste and told to make another appointment. Obviously he had forgotten all this between the room and reception. No explanation given to me and no invite to see the dentist. I had to ask if I could see the dentist. She then told me what she had said to him, and I took appropriate action, including making another appointment. I presumed the receptionist now knew he had dementia, as I had told the nurse and the dentist directly.

I had also indicated his state of mind to the receptionist, which is difficult when he thinks he is fine. Second appointment now due, I take him back, only to be told by the receptionist that the appointment was cancelled and they had phoned dad and told him. Great, of course he had forgotten as soon as he put the phone down. Fortunately I had not had to take time off to go to this appointment, but this was only by chance. Poor communication between the dental nurse, the dentist and reception, and possibly me, but it's difficult when he is with me to tell a stranger he has dementia."

Aims of the toolkit

The aims of this toolkit are:

Firstly to improve the general experience of attending the dental practice for those living with dementia and their carers. By improving understanding of dementia and making simple adjustments within the dental practice, anxiety around attending for dental care can be greatly reduced and consequently dental visits can remain part of everyday life for as long as possible.

Secondly to provide guidance to primary care clinicians around planning dental care for people living with dementia. There is particular emphasis on assessment and treatment planning for those in the earlier stages of the condition and for those who have been recently diagnosed. Careful planning of dental treatment and prevention whilst the patient is in the earlier stages of dementia, and still able to tolerate dental treatment, will reduce the risk of acute and more complex dental problems developing during the later stages when provision of dental treatment becomes more challenging and may require onward referral to specialised services.

The toolkit also includes advice for the primary care dentist providing dental care to those in the middle or later stages of dementia. In these circumstances the primary care clinician may be involved in a shared care arrangement with a specialist service, or required to respond to an urgent dental care need.

Guidance for dental teams

There is a considerable amount of guidance available which can help dentists and dental care professionals manage the dental care of patients living with dementia. These include:

- The BDA evidence summary 'dental problems and their management in patients with dementia' (2013)
- The British Society of Gerodontology: Dementia and Oral health
- Local Standards for oral health care of people with dementia: British Society of Gerodontology
- Public Health England: Delivering Better Oral Health toolkit for prevention
- The Alzheimer's Society
- Dementia UK

This toolkit highlights key information and recommendations from these and other reference documents and includes links to source documents and websites for those who want to research further detail.

Further reading & references

The Prime Minister's Challenge on dementia:

www.gov.uk/government/uploads/system/uploads/attachment_data/file/41434_4/pm-dementia2020.pdf

The national dementia declaration for England:

www.dementiaaction.org.uk/assets/0001/1915/National_Dementia_Declaration_for_England.pdf

Review of dental service provision in north Merseyside for patients with dementia:

Gough L I, Hunter L and Stenhouse L, Public Health England (Cheshire and Merseyside) 2014

SECTION 2

Understanding dementia

Signs and symptoms

The Alzheimer's Society describes dementia as a set of symptoms which include memory loss and difficulties with thinking, problem-solving or language. Any and all of these symptoms may impact on a patient's ability to cope with visiting the dental practice and receiving dental care.

A person with dementia may also experience changes in their mood or behaviour. There are many types of dementia and the most common are Alzheimer's disease and vascular dementia.

Dementia is caused by diseases which damage the brain such as Alzheimer's disease (the most common cause), or a series of strokes – it is not an inevitable part of ageing, as many people believe. The symptoms, particularly in the earlier stages of the condition, will depend on the part of the brain affected and by the type of dementia. Over time the symptoms will gradually get worse although the rate of progression varies from person to person. No two people experience dementia in the same way – it affects everyone differently.

The most common symptoms are cognitive problems (affecting thinking and memory) including:

Memory loss: This particularly affects day-to-day memory, for example forgetting what happened earlier in the day, not being able to recall the reason for being in a particular shop, being repetitive or forgetting addresses. Some people remember things from a long time ago much more easily.

Communication problems: Language problems such as difficulty in finding the right words for things, describing the function of an item instead of naming it. People might also struggle to follow a conversation.

Difficulties with thinking things through and planning: Problems with carrying out everyday tasks such as handling money or carrying out a sequence of tasks such as preparing a meal.

Confusion about time or place: Not recognising or getting lost in familiar places or losing track of time or date.

Sight and vision problems: Increased difficulty with reading and judging distances (such as on the stairs) or mistaking shiny, patterned objects or reflections.

Restlessness or disorientation: In unfamiliar or noisy environments people with dementia may become confused or ill at ease.

Mood may be affected: People with dementia may become sad, angry, frightened, easily upset or withdrawn and lack self confidence.

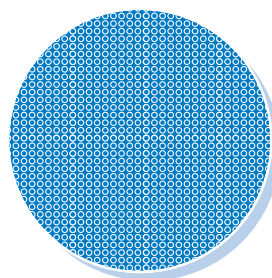
Some people may experience hallucinations or believe things that are untrue (delusions), or exhibit unusual behaviours such as pacing and repetitive questioning.

There are no obvious physical signs that show someone has dementia – although in the later stage there may be muscle weakness and weight loss.

Incidence of dementia

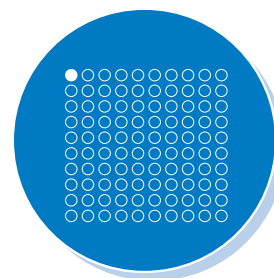
Dementia mainly affects people over the age of 65 but younger people may also develop dementia – there are more than 40,000 people in the UK with dementia under the age of 65.

Incidence by age group:



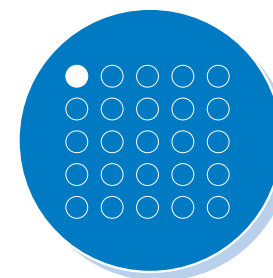
40-64 years

1 in 1,400



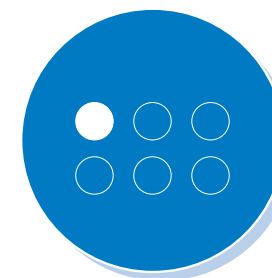
65-69 years

1 in 100



70-79 years

1 in 25



80+ years

1 in 6

(Source Alzheimer's Society)

In Greater Manchester

It is estimated that in 2015, over 28000 people across Greater Manchester over the age of 65 years were living with dementia. This figure is projected to rise by almost 15000 by 2025. The geographical distribution across Greater Manchester in 2015 and the projected change by 2025 is presented in the table below:

Local Authority	Estimated number with dementia in 2015	Projected number in 2025
Bolton	3093	4897
Bury	2180	3411
Manchester	3455	4667
Oldham	2416	3672
Rochdale	2279	3500
Salford	2455	3413
Stockport	4001	6034
Tameside	2507	4004
Trafford	2867	4144
Wigan	3554	5955
Total	28807	43697

(Source: Institute of Public Care, Projecting Older People Population Information System)

Types of dementia

The most common types of dementia are:

- Alzheimer's disease
- Vascular dementia
- Mixed dementia

Less common forms of dementia include:

- Dementia with Lewy Bodies
- Frontotemporal disease

The Alzheimer's Society provides the following brief description of these different types:

Alzheimer's disease

This is the most common cause of dementia (around 62% of cases). Brain cells are surrounded by an abnormal protein and their internal structure is also damaged. In time, chemical connections between brain cells are lost and some cells die. Problems with day-to-day memory are often noticed first, but other symptoms may include difficulties with: finding the right words, solving problems, making decisions, or perceiving things in three dimensions.

Vascular dementia

This accounts for around 17% of cases. If the oxygen supply to the brain is reduced because of narrowing or blockage of blood vessels, some brain cells become damaged or die. This causes vascular dementia. The symptoms can occur either suddenly following one large stroke, or over time through a series of small strokes or damage to small blood vessels deep in the brain. The symptoms of vascular dementia vary and may overlap with those of Alzheimer's disease. Many people have difficulties with problem-solving or planning, thinking quickly and concentrating. They may also have short periods when they get very confused.



Mixed dementia

This is when someone has more than one type of dementia, and a mixture of symptoms. Around 10% of cases are classified as mixed dementia and the most common variation is when Alzheimer's disease and vascular dementia may occur together.

Dementia with Lewy bodies

This type of dementia is relatively rare and accounts for around 4% of cases. It involves tiny abnormal structures (Lewy bodies) developing inside brain cells. They disrupt the brain's chemistry and lead to the death of brain cells. Early symptoms can include fluctuating alertness, difficulties with judging distances and hallucinations. Day-to-day memory is usually affected less than in early Alzheimer's disease. Dementia with Lewy bodies is closely related to Parkinson's disease and often has some of the same symptoms, including difficulty with movement.

Frontotemporal dementia (including Pick's disease)

This accounts for around 2% of cases. In frontotemporal dementia, the front and side parts of the brain are damaged over time when clumps of abnormal proteins form inside nerve cells, causing them to die. At first, changes in personality and behaviour may be the most obvious signs. Depending on where the damage is, the person may have difficulties with fluent speech or may forget the meaning of words or objects.

Risk factors

There is currently a significant amount of research being undertaken around dementia.

The main focuses are improving understanding of the causes of the dementia and prevention, improving understanding of the progression of dementia which may in turn inform potential targets for treatment, and tools for earlier diagnosis. Further information about recent and current research can be found at:

www.alzheimers.org.uk

Whilst research is ongoing, numerous risk factors which are associated with developing dementia have been recognised:

Age

As age increase so does the likelihood of developing dementia. As illustrated previously, the incidence of dementia rises from 1 in 100 at 65-69 years of age to 1 in 6 at 80+ years.

Gender

Current evidence suggests that women are more likely to develop Alzheimer's disease and men are more likely to develop vascular dementia.

Genetics

Current evidence suggest that apart from a link to some of the rarer forms of early onset dementia, family history and genetics plays a minor role in determining the risk of developing dementia.

For many other risk factors, the general rule of **'What's good for the heart is good for the brain'** applies:

Smoking

There is evidence that smoking increases the risk of developing dementia – particularly Alzheimer's disease.

Alcohol

Research is ongoing to determine the link between alcohol consumption and dementia. Very heavy drinking is known to cause a specific alcohol-related dementia.

Healthy eating

Processed and other foods which are high in fat can lead to weight gain which in turn can lead to heart and other health problems as well as increasing the risk of developing dementia. Excess sugars can also lead to weight gain and development of Type 2 diabetes. General 'healthy diet' advice around reducing intake of salt, saturated fat and sugars should be followed.

Physical activity

In addition to other benefits, physical activity has been shown to play a role in maintaining healthy weight and in turn reduce the risk of developing Type 2 diabetes and high blood pressure – both of which increase the risk of developing dementia.

Mental activity

Research into the link between mental activity and dementia is ongoing but to date there is some evidence to suggest that both mentally stimulating leisure activities and continued education reduces the risk of developing dementia.

Other health conditions:

There is evidence that all the following health conditions increase the risk of dementia:

- Parkinson's disease
- Stroke
- Type 2 diabetes
- High blood pressure
- Depression
- Down's syndrome
- Mild Cognitive Impairment (MCI): early memory and thinking problems considered worse than those associated with normal ageing.

Diagnosis & treatment

An initial assessment is commonly undertaken by a GP and this is followed by referral to a memory clinic or other specialised service where a detailed assessment is carried out. There are a number of aspects to the full assessment including: history, tests of mental abilities, blood tests and physical examinations (to exclude other causes of symptoms). A brain scan is sometimes undertaken.

Diagnosis leads to treatment, advice and access to support services which enable the person to live well with dementia. These include talking therapies, access to activities to keep the mind active and rehabilitation services which provide practical help in supporting independent living.

There are a number of drugs which may be prescribed to address some of the symptoms of dementia: These include: donepezil (often known by the brand name Aricept), rivastigmine (eg Exelon) or galantamine (eg Reminyl), medication for depression and anxiety, and in the case of vascular dementia, treatment and advice to address underlying health conditions such as hypertension and Type 2 diabetes.

Progression

Understanding the development and progressive stages of dementia may influence treatment decisions, aid assessment of capacity and may be an indicator of compliance.

Dementia is often described in three stages: early, middle and late stage. In the early (or mild) stage changes in ability and behaviour may be relatively minor. In the middle (or moderate) stage changes become more marked and more support will be needed in day to day life. In the later (or severe) stage, people will need more help and they will become increasingly dependent on others for their care.

It is fairly common to find that:

- There is no fixed order of symptoms developing - some symptoms may appear earlier or later
- The stages may overlap - the person may need help with one type of task but may be able to manage another task or activity on their own
- Some symptoms, such as irritability, may appear at one stage and then diminish, while others, such as memory loss, will worsen gradually over time

A wide range of factors influence how quickly someone's dementia will progress. Age, genetics and general physical health can all influence the rate of progression:

The current evidence suggests that progression is slowest:

- Amongst those with Alzheimer's disease
- Amongst those who remain physically active

Progression of dementia is more rapid:

- Amongst those who develop symptoms before the age of 65
- Amongst those with poorly controlled heart conditions and diabetes
- Amongst those who have had several strokes

Assessing stages of dementia

Although it is not within the remit of the dental practitioner to make a diagnosis of dementia, it is important that dentists and dental care professionals (DCPs) are aware of some of the key signs and symptoms that may indicate that a person has dementia and the stage of its development. Being able to do this may influence treatment decisions, aid assessment of capacity and may be an indicator of how well they may cope with invasive dental treatment.

The table below summarises the stages of dementia, key general signs and symptoms and signs relevant to their oral health and dental care.

Stage of Dementia	Cognitive Decline	General Signs and Symptoms	Signs Relevant to Oral Health and Dental Care
Pre-Diagnosis	No cognitive decline	Normal function, no memory loss	Not noticeable at this stage
Early/Mild	Mild cognitive decline	Forgetting recent events Struggling to find the right words Lose track of day/date Problems with judging distance Lose interest with others, reduced social interaction	May show early signs <ul style="list-style-type: none"> • missing appointments • forgetting where they are up to in a course of treatment

Stage of Dementia	Cognitive Decline	General Signs and Symptoms	Signs Relevant to Oral Health and Dental Care
Moderate/ Middle	Moderate cognitive decline	<p>Need frequent reminders and/or help to carry out basic tasks (e.g. mealtimes, dressing, personal hygiene, toothbrushing)</p> <p>Forgetful of names</p> <p>Repeat questions/ conversation</p> <p>Become confused with surroundings, may get lost</p> <p>May not recognise familiar people</p> <p>Difficulties with spatial perception</p>	<p>May struggle to remember</p> <ul style="list-style-type: none"> treatment plan progress and sequence details of the treatment plan <p>May attend with support, may still not be formally diagnosed</p> <p>You may notice a deterioration in oral health, in a previously well maintained/ motivated patient</p> <p>Patient may lack capacity to consent</p> <p>May:</p> <ul style="list-style-type: none"> struggle to weigh up risks and benefits of treatment be less compliant than at previous visits have fragmented conversations be anxious/agitated during appointment

Dementia Friendly Dentistry

Stage of Dementia	Cognitive Decline	General Signs and Symptoms	Signs Relevant to Oral Health and Dental Care
Late/Severe	Severe cognitive decline	<p>Require increasing amounts of assistance to complete tasks, gradually becoming more dependant on others</p> <p>Profound memory loss, unable to recognise family or familiar objects</p> <p>Increasingly weak, spending more time in bed/chair</p> <p>Difficulties eating/ swallowing</p> <p>Incontinence</p> <p>Loss of speech, no meaningful method of communication</p>	<p>May</p> <ul style="list-style-type: none"> • have difficulties with speech • not remember previous visits • have difficulty cooperating for radiographs • no longer communicate • be totally non-compliant for treatment, including examination • be totally dependent on others to provide dental care and to attend appointment <p>Carers may request domiciliary care</p> <p>Likely to lack capacity to consent</p>

Within the context of the dental surgery, making an assessment of a patient with regard to dementia can be challenging. Quite often, questions that would be asked routinely can give an indication as to the stage of the patient's dementia and subsequently what level of care and intervention is most appropriate.

For example:

In general conversation...

- How did you get to the dental surgery today?
- What did you have for breakfast today/dinner last night?
- Who have you brought with you to your appointment today?
- Can you confirm your date of birth?

More dentally focussed questions...

- Are you having any pain or problems with your teeth or mouth?
- How often do you brush your teeth and do you require any help to carry it out?
- Are they able to complete a medical history form?
- Can the patient recall the treatment plan?

These questions are relevant to the dental appointment, but also may give insight into the patient's stage of dementia by enquiring about the recent past and assessing psychomotor skills. These questions can be of even greater value if cross referenced for accuracy with the responses to the same questions from the carer/family member who attends with them. A similar approach is used for assessing patients who may have dementia in primary medical care services.

Dementia Friendly Dentistry

By combining information from the patient, those accompanying the patient to the appointment, conversations with care home staff (if applicable), or information from the patients' General Medical Practitioner, it is possible to make an assessment of:

- capacity
- likelihood of cooperation
- likely tolerance of dental procedures
- appropriate preventive regime in the dental surgery and at home

Key points

- Every dementia journey is different
- There are recognised stages of dementia which describe the effects on the patient
- A knowledge of these stages is important to help formulate a patient-specific oral care plan

Further reading & references

Dementia UK

www.dementiauk.org

The Alzheimer's Society

www.alzheimers.org.uk

SECTION 3

Improving the overall patient experience in the dental practice environment

This section covers two main themes which can improve the experience of patients with dementia attending primary dental care practices and clinics: **the physical practice environment and communication.**

Maintaining independence for as long as possible is important for people living with dementia, their families and loved ones. Just making a few small changes can make a big difference to the patient and carer's experience, and will help them to continue accessing dental care as part of the normal routine for as long as possible.

Developing a 'dementia friendly' physical dental practice environment

The King's Fund¹ has developed a suite of assessment tools to help health and care organisations review their environment and make changes to design which will make them more dementia friendly. Their assessment tool for health centres covers many aspects which are relevant to the dental practice environment. The link to the assessment tool can be found at the end of this section.

Some of the suggested changes could be difficult to implement e.g. to minimise noise at reception. However, every small change can help to improve the experience for people with dementia and practices may consider 'working towards' implementing some of the adjustments suggested below. Any changes to a dental practice should still conform to the relevant legal and technical standards for healthcare facilities including, but not limited to, requirements to meet the CQC Fundamental Standards of care².

Key points taken from the King's Fund assessment tool which dental practices may consider are that:

1 The environment promotes meaningful interaction between patients, their families and staff:

Being unable to find the entrance and/or reception desk can cause anxiety. Uncared for and unwelcoming spaces can provoke concerns in patients and their relatives about standards of care. The arrangement of furniture provides clues as to the purpose of the space. Seating that enables carers to sit alongside the people they are accompanying will reduce agitation and older people are likely to need chairs with arms.

2 The environment promotes well-being:

Older people need higher light levels and people with dementia may interpret shadows or dark areas as holes in the floor or different levels and avoid or try to step over them. Appropriate artworks can provide interest while waiting. Scenes of local heritage can prompt memories. Familiarity is important for people with dementia. Care needs to be taken with abstract artwork as it may be difficult for patients to perceive as art and potentially cause confusion.

3 The environment encourages active engagement of people with dementia in their care:

People with dementia can become very anxious in unfamiliar environments but being able to have their carer with them throughout is likely to be reassuring. Noisy environments and patient call display systems which use TV screens can be misinterpreted. Keeping people calm will enable them to better participate at their appointment. Distress can be eased by providing a quiet area.

4 The environment promotes mobility:

Being able to walk independently is important. Safety can be enhanced by providing handrails and small seating areas where people can rest. Clear colour contrasts which support design features which are of functional value (e.g. a handrail in a different colour to the wall) can be helpful. People with dementia may interpret shiny floors as being wet or slippery and changes in flooring colour, for example a dark floor mat, as something to step over. Speckles or pebble effects in flooring could look like pieces of litter.

5 The environment promotes continence and personal hygiene:

Not being able to find the toilet provokes anxiety and using the same signs and door colours to denote all toilets will help people find them more easily. Consider using pictures/symbols on doors to identify what lies beyond. 'Contrast sensitivity', i.e. the ability to discern differences between colours, is commonly affected in people with dementia. Ensuring good colour contrast on sanitary fittings will make toilets and basins easier to see and use. Traditional and familiar designs will help ease anxiety and promote self-care. Being plunged into darkness if sensor lights go out can be very frightening.

6 The environment promotes orientation:

People with dementia are likely to become agitated in unfamiliar surroundings and providing visual clues and prompts, including accent colours to help them find their way around is particularly important. Signs need to be placed at a height where they can easily be seen and should be placed on doors, not beside them. Strong patterns on walls, curtains or furnishings can be misinterpreted. Providing clocks and signs indicating the name and address of the centre will help with orientation. Consideration should be given as to where mirrors are placed since some people with dementia can misinterpret reflections. This can lead to increased anxiety.

7 The environment promotes calm, safety and security:

Clutter and distractions, including notices, can cause added confusion and should be avoided. Noise can make concentration difficult and can increase anxiety. There is potential for clinical practice to create noise (unwanted sound) which can be heard in non clinical areas which could be distressing to people with dementia (and others). Minimising noise in other areas so that speech can be clearly heard (e.g. at reception) can also be considered. The use of appropriate music (see the 'communications' section for advice about this) can have a positive effect for people with dementia.

For more detailed information, the Department of Health's Health Building Note 08- 02 Dementia-friendly Health and Social Care Environments³ provides detailed guidance for creating environments to help provide a positive experience for people with dementia.

Effective communication:

The Health Education England has developed a film which is available entitled 'Barbara's Story; The Appointment'. This gives helpful insight into the experience of a dental appointment through the eyes of a patient living with dementia.

To watch the film go to the www.youtube.com/watch?v=EnPUq00UA8c



The following lists of useful tips and advice have been drawn from a number of sources including: carers working in specialist centres for people with dementia, the Alzheimer's Society, oral health promotion officers and dental clinicians with a wide experience of providing care for people with dementia.

On making the dental appointment

- Carefully consider how appointments are booked and how any alterations to appointments will be communicated. Check if there are any carers or relatives who may need to be informed.
- Reminders by phone call or via text message sent directly to the patient may not be appropriate for patients with dementia and alternative methods will need to be considered.
- When offering appointments, ensure that the appointment is booked for an optimal time of the day for the patient and carer to attend the practice.
- Ensure appointments are planned with an appropriate amount of time; these may need to be longer than routine appointments.
- Ask the patient and their carer if they have any specific needs in the dental environment and make a note of these. For example they may like a particular type of music playing – or no music at all.
- Such preferences may change over time and so need to be checked regularly.
- Enquire whether the patient has a copy of 'This is Me' (further details later in this section) or a hospital passport and ask them to bring this to the appointment as this may include additional helpful information.
- If the patient attends with a carer who also attends the practice and they require an appointment then it might be helpful to offer adjacent appointments.

Advice for communicating with patients attending the practice:

- Consider reception staff becoming 'Dementia Friends'⁴ by attending a Dementia Friends Information session or completing the online training available at www.dementiafriends.org.uk. This training may be available free of charge.
- Training sessions around communication and listening skills with the dental team can be helpful – particularly if you focus on the experience of the dental visit from the perspective of someone with dementia or their carer.
- Accompany the patient from the waiting room to the dental clinic and back to reception, particularly if there are long corridors with lots of identical doors.
- Greet the patient as you would any other patient – this allows you to assess hearing, understanding and communication. Be welcoming calm and friendly. If possible shake their hand.
- On meeting the patient try to find out what the patient did for a living or their interests. This often makes the patient more comfortable and allows the patient to feel you are interested in them personally. This can be helpful for patients with advanced dementia as they may be calmed by familiar words.
- Work out what was popular when the patient was in their early 20s - use this era as a talking point and an opportunity for humour and reminiscence if appropriate (eg, dance halls, big band music, 1940s, 1950s, 1960s.)
- Keep language simple and to the point – try and speak in short sentences.
- Giving a simple command rather than asking a question which requires a lengthy thought process may help. For example: 'take a seat' rather than 'would you like to take a seat?'
- If the patient has difficulty hearing, turn off background noise, and ask the patient or their carer which is their good ear. You can then focus your speech to that ear.



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- Do not show any frustration.
- Embrace their reality! Correcting the patient may lead to confusion and upset.
- Give a written treatment plan which has enough detail and description to be understood by the patient and their carer. Repeat and explain treatment plan at every appointment.
- Patients with advanced dementia may speak in a garbled, but pleasant way (i.e speak in a way you don't understand). Try to respond as if you understand, nodding and smiling with additional words such as 'absolutely' or 'I agree'. Try to pick up on odd words and body language for clues. This will all help to settle the patient.
- Some patients with dementia may appear aggressive - knowledge of their former work or interests are helpful to potentially calm the patient - use the key words and assess response.
- Remember dementia has many facets. Just because they have dementia it does not mean they cannot make their own choices.
- Above all treat them kindly and with respect. They may not remember who you are but they will remember how you made them feel.

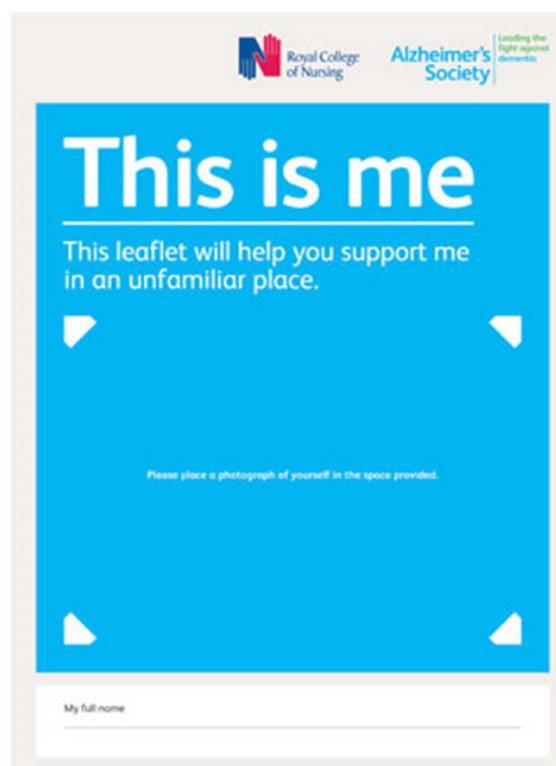
If the patient attends with a Carer (family or professional):

- Include patient and carer with treatment planning and advice - fully explaining treatment required.
- Avoid dental jargon.
- Check for understanding by asking questions.
- Give a written treatment plan. Repeat the treatment plan at every appointment.
- Ensure that any written information is clear and easy to understand.
- Explain to carers to watch for any behaviour change such as alteration in eating and sleeping pattern, as this could be a sign of dental pain.
- If the carer attends with the patient but stays in the waiting room, rather than the surgery, make sure that they are aware when the patient is about to leave.

Helpful resources

'This is me' is a resource produced by the Alzheimer's society for people with dementia who are receiving professional care in any setting – at home, in hospital or any other clinical setting, respite care or a care home.

www.alzheimers.org.uk/info/20113/publications_about_living_with_dementia/415/this_is_me



Not all people with dementia will have this document but it is worth asking your patient or their carer if they do, as it will include some helpful information. 'This is me' includes information about:

- Name, D.O.B, address, carer/support worker
- Present and past life history
- How the patient communicates, indicates pain, moves around, eats and drinks etc
- The patient's: needs, preferences, likes, dislikes and interests

A hospital passport may also be used and in addition to the above, will include details of medications and medical history



References:

- The King's Fund. Developing supportive design for people with dementia. 2014
Available from www.worcester.ac.uk/discover/health-centre-assessment-tool.html
- Care Quality Commission. The Fundamental Standards. 2016.
Available from www.cqc.org.uk/content/fundamental-standards
- Department of Health. Health Building Note 08-02: Dementia friendly health and social care environments guidance. 2015.
Available from www.gov.uk/government/publications/dementia-friendly-health-and-social-care-environments-hbn-08-02
- Dementia Friends website [Internet]. 2016
Available from: www.dementiafriends.org.uk
- The Alzheimer's Society. Communicating. 2012.
Available from www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=130

SECTION 4

Clinical Care Guidance

Evidence and research plays an important role in the support and justification for treatment recommendations and best practice. This section highlights the current guidance and evidence available to the dental team to support the provision of care for patients with dementia.

This is divided into three sub-sections:

- General clinical guidance which is applicable to care of patients with dementia.
- Recommendations and guidance specific to oral care for patients with dementia
- A set of case studies which illustrate how guidance may be applied to patient scenarios

Links to the source documents are given at the end of the Section, should further detail be required.

General clinical guidance applicable to care of patients with dementia

All members of the team should adhere to up-to-date professional guidance on conduct as described in documents such as Standards for the Dental Team (General Dental Council)¹. This includes areas such as confidentiality, record-keeping and data protection.

Public Health England: Delivering Better Oral Health (3rd Edition)¹

Delivering Better Oral Health (DBOH) serves as a guide to preventive advice and recommended actions to prevent oral disease. Particular groups of patients are identified in the DBOH toolkit as being at 'higher risk' of developing dental disease and more intense prevention measures are recommended. Patients who have been diagnosed with dementia should be included in this category because:

- Changes to their diet preferences and eating habits may increase their caries risk
- Carbohydrate rich diets and nutritional supplement drinks required to maintain a level of nutrition may also increase risk of developing dental caries
- The sleep/wakefulness cycle may be disrupted, with increased alertness nocturnally so carers may need to provide food at night, when patients are more prepared to eat. (There may even be periods of high activity lasting several days, followed by rest for a long period of time).
- They may find it more difficult to maintain their oral hygiene and are more reliant on others to help
- Xerostomia (dry mouth) is a common side effect of medication and increases risk of developing dental caries.
- Provision of dental treatment may become more challenging as dementia progresses. Adopting a more intensive approach to prevention early on, will help to reduce the chances of the patient needing active treatment in the later stages

Prevention of dental caries in adults (summary from DBOH)

	Advice	Evidence base *	Professional intervention	Evidence base
All adult patients	<p>Brush at least twice daily, with a fluoridated toothpaste</p> <p>Brush last thing at night and at least on one other occasion</p> <p>Use fluoridated toothpaste with at least 1,350ppm fluoride</p> <p>Spit out after brushing and do not rinse, to maintain fluoride concentration</p> <p>The frequency and amount of sugary food and drinks should be reduced</p>	<p>1</p> <p>3,1</p> <p>1</p> <p>3</p> <p>3,1</p>		
Those giving concern to their dentist (eg with obvious current active caries, dry mouth, other predisposing factors, those with special needs)	<p>All the above, plus:</p> <p>Consider: Use a fluoride mouthrinse daily (0.05% NaF-) at a different time to brushing or use of high concentration fluoride toothpaste</p>		<p>Apply fluoride varnish to teeth twice yearly (2.2% NaF-)</p> <p>For those with active coronal or root caries prescribe daily fluoride rinse</p> <p>For those with obvious active coronal or root caries prescribe 2,800 or 5,000ppm fluoride toothpaste**</p> <p>Investigate diet and assist to adopt good dietary practice in line with the eatwell plate</p>	<p>1</p> <p>1</p> <p>1</p> <p>1</p>

***Evidence base:**

- 1: Strong evidence from at least one systematic review of multiple well-designed randomised control trials.*
- 2: Strong evidence from at least one properly designed randomised control trial of appropriate size.*
- 3: Evidence from well-designed trials without randomisation, single group pre-post, cohort, time series of matched case-control studies.*
- 4: Evidence from well-designed non-experimental studies from more than one centre or research group.*
- 5: Opinions of respected authorities, based on clinical evidence, descriptive studies or reports of expert committees*

*** DBOH recommends prescription of high fluoride toothpaste (5000pp F) for: patients aged 16 years and over with high caries risk, present or potential for root caries, dry mouth, orthodontic appliances, overdentures, those with highly cariogenic diets and dry mouth*

Care should also be taken with regard to some oral hygiene measures; some patients with more advanced dementia may not readily spit out liquids or toothpaste, so use of mouthwash or high fluoride toothpaste may need to be re-considered in the later stages. Patients and carers may also need to use adapted oral hygiene aids to help maintain oral health and should be helped to select suitable equipment.

Prevention of periodontal disease (summary from DBOH)

Stage of Dementia	Advice	Evidence base *	Professional intervention	Evidence base
All adult patients	Self-care plaque removal Remove plaque effectively using methods shown by the dental team. This will prevent gingivitis and reduces the risk of periodontal disease	5 3	Advise best methods of plaque removal to prevent gingivitis, achieve lowest risk of periodontitis and tooth loss Use behaviour change methods with oral hygiene instruction Correct factors which impede effective plaque control including; supra and sub-gingival calculus, open margins and restoration overhangs and contours which prevent effective plaque removal With extensive inflammation start with toothbrushing advice, followed by interdental plaque control	3 1 Good practice Good practice
	Toothbrushing and toothpaste Brush gum line AND each tooth twice daily (before bed and at least one other occasion) Use either manual or powered toothbrush Small toothbrush head, medium texture	5 1 5	Assess patient /carer's preferences for plaque control: Decide on manual or powered toothbrush Demonstrate methods and types of brushes Assess plaque removal abilities and confidence with brush Patient sets target for toothbrushing for next visit Small toothbrush head, medium texture	5

Key points:

- Preventative advice and care should be tailored to optimise oral and general health and wellbeing.
- This will include appropriate prescribing and use of high fluoride toothpaste, supplemental fluoride rinses and professionally applied fluoride varnish to prevent decay and to maintain the existing dentition of people with dementia.
- The prevention plan will probably also include advising carers to support or carry out oral hygiene for the patient – particularly in the more advanced stages of dementia.

NICE Guideline CG19 Dental Recall: Recall interval between routine dental examinations³

All patients receiving NHS primary care dental services have intervals set between examinations as part of the initial oral health assessment and care plan. The guidance emphasises that clinical judgement should be exercised to determine levels of current disease, risk of future disease and the consequences of treatment of dental diseases.

Patients with dementia may have poorer oral hygiene, xerostomia, and may demonstrate reduced cooperation for treatment as their dementia progresses. A shorter recall period may be appropriate, and can be agreed through discussion with the patient and their family/carers. The minimum period of recall between courses of treatment is 3 months – however this does not include urgent or emergency care and a shorter interval gives an opportunity to implement appropriate preventive and maintenance strategies.

Key point:

- Shorter recall intervals may be indicated in a patient diagnosed with dementia as they have increasing risk of, and from, oral disease and treatment.

FGDP Selection Criteria for Dental Radiography⁴

The same criteria for selecting and justifying radiographic examinations apply to patients with dementia as well as the rest of the adult population.

In order to identify new and recurrent caries, bitewing radiographs at intervals dependent upon caries risk are important to enable proactive treatment planning to minimise progression of dental disease.

Periapical radiographs of heavily restored or endodontically treated teeth may be indicated if none are already available or the patient is new to the practice, as these may demonstrate areas of chronic apical periodontitis.

A record of pre-existing radiographs is helpful, as tolerance for intra-oral films may decrease with progression of dementia. OPG radiographs may be indicated, for example where there are multiple grossly carious teeth, or if care is planned under IV sedation or GA – particularly where the current episode of care may be one of the few remaining opportunities for elective intervention. Occasionally oblique lateral films must be taken in an effort to diagnose potential sources of pain.

As dementia progresses, it may become more challenging to obtain films of high diagnostic yield. It may become necessary in the later stages of the patient's dementia journey to refer back to previous good quality films taken prior to deterioration in cooperation. These radiographs can be used for treatment planning, assessment of root morphology and bone levels.

Key points:

- Appropriate radiographs will enable teeth of doubtful prognosis to be identified and treated whilst cooperation is good, and potentially reduce the requirement for extractions in the future.
- Up-to-date radiographs including bitewings at intervals indicated by the clinical assessment are an important adjunct to treatment planning in the short, medium and longer term.
- Ensure that all appropriate radiographs are taken when clinically necessary when the patient is in the earlier stages of dementia – these may also be referred to in the later stages when radiographic examination becomes more difficult.

BDA Evidence Summary: Shorter dental arch (SDA) therapy in older age⁵

The BDA evidence summary describes the shortened dental arch (SDA) concept as a “minimal treatment intervention approach based on the notion that satisfactory oral function can be achieved without complete dental arches and that lost teeth do not necessarily require replacement”. The body of evidence supporting the use of the SDA is limited but the evidence that is available indicates that this approach may provide an acceptable level of function without the need for extensive treatment or prosthetics. It allows emphasis of care to be focussed on anterior and premolar teeth and consequently may be an option to consider for those with both an ‘accumulation of dental disease’ and who are at high risk of developing dental disease.

NHS Commissioning Guide for Dental Specialities: special care dentistry (2015)⁶

The guides describe the development of care pathways with clinicians providing care for patients at 3 levels of complexity. These levels describe the competence of the clinician to deliver appropriate care to that level of complexity.

- Level 1: Special care needs that require a skill set and competence as covered by dental undergraduate training and dental foundation training, or its equivalent.

Whilst Special Care Dentistry patients may receive the majority of their care from primary dental care teams providing Level 1 care, it is recognised that the diverse needs and complexities of this patient group (e.g. access, communication, cooperation and medical issues) might necessitate shared care for a short period of time or a specific treatment episode.

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Providers of Level 1 care need to appreciate their own level of competence and make clinical judgments based upon knowledge, evidence and risk assessment. It is envisaged that the general dental practitioner will be an essential part of an evidence based, prevention focussed care pathway for patients with additional needs.

- Level 2: Level 2 care is defined as procedural and/or patient complexity requiring a clinician with enhanced skills and experience who may or may not be on a specialist register.

This care may require additional equipment or environment standards but can usually be provided in a primary care setting.

- Level 3a: Special care needs that require management by a dentist recognised as a specialist in Special Care Dentistry at the GDC defined criteria.
- Level 3b: Special care needs to be managed by a dentist recognised as a specialist in Special Care Dentistry at the GDC defined criteria and holding consultant status.

Care pathways around the needs of patients will be developed based on the three levels of clinician competence and a Managed Clinical Network will work closely with commissioners to oversee the development and delivery of care pathways across primary and secondary care.

Guidance specific to oral care for patients with dementia

Evidence-based dentistry for this patient group means taking a broad approach to the guidelines, opinions and studies available. In terms of research, the most easily accessed populations are those living in residential care and much of the work that has been undertaken focuses on these groups of patients. The subject group therefore tend to be in the more advanced stages of dementia, with increasing challenges for the dental team in areas such as capacity, communication, diagnosis and operative dentistry. Less is understood about the dental health of those in the earlier stages of dementia, and those living independently in the community with varying levels of support. Much of the guidance is based on the findings of smaller studies and the expert opinion of clinicians with years of experience in planning care for this group of patients, rather than larger studies following up patients over time or higher ranking evidence such as randomised controlled trials, meta-analysis and systematic reviews.

The Seattle Care Pathway⁷

Oral care in the older population was reviewed at a conference of over 100 international multidisciplinary clinicians and academics in Seattle during 2013. The resulting document provides an evidence-based approach to oral health in older patients. Frailty was addressed as a challenge to oral health, with the types of interventions tailored to levels of dependency (pre, low, medium, high). This model encompasses physical, social and psychological well-being - patients with dementia would move throughout the categories of dependency as their condition progresses. Impact and actions required (assessment, prevention, treatment and communication) to secure oral health for older people are summarised, and demonstrated through clinical case studies later in this section.

British Society of Gerodontology (BSG)

BSG have a number of resources available including links to oral health information for people with dementia, those unable to comply with care, and a comprehensive guide specifically relating to dementia.⁸

The advice highlights the importance of understanding the dementia journey, the impact this can have on oral health and how the dental team can support patients and carers.

Guidelines include advice on pragmatic treatment planning, and how treatment approaches may change throughout the disease process.

The focus is on the provision of high quality dentistry which can be maintained well, and the guidelines describe how the approach may change with the progression of disease. There is information on assessment, treatment modalities, clinical care, denture-related issues, and links to various resources.

British Society of Disability and Oral Health (BSDH)

BSDH have guidelines of relevance to provision of oral care for those with dementia, particularly those in residential care⁹ or unable to comply with treatment or require assistance with maintaining adequate oral hygiene. Only those with appropriate training and experience should carry out clinical holding techniques, and the background to this is also discussed on the website.

The main emphasis is the holistic approach to patient care. Quality of life is affected by pain, difficulty eating, embarrassment, and salivary disturbance. The importance of oral comfort is addressed, including care of the oral mucosa. There are measures and resources available which can be used to support patients and their carers, ways to overcome the barriers of a diagnosis of dementia and subsequent help with oral care as dementia progresses.

BDA Evidence Summary: Dental problems and their management in patients with dementia¹⁰

The documents above are summarised in the BDA Evidence Summary¹⁰, with a discussion of oral problems and their link to dementia. A literature search revealed only a few studies directly relevant to the question of oral disease and dementia. Key findings highlight a lack of good quality scientific evidence for dental treatment for patients with dementia and the report makes recommendations based upon the experience of specialists in this area.

Rationale for treatment planning is discussed, alongside the importance of achieving good quality of life. It is vital to ensure that maintenance of a well restored dentition is supported by a robust preventive programme.

Alternative treatment modalities may be required as cooperation deteriorates, however the relevant risks or a procedure, for example IV sedation or general anaesthesia, need to be considered together with assessment of capacity and consent issues.

Key points:

- Every patient with dementia is different on different days, and their disease course is different. Equally, dental histories and motivation varies greatly.
- The main theme is to take a holistic approach to patient care.
- Quality of life is affected by pain, difficulty eating, embarrassment and salivary disturbance.
- It is important to provide high quality dentistry that can be well maintained.
- Prevention is a key priority for a patient with an early diagnosis of dementia.
- Establish a recall interval appropriate to the patient's risk of, and from, oral disease.
- Tailor preventative regimes for individuals in line with 'Delivering Better Oral Health' guidance.
- Individual care plans should be established, reviewed and modified in response to changes in medical, social and dental circumstances.

Summary of the stages of dementia and approach to dental care

(Stages of dementia are linked to levels of dependency as described in the Seattle care pathway)

Stage of Dementia	Cognitive Decline	General Signs and Symptoms	Signs & symptoms relevant to oral health & dental care	Dental Management
Pre-Diagnosis	No cognitive decline	Normal function, no memory loss	Not noticeable at this stage	Management as per dental risk (DBOH, NICE recall guidance)
Early/Mild	Mild cognitive decline	<p>Forgetting recent events</p> <p>Struggling to find the right words</p> <p>Lose track of day/date</p> <p>Problems with judging distance</p> <p>Loss of interest with others, reduced social interaction</p>	<p>May show early signs</p> <ul style="list-style-type: none"> • missing appointments • forgetting where they are up to in a course of treatment 	<p>Assess risk of dental disease</p> <p>Management as per dental risk (DBOH, NICE recall guidance)</p> <p>Robust and appropriate treatment planning (see clinical case section)</p> <p>Consideration of shortened dental arch</p>
Moderate/ Middle	Moderate cognitive decline	<p>Need frequent reminders and/or help to carry out basic tasks (e.g. mealtimes, dressing, personal hygiene, toothbrushing)</p> <p>Forgetful of names</p> <p>Repeat questions/conversations</p> <p>Become confused with surroundings, may get lost</p> <p>May not recognise familiar people</p> <p>Difficulties with spatial perception</p>	<p>May struggle to remember</p> <ul style="list-style-type: none"> • treatment plan progress and sequence • details of the treatment plan <p>May attend with support, may still not be formally diagnosed</p> <p>You may notice a deterioration in oral health, in a previously well maintained/ motivated patient</p> <p>Patient may lack capacity to consent</p> <p>May:</p> <ul style="list-style-type: none"> • struggle to weigh up risks and benefits of treatment • be less compliant than at previous visits • have fragmented conversations • be anxious/agitated during appointment 	<p>Re-assess risk</p> <p>Management as per dental risk (DBOH, NICE recall guidance)</p> <p>Consider conservative acceptable treatments (e.g. ART)</p> <p>Support carers with oral hygiene</p> <p>May require more support to accept treatment</p>



Stage of Dementia	Cognitive Decline	General Signs and Symptoms	Signs & symptoms relevant to oral health & dental care	Dental Management
Late/Severe	Severe cognitive decline	<p>Require increasing amounts of assistance to complete tasks, gradually becoming more dependant on others</p> <p>Profound memory loss, unable to recognise family or familiar objects</p> <p>Increasingly weak, spending more time in bed/chair</p> <p>Difficulties eating/swallowing</p> <p>Incontinence</p> <p>Loss of speech, no meaningful method of communication</p>	<p>May</p> <ul style="list-style-type: none">• have difficulties with speech• not remember previous visits• have difficulty cooperating for radiographs• no longer communicate• be totally non-compliant for treatment, including examination• be totally dependent on others to provide dental care and to attend appointment <p>Carers may request domiciliary care</p> <p>Likely to lack capacity to consent</p>	<p>Reassess acceptability of proposed treatment</p> <p>Management as per dental risk (DBOH, NICE recall guidance)</p> <p>Support carers with oral hygiene</p> <p>Palliative care for teeth</p> <p>Treatment of symptomatic teeth</p> <p>May require more support to accept treatment</p> <p>Treatment planning should be realistic and pragmatic</p> <p>Treatment may not be possible</p>

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References:

- 1 GDC: Standards for the Dental Team.
Available at: www.gdc-uk.org/professionals/standards/team
- 2 Public Health England 2014.
Available at: www.gov.uk/government/publications/delivering-better-oral-health-an-evidence-based-toolkit-for-prevention
- 3 The National Institute for Health and Care Excellence. Available at www.nice.org.uk/guidance/cg19
- 4 FGDP 2013.
Available at www.fgdp.org.uk/publication/selection-criteria-dental-radiography
- 5 BDA Evidence Summary: Shortened dental arch therapy in old age. www.bda.org
- 6 NHS England 2015. www.england.nhs.uk/commissioning/primary-care/dental/dental-specialities/
- 7 The Seattle Care Pathway for securing oral health in older people, 2014.
Pretty et al, Gerodontology 2014;31 (suppl 1):77-87
- 8 Guidelines for the Development of Local Standards of Oral Health Care for People with Dementia, 2006.
Gerodontology; 23 (Suppl. 1): 3–32
- 9 Guidelines for Oral Healthcare for Long Stay Patients and Residents, BSDH 2000
- 10 BDA Evidence Summary: Dental problems and their management in patients with dementia. www.bda.org

Recommended further reading and sources of information

www.gerodontology.com

BSG Oral Health Resource www.gerodontology.com/bsg-oral-health-resource-pack-updated/

www.bsdh.org.uk

www.bda.org

www.alzheimers.org.uk

www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=138

Caring for Smiles NHS Scotland

www.nes.scot.nhs.uk/education-and-training/by-discipline/dentistry/areas-of-education/priority-groups/oral-health-improvement-caring-for-smiles.aspx

Caring for Older People's teeth leaflet (part of the BDA Oral Healthcare for Older People- 2020 Vision (2003 report)

www.bda.org/dentists/policy-campaigns/research/patient-care/Documents/caring_for_older_people%27s_teeth_leaflet.pdf

Guidance: The Eatwell plate: how to use it in promotional material

www.gov.uk/government/publications/the-eatwell-plate-how-to-use-it-in-promotional-material

BDA Summary: Dental problems and their management in patients with dementia. www.bda.org

Clinical Case Studies

Introduction

- The following cases are based on referrals to the Special Care Dentistry department at Liverpool University Dental Hospital.
- The cases have been selected to illustrate principles which can be applied in primary care; they are not supposed to be prescriptive as every case is different and only the relevant details are cited here. Dentists must consider care for each patient based on their individual circumstances.
- By studying each case, it is intended that the reader has greater insight into the additional difficulties and possible management strategies for providing dental care to dementia patients along the dementia journey.
- This should mean that the dental team are better informed to provide appropriate care to patients with dementia including making treatment decisions early and maintaining care within primary care.

Case 1

Early Dementia Management: General Dental Practice

History

- Mrs ST 68 year old female
- Patient known to the practice - seen 3 monthly for periodontal maintenance
- UR1 previous post crown lost - when this occurred 18 months ago the decision was taken by the patient to leave the root in situ and add to existing denture

Presenting complaint

- Advised to see dentist after diagnosis of dementia
- Returned for 6 month assessment

Medical History

- Dementia, hypercholesterolemia and type 2 diabetes

Examination

- OH adequate. Brushing twice daily, intermittent interproximal cleaning-uses bottle brushes
- Lost restoration and caries UL3 distobuccally
- Retained root UR1
- Grade 1 mobility LL8 (2nd molar)
- BPE

3	1	-
2	2	4
- Denture hygiene good



Case 1 - Early Dementia

Proposed treatment plan

- Prevention, diet and fluoride advice (as recommended in DBOH)
- Restore UL3

Dementia related discussion

- Consider extraction of UR1 root and LL8 tooth

Rationale

- Poor long term prognosis – either due to periodontal disease or susceptibility to caries
- Little functional value of UR1 and LL8
- Potentially avoid problems in future

Key learning points

- Focus on preventative advice (as recommended in DBOH)
- Assess long term prognosis of teeth and their functional or aesthetic value to the patient
- Discuss with the patient the options and the rationale for extraction of poor prognosis teeth
- Early discussion with patient +/- family is important to explain how dementia may affect dental care in future

Benefits to patient

- Reduced likelihood of dental disease
- A reduced risk of pain and/or problems when the patient's ability to tolerate invasive dental treatment may be reduced or absent

Case 2

Early Dementia Management: General Dental Practice

History

- Mr KF 59 year old patient
- He has been a patient within your practice for several years
- Despite your best efforts he continues to have a high caries rate

Presenting complaint

- He presents as an emergency patient with symptoms suggestive of an acute periapical periodontitis (Upper Right quadrant)
- Mr KF keen to restore tooth

Medical History

- Alzheimer's disease – diagnosed 18 months ago, Well controlled hypertension and hypercholesterolemia

Examination

- E/O no lymphadenopathy
- I/O heavily restored dentition
- Heavily restored, fractured UR6
- TTP slight buccal tenderness
- Clinical and radiographic evidence of caries



Proposed treatment plan

- Tailored preventative advice (as recommended in DBOH)

Discuss with regard to dementia

- Extraction of UR6 tooth rather than RCT

Rationale

- Tooth already heavily restored and of borderline restorability
- Existing high caries rate
- If restored tooth unlikely to be maintained longer term

Key learning points

- Focus on prevention
- Assess the long term prognosis of teeth
- Pragmatic approach from both patient and dentist are needed to assess the longevity of proposed treatment
- Early discussion with patient +/- family how dementia may affect dental care in future

Benefits to patient

- Reduced likelihood of dental disease
- Reduced likelihood of pain and dental problems when the patient's ability to tolerate invasive dental treatment may be reduced or absent

Case 3

Early Dementia Management: General Dental Practice

History

- Mrs SM 58 year old patient
- New patient
- 3 year history of problems with complete dentures; especially the lower denture since her last remaining teeth were removed

Presenting complaint

- Reports that despite 3 sets of dentures, she cannot eat as well as she would like
- Lower denture moves around and is uncomfortable

Medical History

- Early onset dementia (diagnosed 7 months ago), controlled hypertension and type 2 diabetes

Social and additional information

- Mrs SM attends with her husband
- She answers the majority of the questions but at times looks to her husband for clarification and reinforcement

Examination

- E/O NAD
- I/O Upper denture is unstable, retention satisfactory, slightly under extended. Lower denture has poor retention, well extended
- Lower denture bearing area: ridge resorbed
- Upper ridge has good height and depth of ridge, slightly flabby anteriorly
- From the initial OPG, it appears sufficient bone is present to consider implant retained prosthesis

Treatment options for patient

- Do nothing - this is always an option, however this patient is seeking active care
- An attempt at relining the dentures may provide a cost effective improvement to current dentures
- New conventional complete dentures - improving on minor flaws of current set
- Implant retained removable complete dentures (not routinely available on the NHS so would be a private option).
- Implant retained fixed bridgework (not routinely available on the NHS so would be a private option)

Discussion with patient

- Careful documentation of treatment planning discussions, pros and cons of each option, with a focus on the impact of dementia
- Further attempts at relining or new conventional dentures may give some improvement and should still be considered as an option albeit with a guarded prognosis
- Any implant retained prostheses will be more challenging to maintain in the longer term. Maintaining oral hygiene is essential but may prove difficult when the patient is no longer able to maintain their own oral hygiene.
- All implant retained prosthesis require regular professional maintenance – which again may not be possible as cognition declines
- Implant retained dentures (as an alternative to conventional dentures) will be easier to maintain than implant retained fixed bridgework from both a patient and dentist perspective whilst providing improvements in function

Case 3 - Early Dementia

- Implant retained fixed bridgework is the most challenging to maintain in longer term. It will be difficult for carers to clean adequately if patient resists help with self-care. Also at this stage, if there are implant problems, it may not be possible for dentists to facilitate care.
- If implant retained fixed prostheses are agreed upon then it should be screw retained. This increases the chances of the dentist being able to manage problems if they occur.

Key points

- Every dementia journey is different and we do not know how it will affect this individual in 18 months, 5 or 10 years.
- Careful consideration and discussion should be carried out and documented, highlighting the benefits and risks of treatment. The impact of dementia on the maintenance of any prostheses being provided must also be considered.
- If implants are agreed upon (on a private basis) then the treatment provided should be as simple as possible, and as easy to maintain both from a patient and dentist perspective.

Case 4

Middle Stage Dementia Management: General Dental Practice

History

- Mr JS 68 year old male
- Attends with his wife
- Mr JS's wife answers questions on his behalf

Presenting complaint

- Intermittent pain from lower right, relieved by analgesics. It has disturbed his sleep
- Mr JS was not really sure why he was at the dentist
- His wife reports he was regular attender at current GDP but he has not attended for 18 months

Medical History

- Alzheimer's disease—diagnosed 4 years ago, depression, type 2 diabetes

Social and additional information

- Lives at home with his wife who is his main carer
- Although Mr JS is confused, he allows a thorough examination, including BPE and intra oral radiographs
- He follows instructions that you give in order to complete the examination

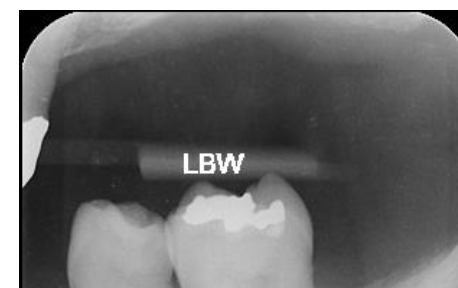
Case 4 -Middle Stage Dementia

Examination

- E/O NAD
- I/O OH adequate
- Deep buccal caries LR7, slightly TTP
- Distal caries LR5-at cemento-enamel junction
- Disto buccal caries UR4 - normal response to ethyl chloride
- Mesial caries UL2

Proposed treatment plan

- Preventative advice (as per DBOH)
- Discussion with Mr JS and his wife that he may need help and support with oral hygiene as dementia progresses
- Attempt treatment in general practice.
- Extraction LR7
- Restorations under LA of UR4, UL2 and LR5
- The patient's wife agrees with the proposed treatment plan



Next step

- Best interests process has already been completed by assessment of capacity and verbal discussion with patient and his next of kin (wife)
- It is important to document the assessment of capacity and the best interests discussion with his wife in the clinical notes
- Onward referral is only indicated when a patient is unable to tolerate care in general practice, or a second opinion is required relating to capacity and consent.

Key points

- Prevention is key
- All the signs suggest that the patient will cope with treatment under local anaesthetic alone
- In this case the consent process is straight forward. Often it is completed routinely as part of consultation and discussion with the next of kin who often accompanies the patient. (see consent section)

Benefits to patient

- It is better for Mr JS to be in an environment with which that he is familiar
- It is preferable for the patient and his wife to be cared for at a practice closer to home

Case 5

Middle Stage Dementia Management: Shared care between General Dental Practice and Community Dental Service

History

- Mrs FD 83 year old
- A new patient to the practice
- Complaining of pain in several areas of her mouth
- Broken teeth which are cutting into her cheeks

Presenting complaint

- On and off symptoms for several years
- Intermittent dull ache which disturbs her sleep
- She cannot remember the last time she saw a dentist
- Recent swelling on LL6 that precipitated referral

Medical History

- Vascular dementia-diagnosed 12 years ago. Stroke 13 years ago, chronic kidney disease stage 3, type 2 diabetes and controlled hypertension
- Mrs FD is a wheel chair user who requires a hoist to transfer to the dental chair

Social and additional information

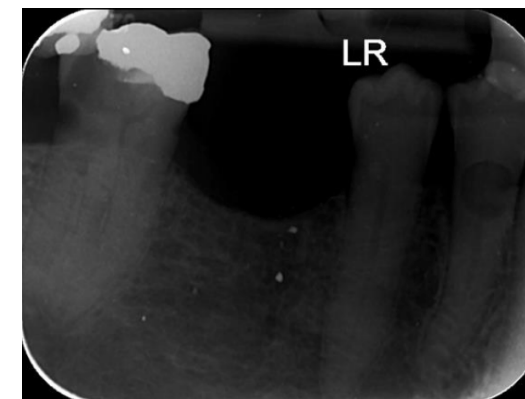
- Mrs FD responds appropriately to questions pertaining to the present but seems to recall few details of recent events, however she remembers distant times more clearly
- Mrs FD cooperates with an examination
- The carer attending with Mrs FD reports that no family members are in contact
- Mrs FD has been brought to the surgery by transport provided by the care home

Examination

- E/O NAD
- I/O oral hygiene poor. xerostomia
- LL6, LL5 retained roots. LL6 is TTP
- LL4 DO caries
- LR7 DOL caries

Treatment in primary care

- Preventative advice (as recommended in DBOH)
- Oral hygiene support and/or assistance to improve oral health is explained to the carer and patient
- Advice re dry mouth including sipping water and the prescription of a saliva substitute
- Referral to nearest level 2 service with additional facilities such as a hoist or wheelchair tipper
- Extraction of LL6, LL5, LL4 LR7





Dementia Friendly Dentistry



Key points

- Every dementia journey is different and the individual and their needs should be assessed
- Although diagnosed over 10 years ago the patient still seems to have capacity and compliance
- GDP will continue to have responsibility for long term care of this patient with a shared care approach with 'level 2' Special Care Dentistry Service

Benefits to patient

- Appropriate treatment in appropriate environment
- Shared care allows ease of preventative advice
- Shared care for operative dentistry improves treatment options and improves quality of care for dentist and patient

Case 6

Management: Shared care between domiciliary care and Special Care Dental Service

History

- Mrs VS 78 year old female
- Lives in residential care with her husband
- Recently fractured lower molar tooth
- Now developed swelling under her eye so her family are concerned

Presenting complaint

- Carers report that a tooth has recently broken however the patient is eating normally
- A recent facial swelling has prompted a domiciliary referral

Medical History

- Alzheimer's disease, osteoarthritis, previous breast cancer treatment, iron deficiency anaemia

Social and additional information

- The patient is still in close contact with her son and daughter.
- Mrs VS can hold a conversation but has a short attention span.
- She lacks capacity as she is unable to retain information given, unable to weigh options in treatment or make a decision.
- On arrival to the residential care facility Mrs VS is able to walk.
- Mrs VS is able to go out escorted to shops and the hairdresser.
- She would therefore be able to attend a dental surgery using a taxi.

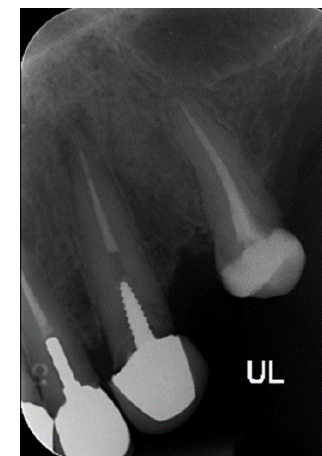
Dementia Friendly Dentistry

Examination

- Patient is able to cooperate with an examination.
- E/O small swelling under left eye
- I/O soft tissues healthy
- LL7 fractured grossly carious, not TTP
- UL3 TTP and tender buccally, recurrent caries around crown
- UL2 carious around crown slightly TTP
- UL5 distal caries not TTP

Proposed treatment

- Preventative advice (as recommended by DBOH)
- Advice to husband and carers to help/support with oral care
- If there is no fluctuant swelling discernable for drainage (at the domiciliary visit) then the only treatment option may be antibiotics (if signs of systemic infection)
- Referral to level 1 provider if the patient is able to cooperate with the treatment planned
- Alternatively, if the patient is unlikely to tolerate invasive dental treatment within a level 1 service then a referral to level 2 services for further assessment as necessary



Key points

- It is not uncommon for domiciliary referrals to be inappropriate
- Robust triaging systems should be in place to minimise this
- Patients who are able to access a dental surgery should be under the regular care of a level 1 service provider (primary dental care)
- In the majority of cases, once treatment is completed in a level 2 or 3 service, patients will be discharged back to a level 1 service

Benefits to patient

- Only limited treatment options are available in a domiciliary setting
- If at all possible care should be carried out within a clinical setting

Case 7

Middle Stage Dementia Management: Shared care between General Dental Practice and Special Care Dental Service

History

- Mr JM is 79 and lives with his 78 year old wife who is his main carer
- Mr JM is a wheelchair user
- He uses a hoist to transfer from his wheelchair
- He recently attended a general dental practice and found it impossible to transfer from his wheelchair to a dental chair

Presenting complaint

- Several teeth are broken
- Brown marks on teeth
- Generalised sensitivity to hot and especially to cold

Medical History

- Parkinson's disease, late onset dementia and COPD

Social and additional information

- Mr JM finds lying back for prolonged periods challenging
- Involuntary movements are minimal especially when appointments are timed closely after medication
- He has difficulty communicating but has understanding in the moment
- His wife now responsible for the patient's oral hygiene
- Mr JM tends to swallow toothpaste rather than spitting out

Examination

- Decoronated teeth UL3, UL4, UL5
- Gross caries distally LR7
- Recurrent caries LR8
- Root caries at margins of crowns UR7 UR4 LR6
- Xerostomia due to medication
- OH very poor

Proposed treatment plan

- Preventative advice (as recommended in DBOH).
- Advised to use 1500ppm toothpaste rather than 5000ppm as patient is swallowing toothpaste
- Regular professional fluoride application, as per DBOH
- Advice to Mr JM's wife regarding support/help with oral hygiene
- Complete consent (patient has capacity)
- Extraction of LR7 UL3, UL4, UL5
- Conventional restoration LR8
- Atraumatic restorative technique (ART) restorations to root caries UR6 UR4 LR6



Case 7 - Middle Stage Dementia

Rationale

- Replacement of multiple crowns and bridges are not indicated as patient is unable to tolerate prolonged treatment.
- Advanced restorative care is also not indicated due to poor oral hygiene and high caries rate.
- Caries risk and prognosis of remaining posterior teeth needs to be monitored moving forwards, with consideration to moving towards a shortened dental arch.

Key learning points

- Maintenance of dentition for as long as possible
- ART appropriate in the first instance to assess compliance and ability to improve oral hygiene
- Appointment times to correspond with timings of medication

Patient returns after 9 months despite request for 3 month recall

On assessment

- Patient reports pain LR6 – suggestive of chronic periapical periodontitis
- Examination shows recurrent caries around LR8 UL6 LL7
- Discussion and decision to move to a shortened dental arch
- Extraction of UR8 (prophylactic) UR7 LR8 UL6 LL7
- Leaving the patient with 9 paired units
- Reinforcement of oral preventative advice (as per DBOH) and appropriate recall interval

Case 8

Late Stage Dementia Management: Shared care between General Dental Practice and Specialist Care

History

- Mr PS is a 64 year old male
- He presents as a new patient with his wife
- Mr PS has toothache, is not eating, complaining of pain and sleep is disturbed
- He is agitated in the waiting room and keeps standing up and walking around

Presenting complaint

- His wife reports the patient complains of severe pain and is becoming unsettled by the pain
- He is refusing to eat if he is in pain
- The pain has been relieved by analgesics, but Mr PS will not always take his medication if he is confused

Social and additional information

- Mr PS is able to hold conversation with you about previous life events
- He refuses to admit he has a problem with his teeth
- He reports that he is 'registered' and recently attended a practice that you know closed over 5 years ago
- His wife has to persuade him to sit on the dental chair
- Mr PS keeps asking where he is
- He lives at home with wife but there is a planned move to residential care

Case 8 - Late Stage Dementia

Medical history

- Vascular dementia diagnosed 2 years ago, poorly controlled hypertension and type 2 diabetes
- He also had a stroke 4 years ago and has had multiple transient ischemic attacks in the last 2 years

Examination

- Mr PS becomes agitated when the chair begins to recline, leading to you assessing him in a semi recumbent position
- E/O no lymphadenopathy or tenderness
- Oral hygiene is poor
- I/O caries detected in LR7, UL6 and LL5. LL5 is TTP
- Buccal sinus LR7
- Intra oral and panoral radiographs are not possible

Treatment in primary care

- Preventative advice (as per DBOH)
- Discussion with Mr PS and his wife that he may need help and or support with oral hygiene as dementia progresses
- Give copies of patient information leaflets for care home staff to follow
- Analgesic advice given
- Referral to nearest level 2/3 service depending on local services
- When the patient was seen on referral, lateral oblique radiographs were taken but were of limited diagnostic value

Treatment provided

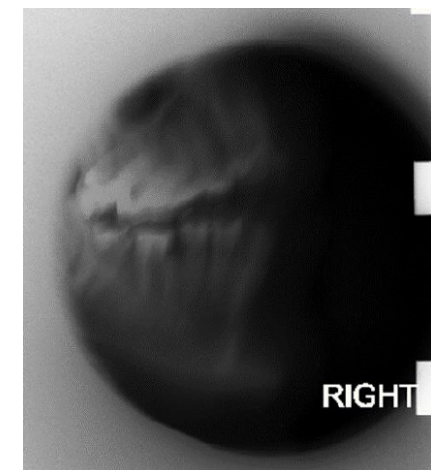
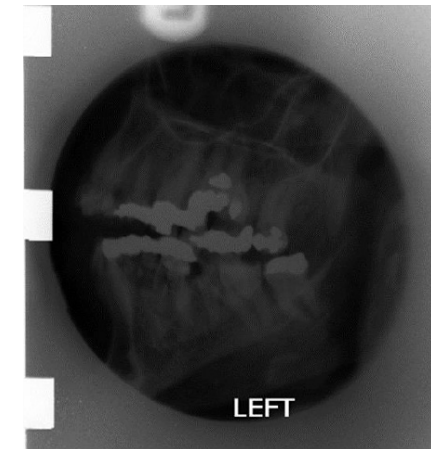
- IV sedation with pre medication
- Extraction of LR7 UL6 LL5 restorations placed at UL7 LL4 LR2 LR3
- Reinforced DBOH advice
- Patient discharged back to primary care

Key points

- A referral for treatment under sedation is justified as the patient struggled to cooperate for a routine examination and radiographs
- Prevention should still be delivered by a general dental practitioner
- The general dental practitioner will continue to have responsibility for long term care of this patient with a shared care approach with SCD specialist

Benefits to patient

- Appropriate care in an appropriate environment
- Shared care more convenient for patient and carers to access prevention plan
- Referral for specialist level treatment to restore teeth and resolve pain



Case 9

Late Stage Dementia Management: No active care

History

- Mrs SB is a 72 year old patient
- Mrs SB attends with her carer
- 3 sets of dentures lost in last 3 years
- Clinical notes suggest her last set of dentures were challenging to make due to ability to tolerate dental care
- Since the last set of dentures were constructed, her dementia has progressed

Presenting complaint

- On direct questioning, Mrs SB does not seem to be aware that the dentures are missing and she does not request a new set
- Mrs SB has not lost weight since the last dentures were lost
- Her diet is unaltered; she tends to consume soft foods and nutrition supplement drinks

Medical History

- Suffers from Lewy body dementia, Parkinson's disease and atrial fibrillation

Social and additional information

- Carers are unsure how the dentures were lost - Mrs SB tends to take them out and leave or hide them
- Carers and next of kin are keen for new dentures to be constructed

Examination

- Mrs SB will not sit in dental chair.
- Attempts at examination are difficult with Mrs SB pushing the dentist away, pursing her lips and shouting
- She rapidly becomes distressed
- The dentist is able to see that the soft tissues are healthy but both ridges are resorbed

Clinical picture

- Poor denture bearing area
- Mrs SB is frail and unable to accept care
- Likelihood of patient tolerating dentures is low – providing treatment would be traumatic for her
- Dementia deteriorating
- Not affecting diet or weight
- Clinical decision – no active treatment but relevant oral health advice given (as per DBOH)

Justification

- Mrs SB is unable to accept dental treatment without sedation
- Sedation is likely to be traumatic/ distressing and may require clinical holding
- Sedation is not without risks for example: aspiration pneumonia, falls at home post sedation or possibly precipitating a medical emergency
- Little clear benefit to Mrs SB in providing new dentures
- Unlikely to adapt to new prostheses if provided

Case 9 - Late Stage Dementia

Outcome

- Discussions with both carers and family are needed to explain the decision
- Often if family are not present at appointments then discussions can be carried out over the telephone
- This decision can be taken within general practice, community service or hospital service depending on the knowledge skills and confidence of the clinician
- If uncertainty regarding treatment or disagreement between the GDP and carers and family persists, then a second opinion should be sought.

Case 10

Late Stage Dementia Management: Referral from General Dental Practice into Specialist Care

History

- Mrs CW 83 year old female
- Referred by general medical practitioner regarding toothache
- Ms CW is unable to tolerate treatment in primary care
- She is visibly frail with a low BMI

Presenting complaint

- Carer is unsure where the pain originated within the mouth.
- Symptoms included crying, grabbing at teeth and refusal to eat food.
- Symptoms resolved following the use of antibiotics and have not yet recurred

Medical history

- Complex- includes hypertension (unsure of control as poor compliance with monitoring), atrial fibrillation, heart failure and depression
- Alzheimer's disease diagnosed 13 years ago
- Limited oral intake – weight maintained by nutrition drinks
- Recent chest infection which was thought to be due to aspiration of food

Case 10 -Late Stage Dementia

Social and additional information

- Lives in 24 hour supported residential care
- Still i
- Wheelchair user and uses hoist transfer

Examination

- Limited but possible if carried out in stages with clinical holding
- Mrs CW cannot tolerate radiographs
- E/O no swellings, tenderness or lymphadenopathy.
- I/O oral hygiene is difficult to assess but very poor - carers report difficulties
- Multiple carious broken down teeth, soft root caries present on majority of remaining teeth which is extensive on some teeth
- No teeth/roots tender to percussion
- No obvious sinuses

Treatment options (within a level 2/3 setting)

- Initial consultation with anaesthetist to confirm risks of sedation or GA
- Active treatment is not carried out; carers to give analgesics as required and provision of antibiotics when required
- Re examination when acute facial swelling reduced and further discussions with anaesthetist as to risks/benefits of treatment at that stage
- Referral to nearest level 2/3 service depending on local services
- When the patient was seen on referral, lateral oblique radiographs were taken but were of limited diagnostic value

Discussion with next of kin and carers

- No clear signs as to which teeth have caused problems
- Risks of sedation/GA are high compared to the benefits of providing treatment
- Multiple appointments and sedation would be required to render Ms CW dentally fit
- GA is not appropriate as is high risk and limited benefit to Ms CW if her symptoms can be managed by analgesics

Key learning points

- In some cases where sedation or GA is required, the risk of providing care may outweigh the benefits
- This can lead to difficult conversations with the patient's family and carers to help them understand and accept treatment is not possible
- The risks or benefits may change with time
- It is still important to highlight preventative advice (DBOH) although this must be tailored according to the patient's needs
- When referring to level 2 or 3 services it is important not to advise treatment that may not be possible and may not be in the patient's best interests

Key points from the Case Studies: General principles of care when treatment planning with patients with dementia

Early dementia

- Diet advice, oral hygiene advice, fluoride regime as per DBOH version 3.
- At the appropriate time, and with sensitivity to individual circumstances, discuss with the patient the potential changes to oral hygiene efficiency, diet and dental treatment which may occur as dementia progresses.
- Consider the dentition as a whole - identify teeth of poor prognosis or retained roots that are of little functional and aesthetic value but may cause problems in the future if diet and oral hygiene decline. Discuss with the patient the possible benefits of early intervention to prevent future problems. Give the patient the opportunity now to avoid problems in the future.
- If the patient is requesting advanced dental treatment, for example endodontics, crown and bridgework or dental implants (either privately or within the NHS), consider oral hygiene standard and caries rate currently and within the context of progressive dementia. Consider how dementia may affect the longevity of any complex restorative work in the future, for example maintenance of satisfactory oral hygiene if the patient becomes reliant on others for personal care. Consider alternative treatment options which would be of benefit to the patient now but be more easily maintained in the future should cognition decline. Discuss options, benefits and risks with the patient and document this. Give the patient the opportunity now to avoid problems in the future.

Middle stage dementia

- Diet advice, oral hygiene advice, fluoride regime as per DBOH version 3.
- Look for signs which may give an indication of the patient's tolerance of operative dental procedures - for example will they sit back in the chair, tolerate a Basic Periodontal Examination, are intraoral radiographs possible? If so these are good indicators that, independent of capacity, the patient will be able to cope with invasive treatment. However, remember that no one gets it right 100% of the time.
- Treatment in familiar surroundings, possibly closer to home, with familiar people is indicated where cooperation is good; and especially where the patient has a strong history of frequent dental attendance or treatment.
- Remember capacity is decision specific and time specific. Don't assume capacity will be impaired, and assess at each visit. Support the patient where possible to make their own decisions.
- If capacity is found to be lacking then often the best interests decision is straight forward and forms part of a normal treatment options conversation. It should include assessment of capacity, the risks and benefits of treatment options, but involving those close to the patient (for example next of kin, friend or non paid carer) in the decision making discussion. It is important to document assessment of capacity and the best interests discussion, including who was consulted, in the patient's clinical notes.
- Disagreements with or between family are rare but are an indication for onward referral for second opinion.
- If onward referral is indicated, consider the most appropriate setting for the patient at that time. This could be level 2 or level 3 services.
- Domiciliary care is often limited to assessment and/or palliative treatment. Careful triage is required.
- For the majority of cases referred to either level 2 or level 3 services the patient will be referred back after a course of treatment with the level 1 referrer maintaining responsibility for continuing care, preventative support and advice and emergency or urgent care as required for the patient.
- Where indicated, consider Atraumatic Restorative Technique restorations. Should there be a rapid, prolonged deterioration in dental health consider a shortened dental arch. Patient-specific indications, options, risks and benefits should be clearly and comprehensively documented in the clinical records to support use of a specified treatment approach.

Advanced / late stage dementia

- Diet advice, oral hygiene advice and fluoride regime as per DBOH version 3.
- Consider the presence of problems with swallowing as this may modify the above, particularly use of mouthrinses or high concentration sodium fluoride toothpaste if the patient is not able to reliably spit out excess. Signs of swallowing problems could include a pureed diet, use of thickened rather than regular fluids, recurrent chest infections, or if the patient is under the care of a Speech and Language Therapy team
- For the majority of cases referred to either 'level 2 or level 3' services the patient will be referred back after a course of treatment with the referrer maintaining responsibility for continuing care, preventative advice and emergency or urgent care.
- Sedation and general anaesthesia are not without risk in this patient group, and although effective, they can still be distressing for the patient and carer, particularly where clinical holding or premedication is required to enable induction of sedation or GA, and in the post-operative period. A careful balance of risk and benefit is essential.
- On occasion, the risks in treating frail patients with multiple co-morbidities can mean that operative treatment is not indicated, and sedation or general anaesthesia cannot be justified.
- Sometimes the level of distress that the patient experiences, and the limited likelihood of a positive outcome which benefits the patient (for example provision of dentures under sedation on a distressed and disorientated patient) means that the decision is made not to provide active treatment.
- The focus is on minimising distress and disruption in the later stages of dementia, and achieving the best possible quality of life.



SECTION 5

Additional important information

Capacity and consent for patients with dementia

The dental team must have a working knowledge of contemporary legislation relating to capacity and consent. Increasing numbers of dentate patients who lack capacity means that primary care practitioners are more likely to have to make best interests decisions.

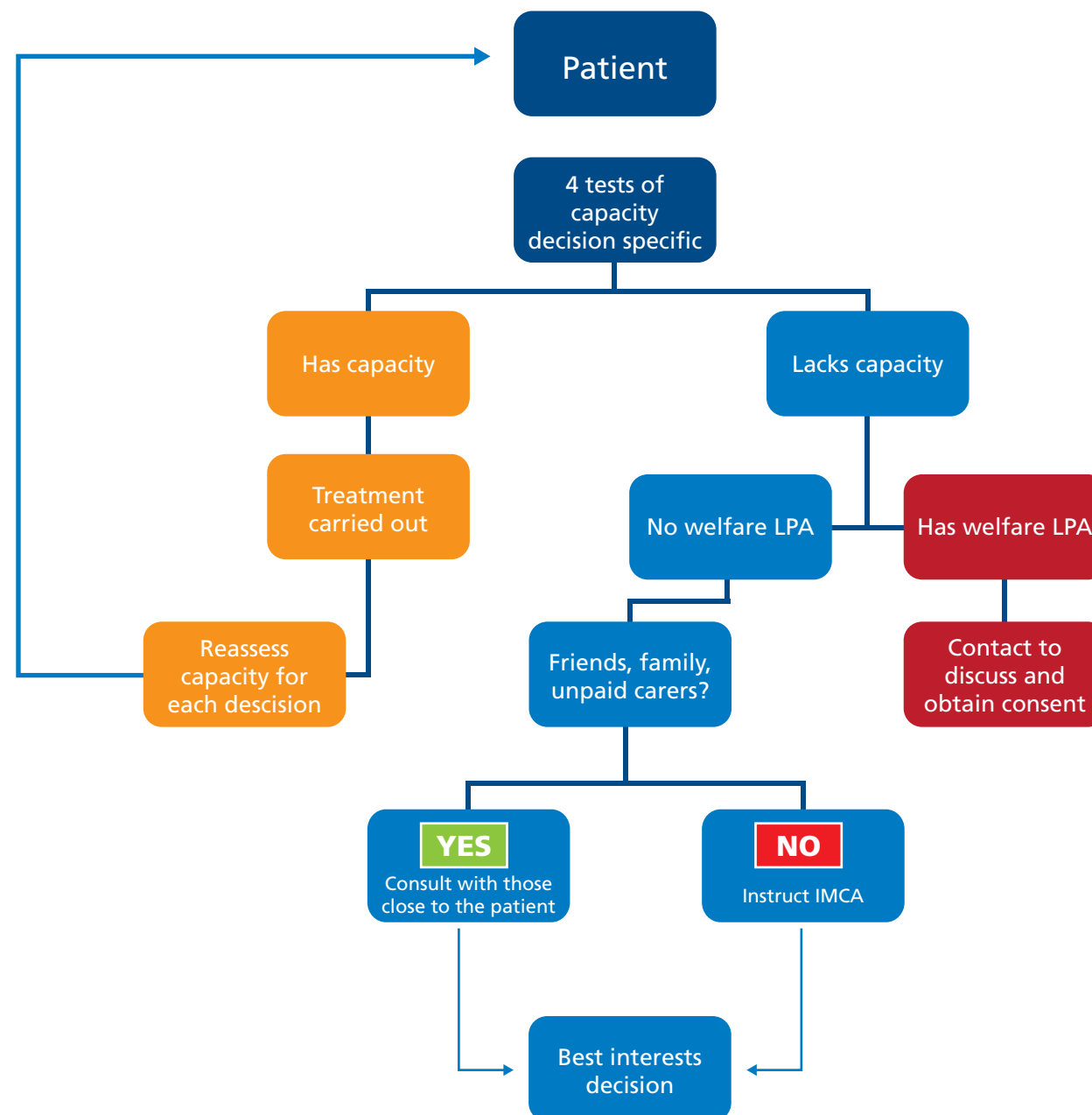
Capacity and consent can also be a common topic in CQC inspection. It is important that capacity and consent is considered on a continuous basis for each stage of treatment. This takes account of the procedure proposed (e.g. examination, restorations, extractions etc.) and the individual's circumstances at that particular time.

Mental Capacity Act 2005 Code of Practice (MCA)¹

If a Dental Professional suspects a patient is unable to make a decision (i.e. lacks capacity to consent) about their treatment then they should follow the Mental Capacity Act and Best Interest Checklist in order to come to a joint decision on treatment.

As highlighted throughout this toolkit, dementia is a broadly progressive condition and there are good and bad days within that progression. This means that capacity can fluctuate over time – an individual may lack capacity at one point in time, but may be able to make the same decision at a later point in time. Where appropriate, individuals should be allowed the time to make a decision themselves.

It is vital that patients are supported and encouraged to consent for their own treatment where possible, and as the professional proposing treatment, it is the dentist's responsibility to assess capacity using the two stage assessment.



Two Stage Assessment of Capacity

Stage 1

Does the patient have 'impairment' in the functioning of the mind?

This may be as a result of a condition, illness, or external factors such as alcohol or drug use?

If 'yes', then capacity must be assessed.

Stage 2

Does the impairment or disturbance mean the individual is unable to make a specific decision when they need to?

Individuals can lack capacity to make some decisions but have capacity to make others, so it is vital to consider whether the individual lacks capacity to make the specific decision.

The Four Tests of capacity enable the clinician to make this assessment:

Is the patient able to?

1. Understand the information, including risks and benefits
2. Retain the information for long enough to make a decision
3. Weigh up the options relating to the decision
4. Communicate their decision by verbal or non-verbal means

If they are unable to do any of the first three functions or communicate their decision (by talking, using sign language, or through any other means), the MCA says they will be treated as unable to make the specific decision in question.

If a patient is found to lack the capacity to make a decision about treatment and such a decision needs to be made for them, the MCA states the decision must be made in their best interests. Capacity to consent may begin to be affected in the middle stages of dementia and is likely to be affected in the later stages.

Where capacity is present

The patient should be informed of:

- the procedure to be carried out
- alternative options
- risks and benefits of the procedure
- consequences of not having the procedure
- any other information they wish to know e.g. prognosis, cost, guarantee of success
- Note: they should be allowed to make 'unwise' decisions (eg refusing the extraction of un-restorable teeth)

Where capacity is questioned

Under the Mental Capacity Act, a person is presumed to have capacity unless all practical steps to help him (or her) to make a decision have been taken without success. The patient should be empowered to make decisions for themselves by:

- allowing sufficient time to make a decision
- explain and communicate using language they can understand
- arranging additional appointments to reiterate and reinforce proposed treatment

Between appointments, it can be helpful to ask family or carers to repeat and remind the patient of the planned treatment at the next visit.

If, on the following visit for treatment, the patient cannot remember what was proposed, it is still possible to seek their consent, ensuring that the person has retained the information for long enough to decide.

Where patient lacks capacity for that specific decision

Most commonly, a **best interests** decision will be required.

Making a best interests decision is a relatively simple process in most cases - especially when the family or next of kin bring the patient to appointments. Disagreements between carers and the dental practitioner are rare, and where they occur may be best managed by onward referral to a tier 2 or 3 provider. For England and Wales, assessment of capacity is detailed in the Mental Capacity Act 2005, and supporting information in the Code of Practice 2.

The dentist, as the healthcare professional proposing treatment, is responsible for acting in that person's best interests and they have a duty to consult with those close to the patient. This may be by telephone, letter or formal best interest meeting.

Particularly where other healthcare professionals are involved in the care of that person. Consulting with others is a vital part of best interest decision-making. People who should be consulted include anyone previously named by the person concerned, anyone engaged in caring for them, close relatives, friends or others who take an interest in their welfare, any attorney appointed under a Lasting Power of Attorney or Enduring Power of Attorney (see below), and any deputy appointed by the Court of Protection to make decisions for the person.

All mental capacity tests and decision made in the best interests of a patient should be recorded fully on their individual patient notes.

Only family members, friends or unpaid carers can sign a best interests decision to show they have been included in the decision making process.

The MCA sets out a checklist of things to consider when deciding what's in an individual's best interests. It says you should:

- **Encourage participation**

Do whatever is possible to permit or encourage the individual to take part.

- **Identify all relevant circumstances**

Try to identify the things the individual lacking capacity would take into account if they were making the decision themselves.

- **Find out the individual's views**

Including their past and present wishes and feelings, and any beliefs or values. Check if there are any advanced directives in place.

- **Avoid discrimination**

Do not make assumptions on the basis of age, appearance, condition or behaviour.

- **Assess whether the individual might regain capacity**

If they might, could the decision be postponed.

Lasting Power of Attorney

The Mental Capacity Act replaced 'Enduring Power of Attorney' with Lasting Power of Attorney (LPA). There are two categories of LPA - one relates to property and financial matters and one which relates to welfare. The Act states:

"The Mental Capacity Act replaces the Enduring Power of Attorney with the Lasting Power of Attorney (LPA). It also increases the range of different types of decisions that people can authorise others to make on their behalf. As well as property and affairs (including financial matters), LPAs can also cover personal welfare (including healthcare and consent to medical treatment) for people who lack capacity to make such decisions for themselves."

In principle a LPA can make healthcare decisions and consent on behalf of a patient who is assessed as lacking capacity. It is important to establish that the LPA has a welfare and not just financial responsibility and if there is an LPA in place, it must be seen by the dentist (decision maker) and a copy available in the notes.

There are a few scenarios where a welfare LPA **cannot** give consent on behalf of a patient:

- where the patient has capacity and can make their own decisions
- where the patients has previously made a decision to refuse the proposed treatment
- where the decision relates to life sustaining treatment – unless specified in the LPA documentation
- an LPA cannot consent or refuse treatment for a mental health disorder for a patient who is detained under the Mental Health Act (1983)

Whilst most of these scenarios are unlikely to affect decisions about treatment provided to a patient within primary dental care, it is important to note that the Code of Practice also clarifies that even when attorneys are able to consent to or refuse treatment, they must always follow the Act's principles and make decisions in the donor's best interests. If a healthcare professional does not feel the decision by the attorney is in the patient's best interests, then second opinions or an application to the Court of Protection may need to be considered if the difference cannot be resolved. (This scenario would be expected to be very rare in the dental setting). On this basis, whilst the appointed welfare attorney can consent to or refuse treatment on behalf of the patient who lacks capacity, the best interests principles still apply.³

Problem solving and Independent Mental Capacity Advocates (IMCA)

Try to get ahead of problems by asking patients in advance of the time they may lack capacity what they would like to happen about treatment or whom they would want you to consult with. If an individual does not have family or friends with whom to consult, it may be necessary to instruct an IMCA in cases where serious medical treatment is proposed. For the purposes of dental treatment, the definition of serious medical treatment is most likely to be related to treatment under GA or IV sedation or surgical interventions such as a dental clearance.

Key points:

- Assessment of capacity is decision and time-specific.
- A person with capacity can make an 'unwise' decision.
- A welfare Power of Attorney may consent for another adult who lacks capacity.
- Where capacity is lacking, the dentist must act in the best interests of the patient.
- The decision-maker must consult with those close to the patient, or if none available, instruct an IMCA for serious medical treatment.
- Referral to specialist services may be indicated if multidisciplinary best interest meetings will be required.
- The Code of Practice will provide a comprehensive guide to the Mental Capacity Act.

Safeguarding and the patient with dementia

There are a number of reasons why people with dementia are more vulnerable to abuse. This may be abuse from strangers or people they know including family members, friends and other carers. Sometimes this may be related to high levels of carer stress.

Abuse can:

- happen anywhere
- be unintentional or deliberate
- be an act of omission, ie a failure to do something
- be an isolated incident or be repetitive or systematic
- amount to criminal acts

Safeguarding children and vulnerable adults is part of recommended CPD for Dental Professionals.⁴ This reflects a key role for the GDC in protecting patients. The GDC's 'Standards for the Dental Team' states:

'You must raise any concerns you may have about the possible abuse or neglect of children or vulnerable adults. You must know who to contact for further advice and how to refer concerns to an appropriate authority such as your local social services department.'

And

'You must find out about local procedures for the protection of children and vulnerable adults. You must follow these procedures if you suspect that a child or vulnerable adult might be at risk because of abuse or neglect.'

The main forms of adult abuse are:

- **Physical**

The non-accidental infliction of physical force that results in bodily injury, pain or impairment

- **Sexual**

The direct or indirect involvement of the adult at risk in sexual activity or relationships, which they:

- 1 Do not want or have not consented to
- 2 Cannot understand and lack the mental capacity to be able to give consent to
- 3 Have been coerced into because the other person is in a position of trust, power or authority

- **Emotional**

Actions or behaviour that have a harmful effect on the emotional health and/or development of an adult who is at risk.

- **Neglect**

The failure of any person, who has responsibility for the charge, care or custody of an adult at risk, to provide the amount and type of care that a reasonable person would be expected to provide. Neglect can be intentional or unintentional.

- **Financial**

The use of a person's property, assets, income, funds or any resources without their informed consent or authorisation.

- **Identify all relevant circumstances**

Try to identify the things the individual lacking capacity would take into account if they were making the decision themselves.

- **Institutional**

The mistreatment, abuse or neglect of an adult at risk by a regime or individuals.

Legislation: The Care Act 2014⁵

The Act states that safeguarding is 'protecting an adult's right to live in safety, free from abuse and neglect.' It emphasises the importance of organisations in helping to prevent and stop abuse and neglect whilst promoting individuals wellbeing and taking into account their wishes, views, feeling and beliefs.

The Act highlights early raising of concerns and it is the responsibility of the healthcare professional to pass on any concerns they have – do not assume someone has done it already!

Dementia and increased risk of abuse

The Alzheimer's Society highlights a number of reasons, why a person living with dementia is at higher risk if neglect or abuse. These include:

- Having dementia can make a person an 'easy target' for an abuser, ie the person may not have ability to remember what has happened to them.
- Even when a person with dementia does disclose abuse they may not be believed, i.e. the attitude may be that the person is confused therefore they cannot be a credible or reliable witness. This makes them more vulnerable.
- Victims of abuse in general often find it hard to talk about their abusive experiences. A person with dementia may be experiencing even more distress because they already have difficulties in communicating their experiences, wishes and feelings.
- It can be very difficult to identify abuse because many of the signs and symptoms of abuse can also be indicators of other conditions (eg Alzheimer's disease) or situations.
- Some physical abuse and neglect can only be detected by professionals following a physical examination, if at all. Detecting abuse can be very difficult in people who are not able to remember or say what has happened to them.
- A person with dementia can abuse other people, eg their carer (informal), care worker or another person with dementia (eg in a day centre or care home).

There may also be a number of factors which increase the risk of an abusive situation developing: carer's stress is probably the most widely recognised, but enforced changes of lifestyle, bereavement, debt and other stresses and problems for carers can all contribute to increased risk.

The dental practitioner and dental care professional who undertake domiciliary work visiting a patient's own home, care home or supported housing may be some of the few people who have a vantage point from which concerns about the safety of an individual or group may come to light. Equally, such signs may present in the patient who attends the surgery.

Dental neglect

Whilst being aware of the potential for abuse, we must appreciate that dental neglect, particularly in our older population, is complex.

There are many barriers which make the provision of daily effective mouth care for dependant adults difficult: most commonly lack of compliance, but also lack of time, lack of awareness and training, lack of awareness of aids and adaptations which can make the process easier for patient and carer. Every effort should be made to support carers to deliver oral care. Despite this, dental teams must consider reporting and recording concerns if they are suspicious that a vulnerable adult is at risk and/or being abused or neglected.

The patient at risk: dealing with concerns⁴

The healthcare professional has a duty of care and a responsibility to report and record any concerns, suspicions or disclosures made by or about an adult who may need protection. Every dental practice should have a safeguarding policy in place should such an event occur.

The role of the dental practitioner in adult protection is three-fold:

- 1 Recognise: Being able to identify an adult at risk
- 2 Respond: Manage the acute situation and inform other services as required
- 3 Record: Document and report in detail the information obtained and the actions taken

If concerns arise or a disclosure is made to the practitioner the following steps outline the initial management

- 1 Remain calm and do not show shock or disbelief
- 2 Listen carefully to what is being said
- 3 Do not ask detailed or probing questions
- 4 Demonstrate a sympathetic approach by acknowledging regret and concern that what has been reported has happened
- 5 Ensure that any emergency action needed has been taken
- 6 Confirm that the information will be treated seriously
- 7 Give information about the steps that will be taken
- 8 Inform them that they will receive feedback as to the result of the concerns they have raised and from whom
- 9 Give the person contact details so that they can report any further issues or ask questions

A non-judgemental approach is important while no attempt should be made to contact the alleged perpetrator nor should forensic evidence be removed. No promises should be made to the individual or assurances that you will keep any secrets. Should there be concerns about the immediate safety of the individual, the emergency services (police or ambulance services) should be contacted.

Making a Referral

Do not seek consent if so doing would:

- place a person (vulnerable adult, child, family member, yourself) at increased risk of significant harm, or serious harm to an adult, **or**
- prejudice the prevention, detection or prosecution of a serious crime, **or**
- lead to an unjustified delay in making enquiries about an allegation of significant harm to a child or serious harm to an adult.

(Adult safeguarding sharing information 2015)⁷

How to escalate/refer concerns/allegations

- Share concerns
- Consider emergency action
- Report to line manager/local safeguarding lead
- Refer to Statutory Agencies (e.g. Adult Social Care, Police etc)
- Record decisions and actions

The recording of every aspect of adult protection is essential to ensure there is a contemporaneous record of events. The time taken to ensure these notes are of a high standard cannot be underplayed as they are important for services to establish if the adult is at risk but also for the dentist and their associated legal responsibilities. Accurate clinical records can demonstrate if a situation is out of character, or part of a developing pattern - for example there have been similar concerns at previous visits. This is particularly important where the staff treating the patient may change.

It is best practice to keep a log of any safeguarding concerns raised by a practice and subsequent outcome, by way of practice development, peer support and compliance with GDC standards as well as for future reference.

References and additional information

- 1 Mental Capacity Act 2005:
Available from www.legislation.gov.uk/ukpga/2005/9/contents
- 2 Mental Capacity Act Code of Practice, TSO 2007.
Available from www.gov.uk/government/publications/mental-capacity-act-code-of-practice
- 3 Consent to dental treatment: their principles and application. Dental Protection.
Available from www.dentalprotection.org
- 4 General Dental Council Standards for the dental team.
Available from www.gdc-uk.org
- 5 The Care Act 2014:
Available from www.legislation.gov.uk/ukpga/2014/23/contents/enacted/data.htm
- 6 Safeguarding vulnerable adults (Scottish dental magazine)
sdmag.co.uk/2015/09/29/the-safeguarding-of-vulnerable-adults/
- 7 Social care institute for excellence 2015 Adult safeguarding-sharing information.
Available from: www.scie.org.uk/care-act-2014/safeguarding-adults/sharing-information/

Contact information for referrals to Community Dental Services

Geographical area	Provider of service	Contact information
Bury, Oldham and Rochdale	Pennine care	Old Street, Ashton Under Lyne, Tameside, Lancashire OL6 7SR Tel: 0161 716 3000
Bolton	Bridgewater Community Trust	Lever Chambers Centre for Health, 27 Ashburner Street, Bolton BL1 1SQ Tel: 01204 462730
Wigan and Leigh	Bridgewater Community Trust	Pemberton Health Centre, Sherwood Drive, Pemberton, Wigan WN5 9QX Tel: 01942 481930 Leigh Walk In Centre, Leigh Health Centre, The Avenue, Leigh WN7 1HR Tel: 01942 48340
Tameside	Bridgewater Community Trust	Ashton PCC, 193 Old Street, Ashton under Lyne, Lancashire OL6 7SR
Stockport	Bridgewater Community Trust	Kingsgate House, Wellington Road North, Stockport SK4 1LW
Trafford	Bridgewater Community Trust	Seymour Grove Health Centre, 70 Seymour Grove, Old Trafford, Manchester M16 0LW
Manchester	Central Manchester Foundation Trust	Adults and Specialist Community Services, Central Manchester University Hospitals NHS Foundation Trust, Chorlton Health Centre, 1 Nicolas Road, M21 9NJ Tel: 0161 860 2920 Fax: 0161 860 2901
Salford	Salford Royal NHS Foundation Trust	Salford Royal NHS Foundation Trust , Community Dental Service, Dental Department, Pendleton Gateway, 1 Broadwalk, Salford M6 5FX Tel: 0161 206 1557

Acknowledgements

Development of this document was supported by the Greater Manchester Health and Social Care Partnership Dental Commissioning Team. Development of the original content was supported by NHS England (Cheshire and Merseyside) Local Dental Network Steering Group.



First Edition | December 2017