

Palliative Dentistry

Authors

Elizabeth Gonzalez Malaga

Specialist Registrar in Special Care Dentistry
Northamptonshire Healthcare Foundation Trust

Deborah Manger

Deputy Medical Director and Specialist in Special Care Dentistry
Northamptonshire Healthcare Foundation Trust

Acknowledgements

MCN Special Care Dentistry

East Midlands and South Central

Denise Birkett

Oral Health Promotion Practitioner
Northamptonshire Healthcare Foundation Trust

Sarah Canavan

General Dental Practitioner - Northamptonshire

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Foreword

There has never been a more appropriate time to release this document. People's lives feel completely disrupted. Amongst the disruption there is a desire to have normality. Normal would be receiving care from the dental practitioner you have grown to know and trust.

The document aims to inform and support colleagues to deliver care collaboratively between general dental practitioners, doctors and Special Care dentists in the best interest of the patient.

“A General Dental Practitioner Perspective”

If someone has a life-limiting condition what can and cannot be managed in dental practice?

- When a patient attends general dental practice wherever possible we need to examine and assess their dental needs.
- If examination is possible and it is established that no treatment is required or if it is required but it can be managed in practice, then the patient should be treated and reviewed in practice as per the NICE guidelines.

If the patient is uncooperative for an examination or assessment and there are concerns that there is pain or infection, then the following can be asked to assess the situation (either the patient and/or carer):

- Is there any swelling?
- Has there been a change of appetite?
- Is the patient pushing away hot and cold food?
- Has there been a general change in behaviour?

If the answer to any of these questions is *yes* and treatment, even stabilisation, cannot be carried out then an assessment to the salaried dental service (SDS) can be made. This is also relevant if the patient has a medical condition that prevents treatment being carried out in primary care.

If there is an obvious swelling or infection, then this should be stabilised with antibiotics prior to referral.

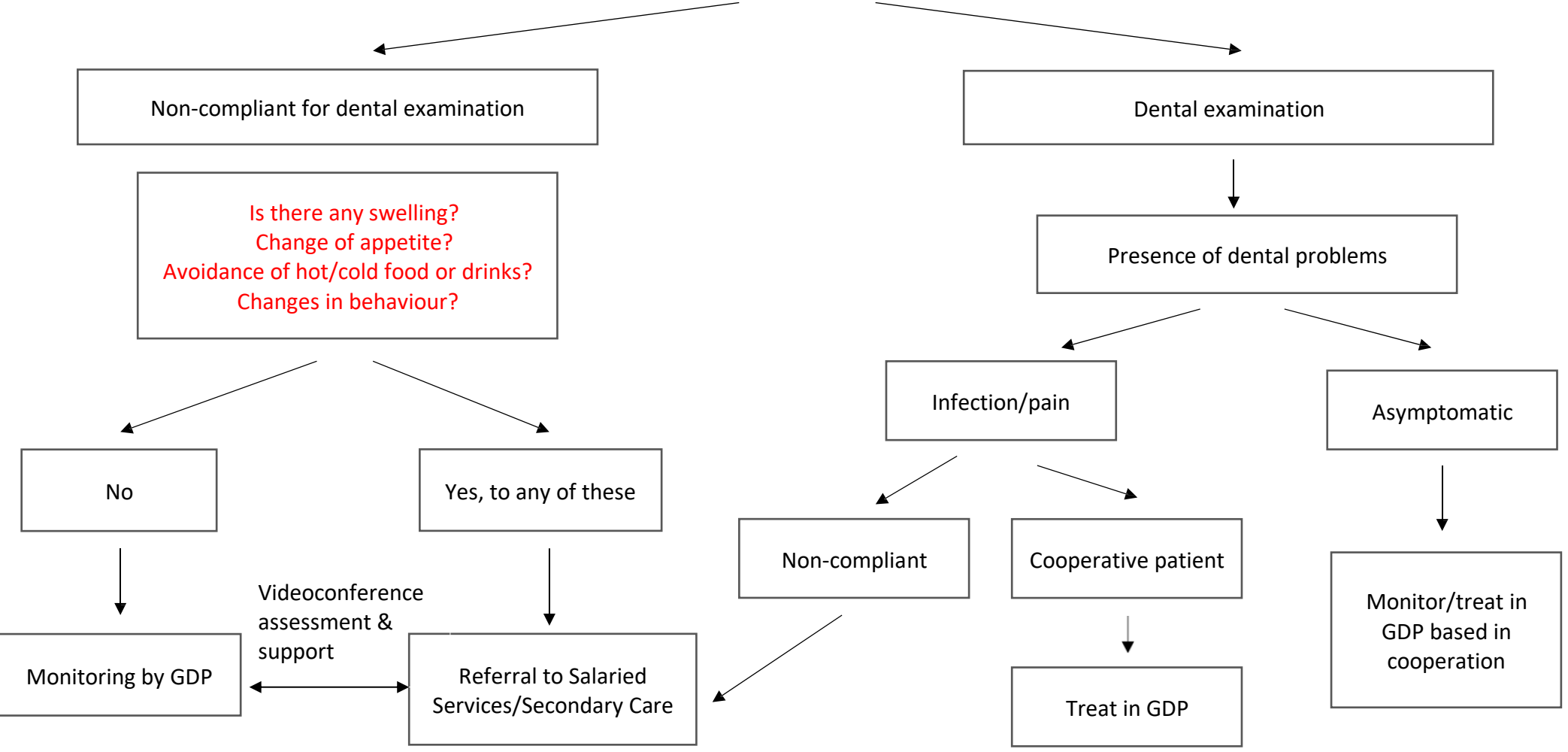
If the answer to these questions is *no*, then there is unlikely to be a dental cause.

- If the patient is not in pain and if there is no sign of infection, then a referral to the salaried dental services is not required at that point.
- Even if an examination but not treatment has been possible and there are obvious issues including lost fillings, broken teeth etc. unless they are in pain or have an infection then the situation should be managed and reviewed in practice.

Remember sometimes doing nothing is all that can be done. It's OK to say no to the patient and the carers explaining that it is ultimately in the patient's best interests. Remember you can say no but record all conversations, plans and conversations in your clinical notes.

Sarah Canavan
General Dental Practitioner
Northamptonshire

Assessment in General Dental Practice of patient with terminal illness



If there is a swelling and you are unable to treat the source (e.g. extraction or incision and drainage), prescribe antibiotics accordingly with current guidelines

Background

Within the last decade Special Care Dentistry has changed, becoming a more challenging specialty. Due to the latest medical advances patients, who before would have not survived, are living with complex medical co-morbidities and other disabilities. Similarly, as reported by the latest surveys, older people are now more likely to retain their natural teeth. As great as all of this is, our patients are more prone to require dental treatment in a moment in their lives where they may no longer cope with dental treatment due to frailty. Giles and colleagues predicted that, by 2031, there is likely to be a 70% increase in the number of older people with severe disabilities due to neurological, musculoskeletal, cardiovascular or respiratory conditions (Mulk et al., 2014).

More and more our services receive referrals for patients with degenerative conditions, such as dementia, terminal cancer or Huntington's disease. If the condition is at an early stage, it gives us the opportunity to plan for the future; however, the dilemma remains for those referred at a late stage with severe physical or cognitive decline, possible inability to cooperate and dental disease (e.g. caries or periodontal disease) affect outcomes.

The main purpose of this project focuses on the dental treatment plan for patients on a palliative/end-of-life route, when to treat or not to treat and when it is agreed not to treat, how to document this decision and how to treat symptoms.

Most of the articles found focus on the importance of the provision of oral hygiene and common oral symptoms for patients receiving palliative care (e.g. mucositis, xerostomia) rather than on the dental management of patients with acute or chronic dental disease. Although prevention is a key element to avoid disease and improve patient's comfort and quality of life, for clinicians our biggest dilemma appears when assessing a patient with dental disease at the end of their lives.

Aims of the document

Promoting patients' quality of life and supporting patients, families and carers through effective communication are at the heart of this document. This document is a guide for dentists and Dental Core Professionals (DCPs), within Primary and Secondary Care, providing care and support for patients whose health is a constant risk to their lives, with a terminal illness and/or approaching end-of-life stage.

Literature Review

Northamptonshire Healthcare Foundation Trust Library, based at Berrywood Hospital, kindly undertook a search on articles about Palliative Dentistry.

Using the following databases: Medline, EMBASE, EMCARE and CINAHL, they carried out a search introducing the subsequent terms: dental care, chronically ill, oral hygiene, terminal care, palliative care, mouth hygiene, terminal care, palliative therapy, terminally ill patient, mouth disease, palliative dentistry, oral health and end of life.

This search produced 60 results; 25 full-text articles were screened and 8 were included in this project (Figure 1).

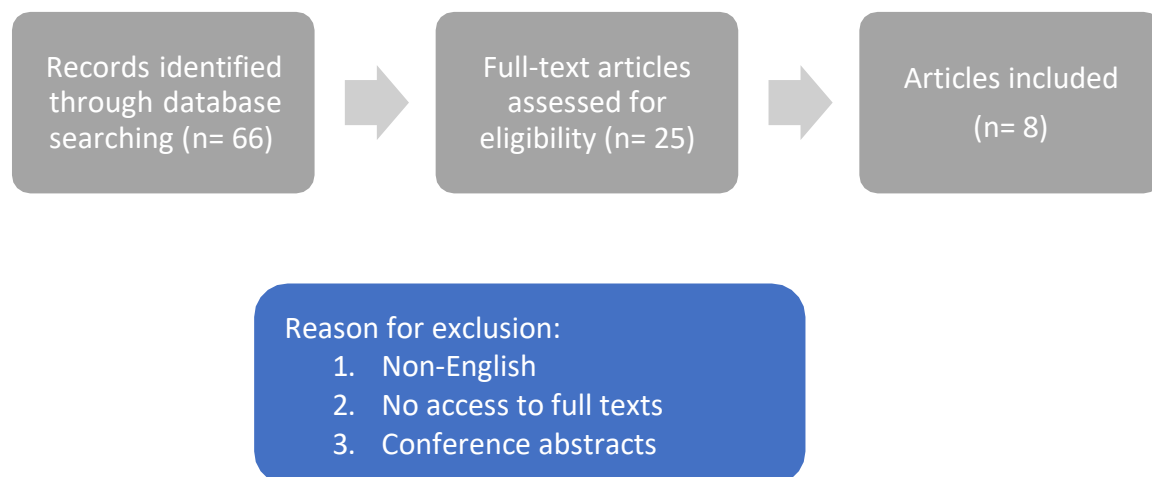


Figure 1- Diagram of literature search

Palliative care vs. end of life care

Figure 2 represents the different phases and layers of care with their main priorities, approach and time-limit to live.

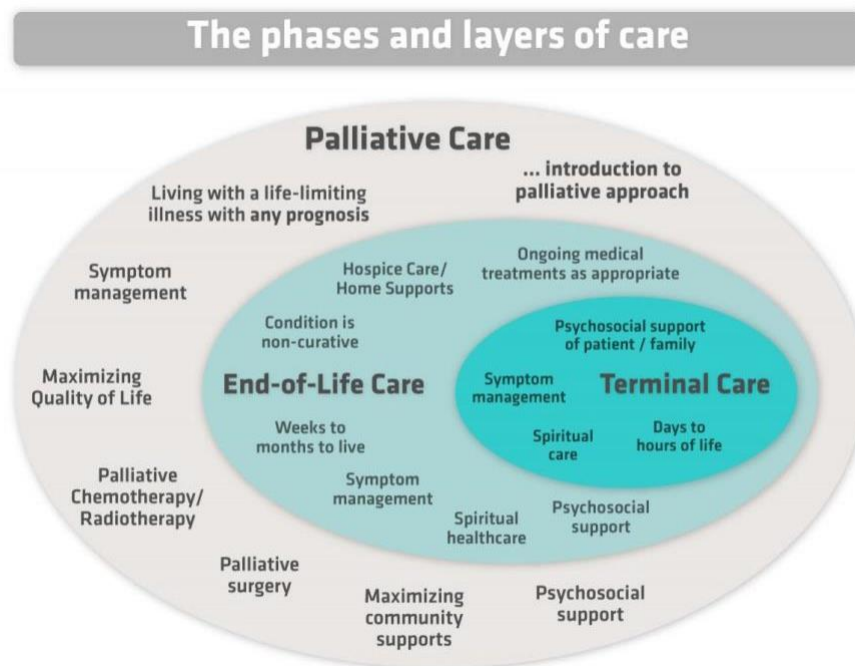


Figure 2- The phases and layers of care

Image obtained from : <http://hpc.providencehealthcare.org/about/what-palliative-care>

Palliative care has been defined by different organisations:

- Palliative care, as defined by the National Cancer Institute, is care given to improve the quality of life of patients who have a serious or life-threatening condition (Negi et al., 2016).
- The World Health Organisation gives a definition where the focus is shared for patients and their families. "An approach that improves the quality of life for patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual" (Negi et al., 2016).

Generally, palliative care refers to any care focused on alleviation of symptoms and side effects but also relief of the psychological, spiritual and social problems arising from the diagnosis and/or therapy of a condition (Negi et al., 2016)

End-of-life care is described by the General Medical Council (GMC) as when a person is likely to die within the next 12 months; including those whose death is imminent (e.g. within a few hours or days) and those with advanced, progressive, incurable conditions (Delgado et al., 2018).

Some of the symptoms indicative of terminal phase of life are: confinement to bed, loss of appetite, profound weakness, dysphagia, dry mouth, weight loss and semi-consciousness with fluctuating unconsciousness (Mulk et al., 2014). Furthermore, the Supportive and Palliative Care Indicators Tool (SPICT) (*Appendix 1*) helps clinicians to identify deteriorating patients, allowing individualised care planning with patients and families. While it is beyond our competency to identify the deteriorating patient, recognising some of the red flag indicators can support us to plan dental care including provision of invasive dental treatment and referral to specialist services. Adapted from this toolkit, *Table 1* summarises some of those clinical indicators per condition.

<p>Cancer:</p> <ul style="list-style-type: none"> - Too frail to accept oncology treatment 	<p>Neurological disease:</p> <ul style="list-style-type: none"> - Deterioration of cognitive and physical functions - Increase difficulty swallowing and communicating - Breathlessness and aspiration pneumonia
<p>Dementia/frailty:</p> <ul style="list-style-type: none"> - Unable to independently dress, walk or eat - Reduction on ability to eat and drink, including swallowing problems - Incontinence - Reduced social interaction and mutism - Frequent falls - Repeated aspiration pneumonia 	<p>Cardiovascular disease:</p> <ul style="list-style-type: none"> - Breathlessness at rest or minimal effort on those with heart failure or extensive/untreatable cardiac disease
<p>Respiratory disease:</p> <ul style="list-style-type: none"> - Severe chronic lung disease with breathlessness at rest or on minimal effort - Long term use of oxygen - Ventilation for respiratory failure - Ventilation is contraindicated 	<p>Kidney disease</p> <ul style="list-style-type: none"> - Chronic Kidney disease stage 4 or 5 - Dialysis not started or stopped
<p>Liver disease:</p> <p>Cirrhosis with at least one of these complications on the following year: ascites, hepatic encephalopathy, bacterial peritonitis, recurrent variceal bleeds.</p> <p>Liver transplant is not possible.</p>	<p>Other:</p> <ul style="list-style-type: none"> - Recurrent unplanned hospital admissions - Significant weight loss

Table 1 - Adapted from Supportive and Palliative Care Indicators Tool

Psychological impact on palliative care patients

Following the diagnosis of a life-threatening illness, patients and families might experience shock, dysphoria, anxiety, depression, fatalism and grief. **Palliative care psychiatry** focuses on the emotional and social impact of a patient on palliative care (Mulk et al., 2014). Inevitably, any of the emotions described above could have an impact on how patients will be able to cope and respond to dental therapy. This should be remembered when treating/assessing a newly diagnosed patient; it is not uncommon to observe disengagement, anger or frustration towards healthcare professionals. Communication, empathy and active listening are qualities that members of the dental team should have when addressing patients and families experiencing distress and uncertainty; conversations can often become awkward, difficult and emotionally challenging (Wiseman, 2000).

A century ago, societies recognised death as a natural part of life. Nowadays, death is not acceptable in a world driven by health and youth. One goal of palliative care is to support a person in preparing the mind to the reality of death (Wiseman, 2000).

Kubler-Ross divided the process of dying or grief in five stages, with patients skipping or reverting to a particular stage and not necessarily following the entire process (Figure 3).

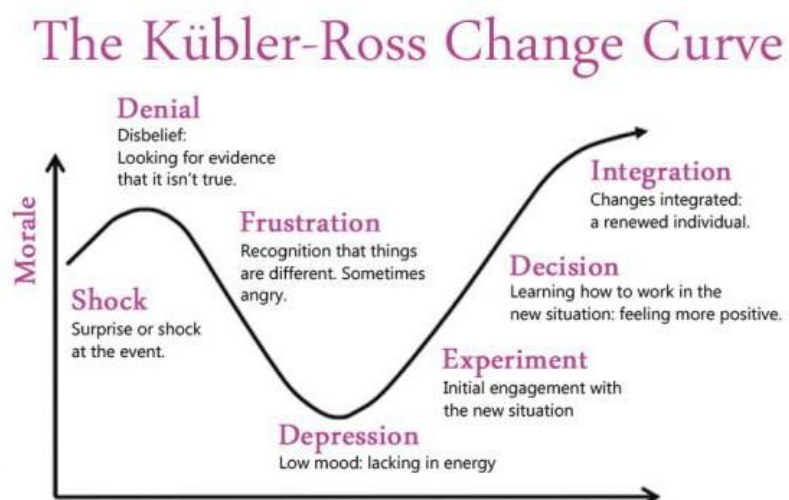


Figure 3 - The Kubler-Ross stages of grief

Palliative Care Dentistry

Palliative Care Dentistry is defined as “the study and management of patients with active, progressive, far-advanced disease in whom the oral cavity is compromised either by the disease directly or by its treatment” (Wiseman, 2000).

Sharing the same goals with palliative medicine, the main objectives of palliative oral care is maintenance of quality of life and mouth comfort; attending to both physical and psychological needs, supporting patients and their families. Early diagnosis of oral conditions and their management is essential to minimize pain and suffering (Casey, 2014).

Patients are often treated by a multidisciplinary team that includes physicians, nurses, speech and language therapists, pain management team, occupational health, dietitians, psychologists and pastoral team. Unfortunately, it is uncommon for the dental team to be part of this holistic approach and their input might not be sought until the patient complains of discomfort. However, up to 89% of patients receiving palliative care will have at least one oral symptom (Casey, 2014). This fact supports the necessity for the early involvement of the dental team in order to maintain patient’s quality of life (Mulk et al., 2014): nutrition, self-esteem, comfort and social interaction with others to peacefully spend their final moments (Nakajima, 2016).

Figure 4 represents the “continuum of palliative care” from diagnosis to the bereavement for the loss of a beloved, including the approach to therapy for each stage.

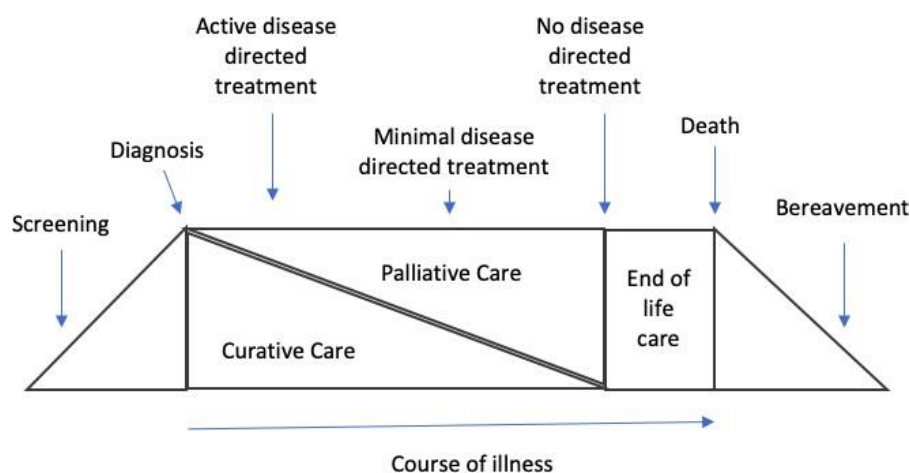


Figure 4 - Continuum of Palliative Care

The dental team should be involved in each of these stages of disease, supporting patients and their families maintaining oral hygiene in complex circumstances and focusing on oral comfort through the management of painful conditions like mucositis and infections (Mulk et al., 2014).

Dental expression in palliative care is defined as “the extended dental services with a central goal of providing pre-eminent feasible oral care to terminally-ill or patients with advanced disease, where oral lesions impact on quality of remaining life of patients whether they are as a result of their disease and/or therapy” (Mulk et al., 2014).

Oral Care at the end of life

It is well known that often oral care is not a priority in a patient’s care plan. This might be due to lack of training, resources or time constraints (Delgado et al., 2018) but also as a result of functional deterioration on a patient’s ability to perform his/her own oral health or even to tolerate others to provide it. Poor oral hygiene increases the risk of developing caries, oral infections and subsequently pain, sepsis and aspiration pneumonia (Wiseman, 2000). This will have an impact on patients’ quality of life limiting their nutritional function but also worsening patients’ behaviour in those with cognitive impairments and overall accelerating patients’ functional decline (Chen et al., 2013).

It is important to remember that patients diagnosed with terminal cancer suffer rapid functional decline in the last weeks or months of life. On the contrary, older adults with frailty or organ failure experience a gradual functional deterioration before death. This difference has a significant role when planning treatment (Chen et al., 2013).

Inevitably, diagnosis of a terminal disease has an impact on patients but also on their families. As the condition/s deteriorates, further support is required from families who may become carers for their beloved relatives. A study conducted by Delgado (2018) explored oral care experiences of palliative care patients from their families and/or carers’ perspectives. Some of them did not provide oral care because they felt they could cause further stress and suffering to their beloved ones but more surprisingly, in some cases they were advised not to

provide oral hygiene. For those that delivered daily oral hygiene, some expressed guilt and worrying that the oral care provided by them may be inadequate or potentially harmful. Oral hygiene was rarely seen as a tool to improve quality of life. Instead, it was delivered when oral signs and symptoms appeared. Some carers honestly admitted that provision of oral hygiene is difficult and unpleasant task to be performed by others (Delgado, 2018). These results support the importance of further oral health training for healthcare professionals and families.

Oral problems in Palliative Care

Oral manifestations can be the direct or indirect result of the primary disease, co-existing conditions and/or side effects from the therapy used for the management of any of their illnesses (Negi et al., 2016)

Mucositis and Stomatitis

- 80% of patients receiving chemo/radiotherapy are prone to mucositis
- Self-limiting but extremely debilitating for patients affecting their oropharyngeal functions and quality of life (Mulk et al., 2014)

Xerostomia

- Dry mouth is the most commonly reported oral problem (Delgado et al., 2018)
- Might be as a result of medication and therapy (e.g. radiotherapy) but it may be subjective with no hyposalivation
- Negative effect on patient's life: diet, speech and incapacity to wear dentures
- Clinical signs include: thick ropey saliva, lip stick, fissured tongue, candidiasis and high caries incidence

Candidiasis

- Between 70-85% of palliative patients present with candidiasis and, in most cases, associated to dry mouth
- Most common type of candidiasis in terminal end-stage immunocompromised patients is pseudomembranous
- Predisposing factors: immunosuppression, dry mouth, poor oral hygiene, denture wearers, poor nutrition and medications (e.g. corticosteroids, broad spectrum antibiotics)

Malnutrition

- Most common causes in palliative patients are dry mouth, dysgeusia, low olfactory function, stomatitis and poor dentition
- Consider a referral to Dietitian and Nutritional teams

Dental treatment in Palliative Care

When considering treatment planning for patients with a terminal illness, it's important to know what the prognosis and life expectancy is for the specific patient in order to appropriately tailor a dental treatment plan. Intensive dental therapy in a terminally-ill patient could break his/her homeostatic balance increasing the risk of systemic health complications or iatrogenic problems (Chen et al., 2013).

The most crucial question is whether or not to provide dental treatment for a frail patient and/or at the end-of-life. A patient-centred care approach should be undertaken at all times, discussing with the patient, families, other healthcare professionals and in consideration of the patient's previous wishes and values; but overall, thinking on how we can help to maximize the patient's quality of life and minimizing harmful treatments (Chen et al., 2013). The emotional impact of life-threatening illness should be considered when planning dental treatment. Patients and families require time to process information and overcome barriers to access care: scheduling multiple appointments, weakness and frailty to cope with travelling or lengthening appointments, and costs associated with dental treatment, particularly for younger adults who are no longer able to work.

Although dental treatment at this stage should be mainly focused on function rather than cosmetics, an exception should be taken for dentures, particularly upper appliances to restore facial appearance. When dentures are lost, we should facilitate a replacement as quickly as possible. This is particularly important at the end of patients' lives, when they receive many visits from their friends and families and maintaining their dignity and self-esteem becomes a priority (Wiseman, 2000).

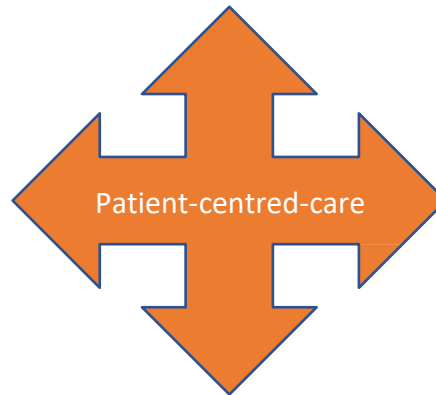
Patient with life-limiting diagnosis

- Communication with patient's lead Consultant/ GMP
- Find out information about prognosis of condition & life expectancy

PALLIATIVE CARE

- Plan ahead for deterioration of condition: lack of cooperation for dental treatment and inability to maintain oral health
- Shortened dental arch in heavily restored dentitions
- Eliminate sources of pain/infection
- Deliver functional and durable dentistry; "easy to maintain"
- Education on oral hygiene and diet advice to patient and carers/family

Patient's wishes, beliefs



Participation in MDT's Family involvement

END-OF-LIFE

- Main goal: facilitate mouth comfort
- Domiciliary care might be deemed necessary
- Management of pain/infection: how to contact dental team in case of emergency
- Prior to dental treatment: liaise with Medical Team
- Daily oral hygiene should be part of patient's care plan

Special consideration to dentures when restoring missing teeth, particular anterior segment: try to deliver those as quick as possible

Cases

The following cases represent patients of different ages and medical conditions; some of them with capacity to consent and others without it. The common factor is found in that all of them had a palliative care approach.

Case 1

92-year-old male

Medical history: history of deep vein thrombosis, advanced Parkinson's disease and alcoholism

Medications: clopidogrel, lansoprazole, paracetamol, allopurinol, Colofac, Evacal, ferrous sulphate, furosemide and simvastatin

Social history: daily consumption of a third of a bottle of whisky, non-smoker, wheelchair user due to reduced mobility and lives with his daughter. Patient has full capacity to consent

Past dental history: referral made by emergency dentist. Irregular attender to dentist, only when in pain. Patient expressed his fear to dental treatment

Current complaint: recent history of bilateral jaw swelling, treated with antibiotics prescribed by General Dental Practitioner (GDP)

Findings on examination:

- Heavily carious UR6/4
- Retained roots of: UR8/3/2/1-UL1/2/3/4/5- LL6- LR4/5/7/8
- Buccal caries LL4

Risk assessment:

1. Increased risk of bleeding: on antiplatelets and alcoholism. Blood tests would be required prior to surgical treatment and use of local measures
2. Limited mobility: patient would have to bring his frame to transfer to dental chair
3. Cooperation: patient very anxious with dental treatment and this worsens involuntary movements

Discussed options with patient: staged extractions with special measures to control bleeding vs. no treatment but accepting risk of further pain, infection and sepsis. Patient understood risks taken but he wished to monitor and only access treatment if experiencing pain or infection. He agreed to return to see our extended-duty dental nurse for oral hygiene instructions. High fluoride toothpaste was prescribed.

Appendix 1 shows the letter that was sent to the patient explaining options, risks and what to do in the case of acute pain/infection. Unfortunately, the patient presented on another occasion with facial swelling but he declined dental treatment and opted for antibiotics.

31-year-old male

Medical history: Down's syndrome, severe learning disabilities, autism, Eisenmenger's syndrome with ventricular septal defect, patent ductus arteriosus, pulmonary hypertension, pulmonary valve regurgitation, heart failure, systolic murmur and sinus tachycardia

Medications: vitamins, zopiclone (PRN)

Social history: non-verbal, and fully mobile. Random sleep pattern: fully awake for 48 hours followed by 48 hours of continuous sleep; this is the main reason why patient has his own apartment with 24 hours support. Patient does not have capacity to consent for dental treatment

Past dental history: previous contacts with Community Dental Services in 2004, 2011 and 2015. Regular visits since 2016 with attendance to clinic and also domiciliary visits. Due to extreme challenging behaviour, it's very difficult to provide dental examination but carers have previously contacted us when he was in one of his sleeping periods, so we could assess at home while sleeping

Current complaint: support workers were unsure if he had dental pain as he kept slapping his face but otherwise he was eating and drinking as usual. Also, reported possibility of loose teeth in 2015, the patient was referred to our Special Care Dentistry General Anaesthetic List at Kettering General Hospital. Following anaesthetist's concerns over the very high risk associated with his GA, a best interest meeting occurred and it was agreed that if patient develops a swelling, he would either get antibiotics or incision and drainage with clinical holding (*Appendix 2*). In 2018, a new best interest occurred to address dental treatment. Serious risk to life and permanent damage from a GA remained the same; *Appendix 3* shows a very detailed letter discussing each option with associated risks.

Recently, the patient presented in the surgery supported by two of his longstanding carers. He was brought in a wheel chair as this was during one of his sleeping episodes. On a limited dental examination, a grade III mobile LR1 was identified. Immediately, a best interest decision was made over the phone with one of our SCD Specialists and also with his carers to have this mobile tooth taken out. Due to potential risk of Infective Endocarditis, 3 grams suspension of Amoxicillin was given and an hour later patient had this tooth extracted with topical anaesthesia and gentle support of hands and head from his carers. Straight away, a different behaviour was noted with patient appearing happy, smiling. No further self-harm to his face was observed.

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Appendix 1



Supportive and Palliative Care Indicators Tool (SPICT)



Use the SPICT to identify people with one or more advanced, progressive, incurable conditions; or at risk of dying of a sudden, acute deterioration for assessment and care planning.

1. Look for two or more general clinical indicators of deteriorating health

Performance status poor

(needs help with personal care, in bed or chair for 50% or more of the day).

Two or more unplanned hospital admissions in the past 6 months.

Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.

Persistent, troublesome symptoms despite optimal treatment of underlying condition(s).

A new event or diagnosis that is likely to reduce life expectancy to less than a year.

Lives in a nursing care home or NHS continuing care unit, or needs care at home.

2. Now look for clinical indicators of advanced conditions

Advanced heart/ vascular disease

NYHA Class III/IV heart failure, or extensive coronary artery disease:

- breathless or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Advanced respiratory disease

Severe chronic obstructive pulmonary disease (FEV1 < 30%) or severe pulmonary fibrosis

- breathless at rest or on minimal exertion between exacerbations.

Meets criteria for long term oxygen therapy (PaO2 < 7.3 kPa).

Has needed ventilation for respiratory failure.

Advanced kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min).

Kidney failure as a recent complication of another condition or treatment.

Stopping dialysis.

Advanced liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Serum albumin < 25g/l, INR prolonged (INR > 2).

Liver transplant is contraindicated.

Advanced cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment due to advanced multimorbidity or advanced cancer.

Advanced neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive dysphagia.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Advanced dementia/ frailty

Unable to dress, walk or eat without help.

Eating less; difficulty maintaining nutrition.

Urinary and faecal incontinence.

Progressive weakness, fatigue, inactivity.

Unable to communicate meaningfully; little social interaction.

Fractured femur; falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

3. Ask

Would it be a surprise if this patient died in the next 6-12 months?

No

4. Assess and plan

Assess the patient & family for unmet needs.

Review treatment / care plan, and medication.

Discuss and agree care goals with the patient & family.

Consider specialist palliative care referral if symptoms are complex or poorly controlled.

Consider using GP register to coordinate care in the community.

Handover: care plan, agreed levels of intervention, CPR status.

Appendix 2

Ref: [REDACTED]

Email:

Willowbrook Dental Care Unit
Willowbrook Health Centre
Corby Community Health Complex
Cottingham Road
Corby
Northamptonshire
NN17 2UR

Tel: 01536 748059
Web: www.nhft.nhs.uk

02 August 2019



Dear Mr [REDACTED]

Many thanks for coming to meet our team yesterday. As you are aware we made the following findings in your mouth:

- retained roots – UR8, UR3, UR2, UR1, UL1, UL2, UL3, UL4, UL5, LR8, LR7, LR5, LR4 and LL6
- caries - UR6, UR4 and LL4

We understand and respect your decision not to have any dental treatment at this stage; however, you are aware of the risk of pain or infection from any of these broken teeth.

Should you require an emergency dental appointment, you are very welcome to contact us on the telephone numbers provided in the attached copy of our Service Information Leaflet.

Please do not hesitate to contact us if you have any enquiry.

Yours sincerely

Ms Elizabeth Gonzalez Malaga
Speciality Registrar in Special Care Dentistry

Enc. Service Information Leaflet

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Chief Executive: **Angela Hillery**

Trust Headquarters: St Mary's Hospital, London Road, Kettering NN15 7PW Tel: 01536 410141 Fax: 01536 452040

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**MAKING A
DIFFERENCE
FOR YOU,
WITH YOU**

Appendix 3

Ref: [REDACTED]

Isebrook Dental Department
Isebrook Hospital
Irthlingborough Road
WELLINGBOROUGH
Northamptonshire
NN8 1LT

Tel: 01933 235478
Web: www.nhft.nhs.uk

02 August 2019

[REDACTED]

Dear [REDACTED]

I am writing to confirm the discussions and actions agreed further to a meeting regarding your oral and general health on the 14th October 2015.

The meeting occurred at your home address. In attendance along with myself were:

[REDACTED] (CPTLD)
[REDACTED] (IST)
[REDACTED]

We discussed oral health; disease and consequences. In particular we discussed the issue related to tooth mobility (witnessed by staff) and tooth loss due to gum disease. Currently no dentist has been able to adequately assess [REDACTED]'s mouth. This would require significant restraint.

We discussed the issue in relation to congenital heart condition and the possible consequences of general anaesthesia; these are significant and can be fatal.

The discussions also included:

- [REDACTED]'s love of food and the general and sensory pleasure he gets from eating. Staff are monitoring his food intake and any problems he is experiencing. They will adapt his diet if any patterns are noted.

- [REDACTED]'s recent episodes of choking. He is being reviewed by Susan Negus, a Speech and Language Specialist with a special interest in dysphagia
- Possible tooth loss and whether this may compromise the airway. This is unlikely but not impossible.
- The effect of advanced gum disease and lack of oral hygiene on the risk of respiratory infection. Staff supporting [REDACTED] are exploring the possibility of him receiving the 'flu jab'.

[REDACTED]'s family have recently experienced a family bereavement; [REDACTED]'s father has died. It was felt that we would like them to be involved in the decision making for the future and that the team at [REDACTED] House would instigate this. When the family are able to attend and feel ready to discuss the issues we will all come together for a meeting.

Whilst awaiting a further meeting the plan is as follows

If [REDACTED] should develop swelling the dental service would consider the following

- Antibiotics and pain relief
- Incision and drainage, under firm clinical holding, if the swelling was extensive followed by antibiotics and pain relief

The contact numbers if there are problems are as follows:

- During Monday-Friday working day 01536 748059 or 01536 748044
- Out of hours advice line 07753 310451

Please do not hesitate to contact me if there are any outstanding issues.

Yours Sincerely

Deborah Manger
Deputy Medical Director
Specialist in Special Care Dentistry

C.C [REDACTED] (CPTLD)
[REDACTED] (IST)

Chairman: Paul Bertin

Chief Executive: Angela Hillery

Trust Headquarters: St Mary's Hospital, London Road, Kettering NN15 7PW. Tel: 01536 410141. Fax: 01536 493147

Appendix 4



Nene
Clinical Commissioning Group

Francis Crick House
Summerhouse Road
Moulton Park
Northampton
NN3 6BF

27th November 2018

Best Interest Meeting Minutes

[REDACTED]

In attendance:

[REDACTED] was not in attendance due to very unsettled behaviour.

- [REDACTED] – Service Manager at [REDACTED] House
- [REDACTED] – Clinical Director for Specialist Dentistry
- [REDACTED] – Duty Social Worker
- [REDACTED] – Student Nurse
- [REDACTED] – Community Learning Disability Nurse
- [REDACTED] – Student Nurse
- [REDACTED] – Learning Disability Health Facilitator (minutes)
- [REDACTED] – Mum
- [REDACTED] – Sister

Reason for meeting

For the past 5 weeks [REDACTED]'s support team have noticed very obvious increase in levels of challenging behaviour, in particular banging the bottom right side of his mouth, this behaviour is out of character and different to usual. Therefore it is suspected that [REDACTED] has tooth ache. [REDACTED] has a severe learning disability and very limited communication, his capacity has been assessed and he lacks capacity to understand the need for a dental examination and treatment.

History

[REDACTED] has a diagnosis of Severe Learning Disability, Down's Syndrome, Autism, Pulmonary Vascular Disease (the hole in his heart is still present).

Medication: [REDACTED] reports [REDACTED] takes vitamins only.

In 2015 [REDACTED] worked with [REDACTED] and the anaesthetist to review his suitability for a general anaesthetic for dental treatment. The results of this were reviewed today and remain the same; [REDACTED] is unsuitable for a general anaesthetic. The risks to [REDACTED] are "serious risk to life" and "permanent damage". Should [REDACTED] ever require a general anaesthetic due to life threatening reasons this would be granted.

Contraindications

Sedation in the form of gas and air, midazolam or intravenously is unsuitable as [REDACTED] body doesn't oxygenate his blood sufficiently, likely resulting in respiratory depression. Local anaesthetic is unsuitable alone due to [REDACTED] refusing, pulling away, hitting and scratching. There was a further concern raised that, should [REDACTED] be sedated for dentistry treatment that all of his teeth may end up being removed, food and the ability



to chew and eat his food is extremely important for [REDACTED] and in his best interest it was felt where possible to treat individual teeth would be more ideal. [REDACTED] and [REDACTED]'s family discussed that there is no way [REDACTED] would allow a dental examination; this has also been previously tried with no avail. [REDACTED] does not allow staff to brush his teeth, therefore, he is likely to have gum disease, [REDACTED] said this does not usually cause pain or swelling. Gum disease causes bacteria to eat away at the bone, causing pus to form around the teeth, the pus continuously drains but is swallowed or inhaled, putting [REDACTED] at risk of pneumonia, but unlikely to be the cause of the pain. The gum disease also makes teeth loose. [REDACTED] asked that [REDACTED] has his ears checked as this can also cause pain around the area that [REDACTED] is banging.

Opportunities

[REDACTED] behaviour pattern is such that he will often go 48 hours without sleep, several times a week. At the end of the 48 hour period [REDACTED] will become very drowsy and levels of challenging behaviour reduce, this could provide an opportunity for [REDACTED] to perform a dental examination at home, but will require support workers to hold [REDACTED]'s arms down to prevent injury. Everyone was in agreement today that this would be the least restrictive option in order to perform a dental examination and ideally locate the source of the suspected toothache.

Plan

- 1) [REDACTED] requires an appointment to see his GP to get his ears examined to rule out ear ache, please can consensus staff arrange for this appointment at the most suitable time for [REDACTED].
- 2) [REDACTED] to continue to receive liquid paracetamol pain relief.
- 3) [REDACTED] to send dental set to [REDACTED]'s support team to enable desensitisation work.
- 4) Support workers at [REDACTED] to carry out desensitisation work.
- 5) [REDACTED] (CTPLD) to create social story to enable [REDACTED] to prepare and understand the dental examination.
- 6) [REDACTED] to work with [REDACTED] staff to prepare for the holding technique to be used for [REDACTED]'s dental examination.
- 7) Once ready and at the optimum time for [REDACTED] to be at his most drowsy [REDACTED] staff to telephone [REDACTED] during Mon-Fri core working hours to schedule the dental examination.
- 8) On the day of the examination the most familiar support workers to be on duty supporting [REDACTED] with the examination and the holding.
- 9) The outcome of the examination will indicate the next course of treatment, if it is a very obvious cause identified at the dental examination [REDACTED] may be able to resolve the issue then, if the problem is more serious or unidentifiable a further best interest meeting may be required.

Copy to all attendees and Dr [REDACTED]

