

oral health & intellectual disability

a guide for dental practitioners

oral health is central to good overall health

Good oral health is required if people with intellectual disability are to:

- ▶ experience good overall health and wellbeing
- ▶ participate in their communities
- ▶ function to the best of their abilities

People with disability are at increased risk of poor oral health and face multiple barriers to accessing dental services.

This guide is for dentists, dental therapists, oral health therapists, dental hygienists and dental prosthetists. It outlines some of the barriers to good oral health experienced by people with intellectual disability. It provides strategies that dental practitioners can use to identify these barriers so that they can engage patients' support networks and provide high quality dental care.

Most patients with mild or moderate disability can be treated successfully in the general dental clinic.



“Oral health is considered integral to general health, with poor oral health likely to exist when general health is poor and vice versa. Oral health refers to the standard of health of the oral and related tissues that enable an individual to eat, speak and socialise without active disease, discomfort or embarrassment. While oral diseases are common, they are largely preventable through population-level interventions (including water fluoridation), and individual practices such as personal oral hygiene and regular preventive dental care.”

(Centre for Oral Health Strategy NSW, 2013:4)

defining disability

The WHO International Classification of Functioning describes disability as an umbrella term, covering:

- ▶ impairments
- ▶ activity limitations
- ▶ participation restrictions

Disability is diverse and includes those who have a range of impairments with or without additional needs. However not everyone with disability will have complex needs. The scope is broad, covering people with physical, sensory, cognitive, medical, emotional or social impairments, or more often, a combination of these factors.

(FDI statement on Oral Health and Dental Care of People with Disabilities, 2016)

This definition highlights the need for dental practitioners and medical practitioners to address the health issues of people with a disability from the perspective of the patient and their individual needs, rather than focusing on the person's diagnosis or impairments. While diagnosis is important, particularly for people whose specific conditions have associated comorbidities, it must be recognised that the barriers to oral health experienced by most patients with intellectual disability relate to social, cognitive, communication, motor, sensory and behavioural factors rather than their formal diagnosis of disability. For most, the experience of disability is defined by social exclusion and the disadvantage caused by societal assumptions and a lack of support, rather than medical or functional diagnoses.

The dental needs of patients with a disability may, in some cases, be greater than other patients in the general community due to patterns of oral disease. These often reflect factors such as social disadvantage or insufficient direct support.

While dental practitioners are familiar with planning both simple and complex treatments, the approach used for treatment planning for a patient with intellectual disability may require modifications such as:

- ▶ Additional attention given to communication and consent.
- ▶ Creative and efficient solutions to some of the practical barriers experienced by patients. Barriers include heightened anxiety, stretched support networks, infrequent dental care, and procedures that require a series of appointments.

people with an intellectual disability tend to have poor health

+ more



Multiple, chronic, complex medical problems

Including epilepsy, vision/hearing impairment, dysphagia, malnutrition, obesity, reflux disease, constipation, skin conditions, and cardiac, endocrine and musculoskeletal disorders.



Mental health issues

Greater risk and fewer resilience factors.



Unrecognised & under treated health conditions

Including physical and mental health.



Medication

Including inconsistency in adhering to prescribed medication, overmedication, polypharmacy, and dry mouth.



Lifestyle risk factors

Including nutrition, Vitamin D deficiency, exercise and socioeconomic disadvantage.



Communication difficulties

— less



Financial resources

Employment and financial information.



Health education/promotion

Regular exercise, healthy eating, access to appropriate smoking cessation and other public health campaigns.



Preventive healthcare & diagnostic screening



Social networks, participation, social connection

lifespan

▶ Potentially avoidable death:

- ▶ Occurs at twice the rate of the general population, with leading causes being circulatory system disease, infections and cancer, coupled with less rigorous care and fewer allied health referrals (NSW: Trollor et al., 2016)
- ▶ More than a third of deaths potentially amenable to health care interventions (UK: Hosking et al., 2016).

▶ Lower life expectancy found in global research:

- ▶ Age adjusted mortality ratio for people with intellectual disability twice that of the general population (UK: Heslop & Glover, 2015)
- ▶ 22% of people with intellectual disability die before age 50, compared with 9% of the general population (UK: Heslop et al., 2016).
- ▶ Gap in life expectancy 13 years for males and 20 years for females (UK: Heslop et al., 2016)

achieving better outcomes

Poor health is common in people with disability. The relationship between disability and poor oral health is more accurately viewed in light of the endemic social disadvantage, neglect and poor support experienced by people with intellectual disability. The chart on the right side of page 2 illustrates the relationship between disadvantage, poor support, disability and oral health.

While there are some dental conditions specific to particular impairments or diagnoses (discussed later), the key challenge for the dental practitioner lies in addressing the support and psycho-social needs of patients, namely:

1. collaboration

Collaborating effectively with medical providers, key support professionals, accommodation services and families is essential to ensure optimum oral health outcomes and completion of home oral care plans, as well as facilitating the early identification of oral disease.

People with intellectual disability usually have at least one plan in place that is used as a central tool for support staff, organisations and family. This may be a **Person Centred Plan** or a **Support Plan**, and possibly a **Behaviour Support Plan** (see Communication, below), a **Lifestyle Plan** or **Consistent Approaches**. One of the best ways to ensure that your dental advice goes home with the patient and is put into practice is to have the advice – particularly advice about serious oral health concerns, treatments and home care – added to the person's planning documents. This may require a discussion with the support professional or family or non-family carer who accompany the person to the consultation.

2. communication

Many people with intellectual disability communicate verbally and in ways that are similar to or the same as any other patient. Dental practitioners who take the time to communicate directly and build a relationship with these patients will achieve better outcomes than if others' perspectives are prioritised over those of the patient. However, some people with intellectual disability do not or can not speak, while others can only do so with difficulty. For these patients, alternative methods of communication may be required. Demystifying communication is one of the most important factors in successfully treating patients with a disability. There are three aspects to good communication with patients with complex communication issues:

- a. **Use of communication techniques with patients who have communication barriers.** This may necessitate the dental practitioner using techniques such as Tell, Show, Do, providing breaks and reassurance, and desensitisation.
- b. **Communication with key support professionals and family members.** The dental practitioner needs to be aware that an individual may have several support professionals or carers and that the accompanying person may not be the main supporter. This will necessitate the dental office following up by email or phone, or providing written instructions. Parents may also be tired or stressed and may have experienced difficulties during prior dental treatment. Supporters, carers and family members will require clear explanations, printed or emailed information, and guidance in collaborating with other allied health professionals. Support professionals, family members and carers can also facilitate communication by supporting the patient's use of communication devices.
- c. **Recognising that what is often referred to as behaviours of concern or challenging behaviour is better viewed through the lens of communication.** A complete outline of the links between communication and behaviour is outside the scope of this guide. However, in summary, it can be said that most challenging behaviour represents communication relating to concerns or issues that the person is experiencing.

Tips or guidelines for communication will often be available in the person's **Behaviour Support Plan** or **Consistent Approaches** documents. Support professionals may be able to share these documents – or sections of them – with dental practitioners.

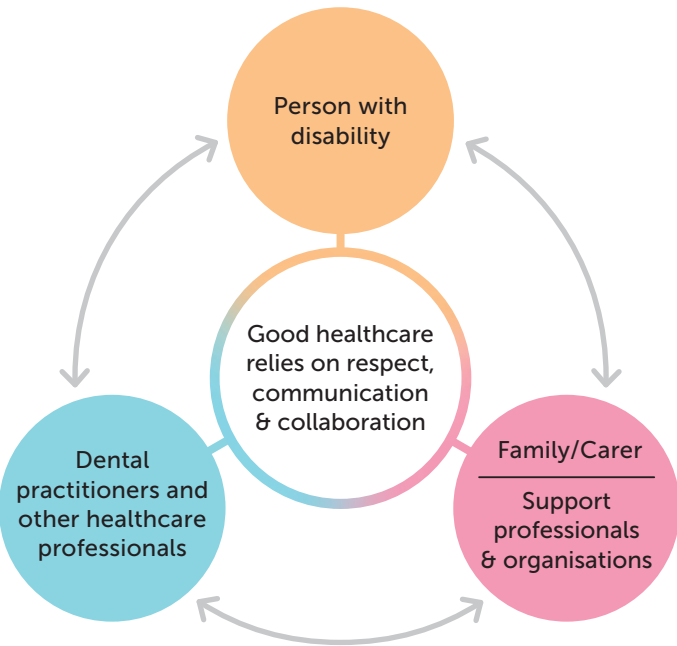
See page 10 for more information about Positive Behaviour Support and Restrictive Practices.



working in partnership

Disability support professionals work across a range of services including family support, respite, recreation, accommodation, day programs, case management and behaviour support. It is important for dental practitioners to recognise that disability support professionals generally have very little health training. Health professionals should not assume health knowledge.

Disability support professionals work defined hours and many work in shifts as part of a team. Some support professionals will be committed long-term practitioners working in permanent positions. Others will be untrained casual staff who will be in the job for a short period.



For various reasons, the oral health of people with intellectual disability living in supported or low cost accommodation is generally not prioritised due to competing interests and support needs. People living in privately owned or rented accommodation may experience similar circumstances.

Good oral care can be achieved by ensuring effective collaboration and communication between all parties, including documenting assessment, treatment and daily oral care. Refer to the planning forms at the end of this Guide, **Oral Health Assessment** and **Home Oral Care Plan**, or visit inclusiondesignlab.org.au/dental.



For videos, animations, and the ADA-endorsed dual-read publication *Your Dental Health*, visit: inclusiondesignlab.org.au/dental

what should the dental practitioner do?

- ▶ Use clear language and avoid jargon when communicating with patients and their support people.
 - ▶ Document summaries of key points in relation to the assessments.
 - ▶ Make sure information is recorded and conveyed clearly.
- ▶ Engage with support professionals to get an understanding of their level of experience and knowledge.
 - ▶ Provide opportunities to practice the skills recommended in the oral care plan.
- ▶ Take responsibility for proactive healthcare and regular review to ensure interventions are implemented effectively and in a timely manner.

Document your assessment, treatment and home oral care. Refer to the planning forms at the end of this Guide, **Oral Health Assessment** and **Home Oral Care Plan**, or visit inclusiondesignlab.org.au/dental

Encourage the dissemination of these documents between all parties.

bridging the gap between oral and overall health

While poor oral health is a significant health concern in itself, the link between oral and systemic health is also well established in literature. Poor oral health has been linked to increased risk of cardiovascular disease, diabetes and other chronic conditions (Bascones-Martinez 2012). For example, diabetes has been linked to the presence of periodontal disease (Bascones-Martinez 2012) with patients having "six times higher risk of worsening glycaemic control and the development of the macro and microvascular complication of diabetes, in particular cardiovascular and kidney disease" (Watanabe 2011).

Individuals with disability have poorer outcomes including: extractions rather than fillings, increased severity of periodontal disease, and a lack of functional replacement of extracted teeth. (Mac Giolla Phadraig et al., 2014)

Inflammation constitutes a major mechanism for the observed link between oral diseases, specifically periodontitis, and several particular systemic diseases. There is evidence for an association between periodontal disease and diabetes, as well as emerging evidence for other conditions including: obesity; coronary artery disease; metabolic syndrome; [poor] oral health after menopause; helicobacter pylori; [and] adverse pregnancy outcomes.

(Sievers et al., 2010:17)

The following table shows some of the causes, conditions and adverse effects experienced by people with intellectual and developmental disability.

difficulty chewing	<ul style="list-style-type: none">▶ Possibly requiring altered duration and frequency of meals▶ Poor or inadequate nutrition▶ Requiring a modified and possibly cariogenic diet	<ul style="list-style-type: none">▶ Social awkwardness▶ Potential for choking and aspiration▶ Possibly requiring a nil oral nutritional intake
dental decay & tooth loss	<ul style="list-style-type: none">▶ Impact on speech, appearance, self esteem, eating and language development▶ May cause oral malodour▶ May adversely impact on social inclusion and participation▶ Pain and discomfort▶ Periodontal disease	
medications	<ul style="list-style-type: none">Some medications may cause:<ul style="list-style-type: none">▶ Gingival hyperplasia▶ Xerostomia▶ Hyposalivation	<ul style="list-style-type: none">▶ Erosion▶ Plaque accumulation▶ Gingival inflammation▶ Low saliva pH, less buffering, and altered consistency <ul style="list-style-type: none">▶ Caries and periodontal disease▶ Soft tissue diseases
severe caries	<ul style="list-style-type: none">▶ Necrotic tooth pulp	<ul style="list-style-type: none">▶ Pain & distress▶ Halitosis, cellulitis, sinusitis, bacteremia
aspiration of oral bacteria	<ul style="list-style-type: none">▶ Aspiration pneumonia▶ Recurrent infection▶ Respiratory diseases: Oral care interventions have led to a 90% reduction in ventilator associated pneumonia (Hutchins et al., 2009).▶ Dry, crusted saliva mixed with mucous from elsewhere in the gastrointestinal tract sitting around mouth and lips	

common conditions found in patients with intellectual disability

Among dentists who do treat individuals with intellectual and developmental disability, 99% have identified poor oral hygiene as the single greatest threat to their patients. (Binkley et al., 2014)


The following chart outlines some of the common issues experienced by people with a particular diagnosis. Dental practitioners should screen patients for issues common to patients with particular conditions. This list does not include all possible conditions or common issues.

Diagnosis or condition	Common or occasional issues
Intellectual disability	<ul style="list-style-type: none">▶ Difficulty understanding health promotion strategies and the importance of good oral health▶ Reliance on carers and supporters to assist them with food selection, daily oral hygiene, and arranging dental treatment▶ Medication which may affect gingivae and saliva production, quality and function▶ Epilepsy and the associated risk of damaged oral structures and prostheses▶ Oro-motor dysfunction with reduced food clearing and contribution to occlusal issues▶ Poor diet (relating to access to information about healthy food, financial issues, peer modelling, constraints on time of support professionals etc)▶ Stressors related to accommodation and daytime activities whereby choice has been restricted▶ TMJ disorders
Down Syndrome	<ul style="list-style-type: none">▶ Developmental dental anomalies▶ Greater incidence of cardiac anomalies▶ Fine motor issues that compromise the ability to clean teeth effectively▶ Increased incidence of periodontitis▶ Increased incidence of epilepsy
Cerebral Palsy	<ul style="list-style-type: none">▶ Parafunction and attrition▶ Oro-motor dysfunction▶ Gastro-oesophageal acid reflux▶ Fine motor issues that compromise the ability to clean teeth effectively.▶ Tactile intolerance▶ TMJ dysfunction▶ Dysphagia
Autism Spectrum Disorder	<ul style="list-style-type: none">▶ Sensory issues, such as increased or decreased sensitivity to touch, sounds, light, liquids, and temperature▶ Damaging oral habits are common including: bruxism, tongue thrusting, and self-injurious behaviour such as picking at the gingiva or biting the lips▶ Periodontal disease, contributed to by poor daily oral hygiene and medication, occurs in people with autism in much the same way it does in persons without developmental disabilities▶ Trauma and injury to teeth from falls or accidents that may occur in people with seizure disorders▶ Violent and self-injurious behavior triggered by the invasive nature of oral care, particularly when there has not been a positive desensitisation appointment to familiarise the patient with the staff, office and equipment using a step-by-step process


The following conditions are not as common as those on the previous page. Better outcomes for patients with these conditions can be achieved through increased collaboration with patients’ support networks and enhanced oral home care.

Diagnosis or condition	Common or occasional issues
Rett Syndrome	<ul style="list-style-type: none">▶ Hypersalivation, micrognathia, abnormal chewing, narrow maxillary arch, and high arched palate▶ Bruxism, drooling, biting hands, digit/hand sucking, and tongue protrusion as habits
Williams Syndrome	<ul style="list-style-type: none">▶ Malocclusion, hypodontia, malformed teeth, taurodontism, pulp stones, increased space between teeth, enamel hypoplasia and high prevalence of dental caries.▶ Variation in dental development, agenesis of permanent teeth in combination with aberrations in tooth size and morphology may affect dental esthetics and complicate orthodontic and prosthodontic treatment.
Fragile X	<ul style="list-style-type: none">▶ Significantly higher occurrence of malocclusion


Dental practitioners should remember that patients with intellectual disability often have complex issues such as:




Financial considerations that may necessitate choice between oral care and other systematic care.




Care providers being overwhelmed with the burden of complex medical care and day to day care at the expense of prioritising oral health. Dental practitioners may not be able to alleviate these burdens directly, however recognising that such stressors exist may enhance communication and understanding.



Oral health problems failing to be recognised, discussed or considered by medical or other allied health practitioners.



Medical treatment requiring the intake of medications, modified diets or alternative feeding methods that may also increase the risk of decay in these patients.

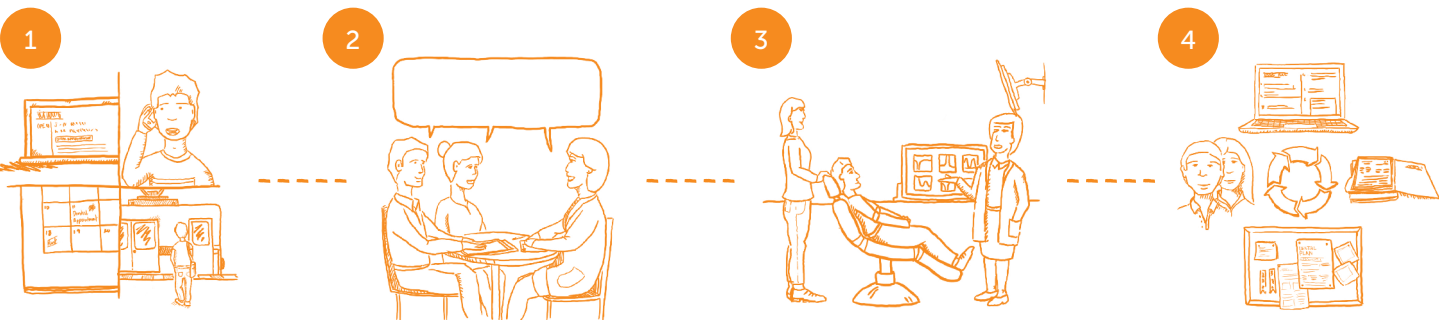


Fine motor conditions such as Parkinson’s or arthritis presenting physical challenges to oral care routines.

treatment pathway

Good oral health for people with intellectual disability can be achieved and sustained if communication, reporting and monitoring channels between the patient, the dental clinic and the patient’s home are developed and maintained. The following treatment pathway outlines the questions and suggestions dental practitioners can use during appointments to ensure the oral care plans they create with their patients are effective.

A video based on this pathway, Dentistry and Disability, can be found at inclusiondesignlab.org.au/dental.



1. Access to services: preparing for appointments, accessing dental clinics, transport

Does this person have a Medical Decision Maker or Advanced Care Directives? Does the patient have an *Oral Care Plan* or *Home Oral Care Plan* they can bring with them? Does this plan include specific instructions relating to treatment?

What is the inter-professional context around the person, including current protocols prescribed by their GP and therapists? Is the information relevant to oral/dental care? Plans developed by dietitians or speech pathologists, such as modified texture diets, and lists of current medications are particularly relevant. Can this information be accessed by the dental practitioner? Is consent required?

- Pre-planning is vital.
- If possible, consider booking more time to get to know the patient.
 - Extra time may also allow for a thorough assessment of the current Oral Care Plan – including diet and social history – and provide space to determine the barriers to good oral health care experienced by the patient.
 - Dental practitioners need to assess the patient’s ability to tolerate lengthy procedures. If the patient is not in pain and does not need an emergency procedure, a series of initial preventative appointments can familiarise the person with disability with the dental environment and the dental practitioner’s approach (ie need to build trust first). This may enhance the patient’s capacity to tolerate a lengthy procedure in the dental chair.
 - Good planning, familiarisation, and regular preventative appointments can also help minimise the reliance on chemical restraints (sedation and general anesthesia).
 - Preventative appointments and good home care can prevent diseases from manifesting themselves.

Are transport and scheduling arrangements required to get the patient to the dental clinic? Is the clinic accessible to the person, including the entrance, width of doorways, stairs, toilet facilities and the dental chair? Simply getting to the appointment can be a challenging experience for the patient. Is accessible parking required and available? Accessibility is a journey for every organisation, business and workplace. Examining accessibility legislation and developing an accessibility plan is a great way to get started.

2 In the clinic: interaction and roles of family members, carers and support professionals

What is the relationship of the accompanying person to the patient? Does the person support or live with the patient regularly? Has the dental clinic requested that a regular staff person or family member attend the appointment? How well do they know each other?

If unsure of the level of experience and practice of the support professionals accompanying the patient, it is appropriate for dental practitioners to ask for clarification.

Does the accompanying support person have access to the patient’s disability support plan, behaviour support plan or consistent approaches documents? Can you ask them to bring these documents with them? Will they be supporting the patient after the appointment?

3. Communication, behaviour and consent

Instead of viewing consent as a one-off verbal affirmation, consent should be viewed as a process that begins in planning before the appointment and is confirmed (a) during the introductory conversations between dental practitioner, patient and supporter(s), subject to the person’s communication style, (b) throughout the consultation, and (c) at the end of the consultation when planning future appointments. Consider sending forms to the patient’s home so that the supporter responsible can have a conversation about consent, the appointment, and details about the treatment with the patient before the appointment.

Communicate using the style that patient/carer has identified as their preferred style. For many this will be simple, plain language. Communicate directly with the patient, and provide opportunity for accompanying supporters to be involved in the discussion and for the patient to ask questions. **Do not speak down to people with intellectual disability or refer to their IQ or ‘mental age’.**

Spend a few minutes conversing in their communication style (and practising using communication equipment if relevant) before beginning clinical assessment/treatment. Invite feedback and guidance from the patient and accompanying support person.

If the procedure is lengthy consider taking breaks. Involve the patient and accompanying support person in making decisions about what can be done to keep the patient comfortable during the appointment.

Using a portable device or tablet, show videos or use pictures to explain any procedures that may cause concern to the patient, including information about the X-ray machine, fillings and complex procedures. The **Your Dental Health** video series and dual-read guide are ideal tools (inclusiondesignlab.org.au/dental).



4. Management of care at home

It is vital that the patient’s *Home Oral Care Plan* makes its way to the patient’s home and on to a support plan. This might be a Person Centred Plan, a Support Plan or a Personal Schedule. Ensure that the instructions can be communicated clearly to senior support professionals and/or can be added to the person’s disability support planning documentation. This may involve a slightly different process for each patient.

This step may be the difference between consistent and inconsistent oral health care for the person.

The dental practitioner should discuss the *Home Oral Care Plan* with the support professional, family member or carer, including plan updates.

Ensure further appointments are booked. This may involve more frequent appointments or booking multiple appointments in advance.

People with intellectual disability may be able to obtain funds through their NDIS plan to allow oral health professionals to come to their home, however this is on a case-by-case basis and is dependent on a range of factors such as level of support, diagnoses and outcomes. This should be discussed in detail with NDIA planners.

effective planning

The forms on the following pages have been developed to aid communication between (a) dental practitioners and general practitioners and (b) dental practitioners and the primary supporters of patients with intellectual disability.



Oral Health Assessment

The dental practitioner can use this form to outline dental issues, support needs, treatment, and follow up protocols for the patient. This form can be directly communicated to general practitioners and allied health professionals allowing for a shared understanding of the link between oral health and overall health in the patient’s life.



Home Oral Care Plan

Dental practitioners can use this form to outline the ideal home care for the patient. This form is best completed with the input of the patient and any supporters who accompany them to the appointment. The form provides clear, simple directions for supporters so that they can gather helpful information using observation between appointments.

oral health assessment

Patient Information

Name

Address

Date of Birth

Name(s) of person attending with patient

Family

Friend or advocate

Support Professional

Medical Practitioner

Formal disability diagnoses

Reason for consultation /current dental issues

Dental Assessment (completed by dental practitioner)

Notes from discussion with support professional or carer. Include a brief review of Home Oral Care Plan.

- CHECKS FOR DENTAL PRACTITIONERS:
- Develop rapport and familiarise the patient with the dental clinic/environment.
 - Obtain understanding of patient’s tolerance for dental examination.
 - Explain what will be completed today including sedation, medication and each step of the treatment.

Dental observations (including treatment completed)

Follow up treatment required

NOTE TO DENTAL PROFESSIONALS:

Write instructions clearly so the Medical Practitioner, the patient and carer clearly understand necessary treatment. Details clearly outlining procedures will ensure that appropriate transport, post assessment meals and direct support can be coordinated.

Notes for the Medical Practitioner

Administration

Date of appointment to complete above work

Date of next **preventative** treatment

☐

Patient and support professional have been reminded to bring Home Oral Care Plan to all appointments.

A copy of this form has been provided to:

☐

Medical Practitioner (as listed at the top of this form)

☐

Support Professional / patient. Please write name below.

To download a copy of this form visit inclusiondesignlab.org.au/dental

home oral care plan

Name

Name(s) of regular Support Professional(s)

Name of Dentist

Name of Medical Practitioner

The **Home Oral Care Plan** describes the specific routine required for this individual. It includes information to support and maintain optimal daily oral care.

Daily Oral Care Routine

☐

Brush teeth - Instructions:

☐

Toothpaste

☐

Interdental brush or Flossette - Type and size:

☐

Toothbrush - Type and size:

☐

Other

☐

Reminder to avoid:

Assistance and support for daily oral care routine

Which part of the oral care plan can the person do themselves?

What do support professionals need to assist with?

List the skills required by support professionals to support the patient’s daily oral care routine:

Assistance and support for daily oral care routine (continued)

Strategies for approaching specific issues, including behaviour, understanding, desensitisation and important preferences:

Which support professionals currently have the skills to provide daily oral care support? (to be nominated by a senior support professional, house supervisor, carer or family member)

For support professionals

Inform the dental practitioner if the following occur:

Category	Warning Signs	Tick
Daily oral care regime	Regularly refuses / not completed	<input type="checkbox"/>
Lips	Dry / Chapped	<input type="checkbox"/>
Gums	Red / Swollen / Bleeding	<input type="checkbox"/>
Saliva	Dry Mouth	<input type="checkbox"/>
Jaws	Clicking / Problems eating / Sore teeth	<input type="checkbox"/>
Dentures	Missing teeth / Broken / Loose	<input type="checkbox"/>
Oral appearance	Visible food particles / Tartar / Thick plaque / Yellowness	<input type="checkbox"/>

Where and how will information about the person’s oral health be recorded?

Designate frequency and record keeping tool here:

Updating this Plan

This Home Oral Care Plan should be viewed on a daily basis to ensure the routine is followed. The Plan should be taken to the Dentist and Medical Practitioner for review and update during assessment. To download a copy of this form, visit inclusiondesignlab.org.au/dental

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This guide is endorsed by the Australian Dental Association



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