



# CDA Dental Patient with Special Health Care Needs Transition Process



### **Executive Summary**

In dentistry, when a young person approaches or reaches age 18, they usually transfer from a pediatric dentist to a general dentist who will continue to provide them with oral health care as adults in a new dental home. This process is called transition.

Dental and health care teams currently manage this transition in a variety of ways. The Canadian Dental Association's (CDA) National Coordinating Working Group on Access to Care (Working Group)—in **collaboration\*** with community-based pediatric dentists, general dentists, and a parent—adapted an evidence-based, adolescent-to-adult transition process from a medical setting in the United States. It is based on best practices for persons with special health care needs (SHCN) and creates a consistent transition process for the Canadian oral health care environment. These adapted best practices can be used in any SHCN patient group for assisting in transitioning young people into the adult oral health care environment.

For patients and families/caregivers, a formalized transition process will help guide them through the transfer from pediatric to adult oral health care smoothly. For dentists and the dental team, following a step-bystep process will help ensure a more organized and consistent clinical protocol for facilitating transition preparation and patient transfer. Overall, this will result in a more seamless, patient-centered integration of young people into oral health care for adults, or when adults move from one dental environment to another. More importantly, it will improve <u>communication</u>\* between the oral health care provider, the patient and their <u>legally authorized representative(s)</u>\*, herein after called "families and caregivers," and it will enable establishing a better rapport.

The CDA Dental Patient with Special Health Care Needs Transition Process consists of three steps that are based on the Six Core Elements of Health Care Transition 2.0 by Got Transition (Figure 1), created by the Center for Health Care Transition Improvement and the National Alliance to Advance Adolescent Health. The three steps of the CDA Dental Patient with Special Health Care Needs Transition Process are:

Step 1: Transition Readiness Assessment

Step 2: Dental Summary and Care Plan

Step 3: Meet and Greet

Step 2 includes a form to be prepared by the transferring dentist that usually takes about 15-20 minutes to complete. This provides as much information as possible about a patient's broader life circumstances and past oral health care to support a successful transition.

Some patient medical conditions or terms may be unfamiliar. Helpful videos on a range of topics are linked throughout this document and are marked with an asterisk (\*). These videos and other useful links are also available on **www.cda-adc.ca/transition**. For quick reference, please bookmark this webpage and check back regularly for new resources.



#### Patients with Special Health Care Needs (SHCN)

Transitioning to adult oral health care may be challenging for some adolescents and their families/ caregivers, especially for individuals with special health care needs. Some patients may find it difficult or uncomfortable to be exposed to new environments, care providers, routines, or sensory experiences. The overall health care for patients with SHCN offen involves intensive and/or ongoing supervision and coordination between medical and dental care teams. A coordinated and planned approach can ease the transition process and reduce potential logistical and/or behavioural challenges. It encourages prioritizing patient goals and independence; it also enables the provider to view the patient as knowing themselves better than anyone else could.

#### The Power of Language

Language is a powerful tool that can reflect biased attitudes and beliefs. Some words can make a person feel uplifted or supported, while others can make a person feel disrespected or stigmatized.

There are varying opinions about the most appropriate way to describe individuals or groups who live with a disability or other differences. This tool has adopted person-centred language with the goal of providing advice and making information as broadly useable for oral health care providers as possible.

Person-centred language places emphasis on the individual as a whole human being first, not their disability, condition, or diagnosis. Using person-centred language helps to avoid the assumption that a person's disability or condition is a characteristic of their personal identity, therefore placing the patient's condition or disability as secondary to who the person is.

Some patients may prefer "identity-first" language, such as "autistic person" rather than "a person with a disability." These language preferences are based on the value an individual places on their disability as being a vital part of who they are, and the community or culture they identify with.

As a best practice, the dental team should always ask patients and their families/caregivers to confirm their language preferences. Making thoughtful language choices can enhance collaboration and help strengthen patient outcomes in terms of meeting their individual oral and overall health goals.

## Addressing Dentists' Top Training and Knowledge Needs when Caring for Patients with SHCN

One of the CDA's priorities is to advocate for accessible oral health care for all of Canada's populations, including patient groups who have SHCN. In 2018-19, CDA engaged in research to determine how to further improve communication efforts and access to quality oral health care for persons with SHCN. Nearly 1,500 dentists across Canada participated in focus groups, in-depth telephone interviews and an online survey. Dentists shared their views on where they felt they could use further training or support when caring for persons with SHCN. Developing the *CDA Dental Patient with Special Health Care Needs Transition Process* in part addresses dentists' top training and knowledge needs when providing oral health care to persons with SHCN.



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### **1. Getting Started**

### Goals of the CDA Dental Patient with Special Health Care Needs Transition Process

The CDA Dental Patient with Special Health Care Needs Transition Process package aims to:

- 1. Guide patients, families/caregivers and oral health care providers seamlessly through the transition process when an adolescent moves from pediatric to adult oral health care, or when an adult moves from one dental practice to another;
- 2. Improve a patient's abilities to better manage their own oral and overall health care;
- 3. Help individuals use oral health care services more effectively; and
- 4. Promote an organized clinical process in pediatric and adult practices to better facilitate:
  - transition preparation;
  - patient transfer;
  - a smooth integration into adult-centred care; and
  - improved communication between the provider and patient/family/caregiver.

#### Nine Essential Guiding Principles of the CDA Dental Patient with Special Health Care Needs Transition Process

Nine essential guiding principles can help to ensure the wellbeing, safety and quality of care for transitioning patients from pediatric to adult oral health care:

- 1. Adult-centred and recognition of strengths: Importance of the individual with special needs to be adult-centred and focused on their strengths.
- 2. Autonomy: Emphasis on self-determination, self-management, and family and/or caregiver engagement.
- 3. Awareness: Acknowledgement of individual differences and complexities.
- 4. Recognition: Recognizing vulnerabilities and the need for a distinct population health approach.
- 5. Continuity: Need for early and ongoing preparation, including the integration into an adult model of care.
- 6. Collaboration: Importance of shared accountability, effective communication, and care co-ordination between pediatric and adult clinicians and systems of care.
- 7. Culturally aware: Recognition of the influence of cultural beliefs and attitudes as well as socio-economic status.
- 8. Equity: Emphasis on achieving health equity and elimination of disparities.
- 9. Support system: Need for family and caregivers to support individuals in building knowledge regarding their own health care skills in making health related decisions.

# Best Practices: Using the CDA Dental Patient with Special Health Care Needs Transition Process Package

Dentists and dental teams are committed to improving transitions of care for their patients, but sometimes are unable to institute a formal program or process for a variety of reasons. Since no standardized process for oral health care transition exists in Canada, the CDA suggests an alternative approach by implementing three steps as part of *CDA Dental Patient with Special Health Care Needs Transition Process*, which will improve the care-transition process for patients, families/caregivers and the dental team through:

**Step 1:** completing a transition readiness assessment;

Step 2: creating a dental summary and care plan; and

Step 3: having a meet and greet with the patient.





### Additional Educational Resources: Videos and Links to Helpful Information

As an oral health care provider, you may feel unfamiliar with some patient conditions or terms that each step of the CDA Dental Patient with Special Health Care Needs Transition Process may highlight. Do not be worried. This is intentional and presents an opportunity to learn more about a patient's specific condition(s) and needs.

The CDA Dental Patient with Special Health Care Needs Transition Process webpage lists helpful videos and useful links to learn more. Be sure to bookmark this webpage for ease of reference: **www.cda-adc.ca/transition** 

### **Shared Accountability**

The CDA Dental Patient with Special Health Care Needs Transition Process is enhanced through shared accountability; the oral health care provider who is transitioning the patient and the practitioner who is receiving the patient are both accountable to the process. This ensures that oral health care providers manage the oversight of the patient's care during the transition process and that the receiving dental office can review the timely and adequate information provided from the sending dental office. As a best practice, each site can contact each other for follow-up questions to ensure that the patient receives the best care provision possible.

Practice/ Provider	<b>#1</b> Transition policy	<b>#2</b> Tracking and Monitoring	<b>#3</b> Transition readiness/ Orientation to adult practice	<b>#4</b> Transition planning/ Integration	<b>#5</b> Transfer of care/ Initial visit	<b>#6</b> Transition Completion/ Ongoing
Pediatric	Create and discuss with youth/family	Track progress of youth/family readiness for transition	Transition readiness assessment	Develop transition plan including needed readiness assessment skills	Transfer of care with information and communication	Obtain feedback on the transition process
Adult	Create and discuss with young adult (YA)/guardian, if needed	Track progress to increase YA's knowledge of health and adult health care system	Share/discuss Welcome and FAQs Letter with Young adult/guardian, if needed	Update transition plan with additional skills required	Self-care assessment	Ongoing care with self-care skill-building

Figure 1: Got Transition's Six Core Elements of Health Care Transition 2.0., created by the Center for Health Care Transition Improvement and the National Alliance to Advance Adolescent Health. The CDA Dental Patient with Special Health Care Needs Transition Process includes steps three to six, highlighted in green, which are aimed at strengthening the care-transition process for patients, families/caregivers and the dental team. This chart reflects the U.S. legal system and terminology; however, the CDA Dental Patient with Special Health Care Needs Transition Process document reflects the language of Canadian health care consent laws (i.e., instead of guardian(s), this tool uses family/caregivers, or legally authorized representatives).





### 2. The CDA Dental Patient with Special Health Care Needs Transition Process

#### Step 1: Transition Readiness Assessment

#### **Explanation:**

Assessing an adolescent's transition readiness and self-care skills is the first step in the CDA Dental Patient with Special Health Care Needs Transition Process. Using a standardized transition assessment tool is helpful in engaging adolescents and their families and caregivers in setting oral health priorities and goals, addressing self-care needs to prepare them for an adult approach to care in transition, and navigating the adult oral health care system.

Conducting a transition readiness assessment with patients and their families and caregivers will help identify any particular needs and goals in self-care. As such, it can begin to prepare the patient and their families and caregivers for what the near future may hold so that the transition process is not a surprise. Difficulties such as lack of communication, coordination, and challenges in locating clinicians with specialized knowledge can begin to be addressed with information captured in this tool. Oral health care providers can use the results to jointly develop a plan of care and setting goals. The transition readiness assessment process can begin as early as age 12 and continue throughout adolescence, young or late adulthood, as required.

A Take Home Letter template is available and can be modified by the oral health care provider, as needed. The letter can be given to the patient's families and caregivers who may be overwhelmed with information or who may require more time to think through the information or issues that should be noted on the Transition Readiness Assessment tool. Providing the families and caregivers with the option to be heard following the appointment can help develop a relationship of trust.





### **Transition Readiness Assessment Tool**

Please complete both pages of this document. If you are not able to, your family/caregiver can fill in the information on your behalf. This information will help us to assess your readiness to transition from a pediatric care office/facility (for children under age 18) to an adult oral heath care dental office/facility (for persons age 18 and over). For persons age 18 and older, this information will help us assess your readiness to transition to another dental office.

Patient name:
Date of birth (DD/MM/YY):
Completed by:
Relationship to patient (if applicable)
Date completed (DD/MM/YY):

Leg	al Choices for Making Oral Health Care Decisions	Personal Care					
	Patient can make own health care choices		Patient independently cares for all oral health needs				
	Patient needs some help with making health care choices		Patient requires some assistance				
	Patient has a person authorized to provide legal consent		Patient requires total help with oral care				
	name:						

	Transition / Self-Care Importance and Confidence On a scale of 0 to 10, please check the number that best describes how you feel right now																				
How	ı important is	it for t	the pa	tient t	o take	care	of thei	r own	oral h	ealth	care a	and cl	nange	to an	adult	dentis	t <b>?</b>				
	0 (not)		1		2		3		4		5		6		7		8		9		10 (very)
How	v confident do	bes the	e patie	nt fee	l abou	t thei	r abilit	y to to	ake cai	re of t	heir o	wn or	al heal	th an	d char	nge to	an ad	ult de	ntist?	· · ·	
	0 (not)		1		2		3		4		5		6		7		8		9		10 (very)
How	How confident does family/caregiver feel this individual has the cognitive and physical ability to care for their own oral health?																				
	0 (not)		1		2		3		4		5		6		7		8		9		10 (very)
				· · · ·				^			<u> </u>										

<b>Oral Health Awareness</b> Please check the box that applies to you right now	Yes, I know this	l need to learn this	Someone needs to do this List who?
Knows oral health needs			□
Can express oral health needs or concerns			□
Understands importance of regular dental care			





Patient Tolerance of Dental Environment Please check the box that applies to you right now	YES	NO
Exhibits anxiousness in the chair, lights, noises, smells		
Resists close personal contact		
Resists reclining in dental chair		
Allows dentist/hygienist to examine mouth		
Requires protective support (safe holding)		
Requires sedation (nitrous oxide, oral sedation, general anesthesia)		

Comments:

1. List anything that might cause issues/problems during this transition.

2. What actions, if any, would be helpful in making this transition smooth and successful?

3. What is the name of the dentist who you would like to transition to:

Dentist name:	 
Office phone number:	 
If you don't have a preference, would you like us to suggest a dentist?	

Summary of discussion and plan If you are unsure of what to write in this section, you will be given a letter to take home that will help you think through some topics or potential issues to note.

Primary care provider signature

Print name





### Take Home Letter (Sample for patients who are children and adolescents)

**Note:** This letter should be personalized and sent home with the patient's family/caregiver, along with the Transition Readiness Assessment Tool to be completed. If the patient or the family/caregiver completed the Transition Readiness Assessment Tool in office, then a Take Home Letter is not required.

Dear	(family/caregiver),
Preparing to transition from a pediatric dental office to a general c significant milestone. This milestone should be celebrated; a youn and exciting.	
We are thrilled that	(Patient Name)
is reaching this milestone, and we believe that investing time of success.	
We understand that a change in routine can be challenging for especially for those who require specific supports. These chang This is why it's so important to involve everyone in the transition patient, you as the family/caregiver, as well as the new dental	ges can also be hard on families/caregivers. planning process early on, including the
Enclosed is the Transition Readiness Assessment Tool to be complete information related to legal choices, personal care, confidence for etc. The information provided will help ensure the successful transi	or self-care, tolerance in a dental environment, tions planning of
from Dr.	(Patient Name)
Please view completing the form as an opportunity to identify down any questions you may have, and please return the com convenience.	• • • •
Rest assured that we will do everything possible to make the tra are here to help and address any questions you or	
Sincerely,	
	(Pediatric Dentist Name)
	(Dental office contact info)





### Take Home Letter (Sample for adult patients)

**Note:** This letter should be personalized and sent home with the patient's family/caregiver, along with the Transition Readiness Assessment Tool to be completed. If the patient or the family/caregiver completed the Transition Readiness Assessment Tool in office, then a Take Home Letter is not required.

Dear	·	(family/caregive	<b>r)</b> ,

Preparing to transition from our dental office to another can be challenging for some patients, especially for those who require specific supports. These changes can also be hard on families/caregivers. This is why it's so important to involve everyone in the transition planning process early on, including you as the family/ caregiver, as well as the new dental team.

Enclosed is the Transition Readiness Assessment Tool to be completed. The document captures key patient information related to legal choices, personal care, confidence for self-care, tolerance in a dental environment, etc. The information provided will help ensure the successful transitions planning of

from Dr. \_\_\_\_\_\_ (Dr.'s name) to a general dental practice.

Please view completing the form as an opportunity to identify any potential challenges that may arise. Write down any questions you may have, and please return the completed form to our office at your soonest convenience.

Rest assured that we will do everything possible to make the transition process a positive experience. We are here to help and address any questions you or \_\_\_\_\_\_(Patient Name) may have.

Sincerely,

(Pediatric Dentist Name)

(Dental office contact info)





#### Step 2: Dental Summary and Care Plan

#### Explanation

Based on the information provided by the patient/family/caregiver on the Transition Readiness Assessment Tool, and once it has been determined that transition will take place, this form should be completed by the patient's existing dental practitioner and should be forwarded for review by the new dentist as a basis for ongoing care.

In some cases, a patient's pediatric dentist may also become their general dentist in adulthood. However, this is not always the case, since many patients transition from one dental office to another, relocate from one community to another community, or move from a hospital environment to a community-based environment, etc.

Difficulty may arise in finding a suitable dentist to which a patient can transition. This form is intended to provide information related to:

- any personal and environmental factors that impede or aid oral health care;
- any specific dental interventions that have worked or not worked; and
- a brief history of oral care provided.

**Note:** Normal medical and drug data is not included in the form since this information needs to be collected and updated as per normal process by any new provider.

This form is 5 pages and may take 15-20 minutes to complete. Providing as much information as possible about a patient's broader life circumstances and past oral health care helps ensure a successful transition. A fee may be charged to complete this form, however, no specific code is currently available.

A glossary of terms is available at the end of this document that provides definitions of specific terms, conditions, etc. An asterisk indicates that a short video is available on the *CDA Dental Patient with Special Health Care Needs Transition Process* webpage (www.cda-adc.ca/transition) that will explain an aspect/term in further detail. For quick reference, please bookmark www.cda-adc.ca/transition and check back regularly for new links, videos and other helpful resources that will be added over time.

Anxiety experienced by the patient/family/caregiver may result in lack of dental care and lack of long-term access to oral health care. Increased familiarity with the new terms, as well as the practitioner's ability to **listen\*** and provide individualized care, will help develop a trusting relationship with the patient and their family/caregiver. A strong relationship helps decrease anxiety among those involved.





### **Dental Summary and Care Plan**

All pages of this form should be completed by the patient's current dental practitioner and be forwarded to the next dental practitioner. Instances where an asterisk (\*) appears indicates that a short video is available on the *CDA Dental Patient with Special Health Care Needs Transition Process* webpage (**www.cda-adc.ca/transition**) to learn more. For quick reference, please bookmark this webpage and check back regularly for newly added links, videos and other helpful resources.

Form completed by:					
Date completed (DD/MM/YY):					
Patient contact info					
Name:	D.O.B. (DD/MM/YY):				
Address:	City:				
	Postal Code:				
Cell phone:	Preferred method of contact:				
Home phone:	Cell phone Home phone				
Email:	□ Email				
Legally authorized representative contact info					
Name:	Relationship to patient:				
Address:	City:				
	Postal Code:				
Cell phone:	Preferred method of contact:				
Home phone:	Cell phone Home phone				
Email:	□ Email				
Family/caregiver contact info (if different from above)					

Family/caregiver contact into (it different from above)	
Name:	Relationship to patient:
Address:	City:
	Postal Code:
Cell phone:	Preferred method of contact:
Home phone:	Cell phone Home phone
Email:	□ Email

Person responsible for arranging patient appointments (if different from above)		
Name:	Relationship to patient:	
Address:	City: Postal Code:	
Cell phone:	Preferred method of contact:	
Home phone:	Cell phone Home phone	
Email:	□Email	



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Dental insurance plan	
Private insurance:	Government insurance:

Known allergies and procedures to avoid	
Known allergies:	Reactions:
Medications to avoid:	
Procedures to avoid (explain):	

Developmental disability		🗆 Verbal 🔲 Non-verbal	
Nervous System:	Co-occurring Psychological Issues:	Other:	
Autism spectrum disorder*         Cerebral palsy*         Down syndrome*         Fetal Alcohol Syndrome         Fragile X         Intellectual disability         Rett syndrome         Spina bifida         Tourette syndrome         Other (Specify):	<ul> <li>Depression</li> <li>Aggression</li> <li>Anxiety</li> <li>Relational</li> <li>Self-injurious behaviour</li> <li>Other (Specify):</li> </ul>	ADHD Hearing impairment Cochlear implant Visual impairment <u>Seizures*</u> Cardiac condition Obesity Obstructive Sleep Apnea Other (Specify):	
Degenerative:	Metabolism:	Sensory System*:	
Muscular dystrophy Other (Specify):	Congenital hypothyroidism Phenylketonuria Other (Specify):	Avoidant       Seeking       Impaired         Visual	





Diagnoses and current issues	Details and recommendations
Primary diagnosis	
Secondary diagnosis	
🗆 Behavioural	
Feeding and swallowing	
Hearing/vision	
Learning	
Orthopedic/musculoskeletal	
Physical anomalies	
Respiratory	
□ Sensory	
Stamina/fatigue	

Adaptive functioning domains*
Communication:
Social:
Self-direction:
Community activities:
Work:
Home living:
Leisure:
Sleep issues:
Nutritional issues:
Quality-of-life issues:
Safety issues:

Dental history		
Initial consult date:	Recommended recall frequency:	
Most recent recall date:	Recent radiograph date:	
Treatment provided:	Treatment needed:	
Comments:		
Oro-motor function*: Explain:		





Home <u>Oral Hygiene*</u> History:          Independent         Needs assistance         Totally dependant	Adjunctive Aids Recommended: Medicaments: Oral health aids:	
Behaviour Treatment History:  Independent Caregiver presence	Details:	
Behavioural triggers:		
Protective support (safe holding)*		
Pre-sedation:	Drug used:	
In-Office sedation:	Drug used:	
General anesthesia:	Hospital setting:	
	In-office setting:	
Quiet room:		
Quiet days:		
Patient-guided sensory integration*:		
Music therapy* / Support animals:		
Other:		

Equipment, appliances, assistive technology			
Gastrostomy	Adaptive seating	Communication device	
Tracheostomy		□ Nebulizer	
	Crutches	Apnea monitor	$\Box$ 0 <sub>2</sub> monitor
🗆 Wheelchair	🗆 Walker	Cardiac monitor	Glucose monitor
Other (specify):			





Please add any special information about strengths that the patient/family/caregiver wants their new health care team to know. See glossary of terms for further explanations	
Disconserved other helpful information that the new evel health are term should be guard of $(i, j)$ traumatic injurice)	

Please provide other helpful information that the new oral health care team should be aware of (i.e., traumatic injuries). See glossary of terms for Traumatic Injuries.

What else should our dental office be aware of to help make dental visits as comfortable as possible for everyone involved? Please describe:

Next suggested evaluation date:

Patient/legally authorized representative/ family/caregiver signature Print name

Primary care provider signature

Print name



Date

Date



#### Step 3: Meet and Greet

#### Explanation

Tips:

- 1. The success of this process is dependent on the referring dentist to complete the Dental Summary and Care Plan form (in Step 2) and the receiving dentist to invest the time to read the information and engage the patient/ family/caregiver in developing a new care plan.
- 2. It is a good idea for both oral health care providers to set up a feedback process to ensure ongoing improvements throughout the patient's transition process and overall care journey.

As the patient's new practitioner, this portion of the transition process can be carried out in a way to best suit your practice. The meet and greet appointment can occur virtually or face-to-face. If patients must travel far for a dental appointment, a virtual meeting may be more comfortable and/or offer other benefits.

Use this appointment for the following:

- Z Review the oral health history forms (Dental Summary and Care Plan) provided by the former dental office.
- $\blacksquare$  Ask the patient/family/caregiver about the most important aspects for ongoing care and communication.
- Generally, assess the need for individual treatment. However, additional appointments may be required to establish a long-term relationship.
- Evaluate the patient's tolerance for an appointment. For example, some individuals with special health care needs may have experienced some form of trauma which may/may not trigger certain behaviours. It is important to be aware of former traumatic injuries which may impact the provision of oral health care. See Traumatic Injuries in the Glossary of Terms for more information.
- ☑ Openly discuss the cost of available care options with the patient/family/caregiver. Often, government-funded programs do not cover certain costs of care delivery. This will help them in decision-making processes.

Consider sending a meet and greet letter to the patient/family/caregiver after the first meeting has taken place. Please see a sample, Meet and Greet Letter, on the next page. It is recommended that the letter be short and written at a grade 6 reading level.





### Meet and Greet Letter (New Patient Post-Meeting)

Dear \_\_\_\_\_ (name of new patient/family/caregiver)

Thank you for meeting with me today to discuss becoming a new patient at \_\_\_\_\_\_ (name of clinic).

We understand that change can be uncomfortable sometimes. We will do everything we can to make this dental care change as smooth and successful as possible.

Regular dental care is very important for a healthy mouth and body. We want your dental visits to our office to be comfortable. Any information you share will help us to ensure a positive transition experience. We will learn more as we get to know you better.

Please contact our office if you have any questions that were not answered today, or if you have more information that would be helpful for us. We can arrange to talk on the phone or perhaps meet again.

My receptionist's name is

We look forward to seeing you again soon.

Sincerely,

Dr.





## Conclusion

Regular dental care is important to maintain a healthy mouth and body. Changing oral health care providers can sometimes be uncomfortable and challenging for patients with special health care needs (SHCN), their family/caregivers, and for the dental teams.

There are many factors that go into making the transition from one dental practice to another as effective and successful as possible. The Canadian Dental Association (CDA) hopes that this transition tool will help ease the transitioning process for patients during a critical time in their lives.

Patients and their families/caregivers will benefit from a more formalized transition process by being guided through the process; being more aware of what to expect; and knowing what type of information to share with the new oral health care provider. For the oral health care teams on both the departure and receiving ends of patient care, following this step-by-step transitioning process will enable an organized, coordinated and consistent clinical protocol for facilitating transition preparation and patient transfer.

The best practices outlined in this tool can be used for and adapted to any SHCN patient group for assisting in transitioning both young people into the adult oral health care environment, and adults who are moving from one dental environment to another. The end goal is to provide a seamless, patient-centred integration which encourages the move to individual autonomy within the new oral health care facility.





### **Glossary of Terms**

Adaptive Functioning Domain (AFD): Adaptive functioning refers to how well a person handles common demands in life and how independent they are compared to others of the same age and background. The domains of adaptive functioning—most often including practical skills, conceptual skills, and social skills—help contextualize how personal and environmental circumstances impact an individual. For example, living in a shared space where co-habitants may either disturb or enhance their experience. See International Classification of Functioning (ICF) below for further explanation.

**Attention Deficit Hyperactivity Disorder (ADHD):** A condition where a person has trouble paying attention or focusing on tasks. Examples may include tendencies to act without thinking or having trouble sitting still. It may begin in early childhood and can continue into adulthood.

Adult Services: Inclusive of medical, nursing, allied health, educational, living, financial and complementary services after an individual leaves pediatric services, typically between 17 to 19 years of age.

**Caregiver:** A person who is typically over age 18 and provides care and support for another with a physical and/ or mental impairment. A caregiver is responsible for the direct care, protection and supervision of an individual for some or all of the basic necessities of life (i.e., acts of daily living), such as, but not limited to, providing personal cleansing and dressing, preparing meals, transportation, running errands, managing appointments, etc. See also Legally Authorized Representative for more information.

**Children and Youth with Medical Complexity:** Children with a unique combination of substantial family-identified service needs, characteristic chronic and severe conditions, functional limitations, and extraordinarily high health care use.

**Clinical Protocol:** A specific, formalized process that a clinic can use to introduce and welcome persons with SHCN to the clinical setting. This may include seeing a patient at a certain time of day, providing the patient/ caregiver with pre-appointment letter that details best practices for coming to the clinic, specialized waiting rooms, etc.

**Developmentally appropriate:** Ensuring teaching practices are appropriate to age and developmental status, attuned to patients as unique individuals, and responsive to the social and cultural contexts in which they live.

**Family:** Those individuals who provide care, legal authority or whom the young person deems important and vital in supporting their health. See also **Legally Authorized Representative** for more information.

International Classification of Functioning (ICF): <u>The World Health Organization International Classification of</u> <u>Functioning (WHO ICF)\*</u> is a biopsychosocial model that examines the interplay of medical conditions with the environment and personal factors to paint a picture of the overall disability and functioning of an individual. When considering patients' barriers to oral health, it is important to examine how diagnoses and environmental factors interact to impact functioning. Figure 2 below provides an example of an individual living with autism.





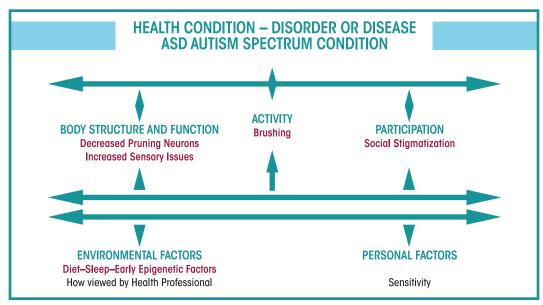


Figure 2: Based on the WHO ICF, this figure depicts the interplay of a medical condition with the environment and personal factors. This example provides a snapshot of the overall disability and functioning of a person living with autism.

Legally Authorized Representative: A person with the legal authority (and the corresponding duty) to care for the personal interests of an individual. Typically, legislation governing health care consent empowers family members, beginning with parents, followed by siblings to extended family, and finally to legally appointed substitute decision-makers. For more information, see also *Tip Sheet: Recommendations for Minimizing Legal Risk and Best Practices for Dentists Treating Patients with a Disability*. Note: In Canada, legislation dealing with providing consent to treatment varies from province to province. Language around the provision of legal consent used throughout the *CDA Dental Patient with Special Health Care Needs Transition Process* aims to make information as broadly useable for Canadian oral health care providers as possible. This document does not replace professional legal advice. As a best practice, dentists who have concerns regarding the provision of legal consent to treatment in an individual's specific case, or in their practice generally, may wish to consult a lawyer for advice in their provincial or territorial jurisdiction.

**Music/Equine Therapy:** Specific therapies that can aid a person with SHCN to adjust to and become desensitized to the clinical environment. Music therapy can be used prior to or during an appointment. In certain circumstances, music therapy may aid in daily oral health procedures. Equine (or horse) therapy can also be used primarily to help desensitize sensory disorders prior to medical appointments. <u>View this music therapy \* video</u>.

**Medical Procedures to be Avoided:** If a patient has procedures that are known to be difficult for them, the procedures should be avoided, if possible. For example, with a patient who has had poor experiences with injections, injections should be avoided. Each patient is unique. As such, their circumstances and personal preferences are also unique.





**Medications to be Avoided:** If a patient has a known difficulty with a medication (though not an allergy), the medication should be avoided if possible. For example, some people have negative, or paradoxical, responses to sedation.

**Obstructive Sleep Apnea (OSA):** This is a type of sleep apnea that is characterized by repeated episodes of complete or partial obstructions of the upper airway during sleep, despite the person's effort to breathe. It is usually associated with a reduction in blood oxygen saturation.

**Oral Health Summary:** A comprehensive letter written at the time of an individual's transfer from pediatric to adult services, which includes pertinent dental, emotional, and social content.

**Oro-motor function:** Refers to the movement of the muscles of the face, such as the mouth, jaw, tongue, and lips. This can also include muscle tone, muscle strength, range of motion, speed, coordination, dissociation, and the ability to move oral structures, such as the tongue and lip, independently of each other. For example, persons with Down Syndrome often do not masticate fully and swallow large boluses of food instead of chewing first.

**Patient Guided Sensory Integration (PGSI):** This refers to a specific course of action that individualizes therapy and intervention for people with autism spectrum disorder (ASD). This requires information regarding the sensory needs of a person, followed by creating an intervention to help decrease trigger zones, which may allow integrating oral therapies without the triggering affect of the therapy. <u>View this PGSI\* video</u>.

**Quality of Life (QOL):** Defined by the World Health Organization as "an individual's perception of their position in life in the context of the culture and value systems within their society." See the ICF classification where environmental and personal domains are as essential as structural or functional deficiencies.

**Quiet Room:** A specialized room or space where environmental stimulators, such as noise, light, touch and smells are minimized for the person with SHCN.

**Quiet Days:** Days an office may be open where stimulators, such as noisy children, are limited. Quiet days render the dental office a quiet room.

**Papoose:** A medically designed protective support device for safe holding. For more details about protective support devices, see below.

**Protective Support (safe holding):** The level of support required in order to help stabilize or keep a patient safe. Some examples include: 1) a family member/caregiver holding a patient's hands and/or feet; 2) helping an individual ground by pushing their feet onto the floor or wheelchair base (often used with patients with cerebral palsy who have uncontrollable movements); and 3) using a papoose, weighted blankets, cushions or vacupacs to support a neck or particular part of the patient's body.

**Readiness:** A rating of the level of capacity that a young person (with or without the help of others) has to engage in behaviour and/or activities required by the adult health care system.

**Safety Issues**: When safety issues arise with a patient, there is an opportunity to stop and re-examine the situation. Non-compliance may be a patient's way of communicating.





**Self-management:** Relating to the tasks that an individual must undertake to live well with one or more chronic conditions. These tasks include gaining confidence to deal with medical management, role management, and emotional management.

**Sensory Processing Disorder\***: An impairment in sensory detection, modulation and/or interpretation, which can lead to misinterpretation of everyday information such as touch, sound and movement. In turn, this can lead to behavioural issues, coordination problems or other complications.

**Sensory System:** Persons with SHCN often have sensory disorders where sensations can be perceived in a heightened or a decreased manner. For example, persons with SHCN may avoid light touch but seek firm body contact, or visa versa.

**Avoidant:** This involves a sensory function where a specific type of sensation is avoided by the person with SHCN. Slight input, such as touch, smell or taste, can cause the patient to experience an extreme reaction. A person with SHCN may not want to make eye contact, avoid being touched, or prefer to be touched in a specific way exclusively.

**Seeking:** This involves a sensory function where a specific type of sensation, often requiring a stronger sensory input, is sought by the person with SHCN. Examples include the patient seeking a weighted blanket, a firm touch, intense tastes like salt or chili peppers. When providing treatment to a person with this type of function, it is often wise to provide the sensation they are seeking before initiating any kind of care. This can involve intensely or deeply massage the patient's hands, neck or head before looking intra-orally.

**Impaired:** This is a type of sensory function where a person with SHCN is neither seeking or avoiding a any particular sense.

Gustatory: This refers to the sense associated with eating or taste.

Olfactory: Sense of smell.

Proprioceptive: Sense of self-movement and body position. It is important for persons in wheelchairs.

Tactile: Sense of touch.

**Vestibular:** This refers to and includes the parts of the inner ear and brain that process the sensory information involved with controlling balance and eye movements.

**Strengths:** Often family/caregivers and practitioners emphasize problems and concerns. This is a section that is meant for the family/caregiver to think about the strengths of the individual. Knowing strengths will also help clinicians customize treatment for each patient. Examples of strengths: loves and responds well to music or singing, are strong willed, responds well to social reinforcement (with explanation), responds well to contingent distraction, such as counting, movies, etc.

**SHCN:** Special health care needs.





**Transfer:** A one-time event that occurs when a young person is transferred out of the child health system and into the adult care system.

**Transition:** A purposeful, planned movement of young people with chronic medical conditions from childcentered to adult-oriented health care that is supported by individualized planning in the pediatric and community settings, a coordinated transfer of care and secure attachment to adult services.

**Traumatic Injuries:** These can include physical damages to the mouth, gums or teeth caused by a fall, accident or blow to the face. Traumatic oral injuries may cause broken, cracked, split teeth or dislodged teeth, or an injury to the root of the tooth. It is important to be aware of/communicate any type of traumatic injuries to the dentist/dental team. Note that traumatic injuries are different from trauma-informed care. Learn more about the meaning of **trauma-informed care in dentistry**.

**Vacupac:** A specialized bean bag or cushion that is used for protective support. It allows air to be withdrawn, providing added support for the person with SHCN. A vacupac is often used in orthopedic surgery to help keep an area of the body in a constant stable position. It is useful when treating persons in a wheelchair. For example, the vacupac can be placed behind the patient's head and neck to support structures, decreasing the need to transfer the patient into the dental chair. See **figures 3-5** below.



Figure 3: A type of vacupac in the dental chair.



Figure 4: Demonstration of a vacupac providing support for the patient in the dental chair.



Figure 5: Various sized cushions are being used to better support the patient's neck, arms and legs.

Youth: A person between 12 to 25 years of age.

Youth with Special Health Care Needs (YSHCN): A youth requiring specialized health care and services for physical, developmental and/or mental health conditions.





### References

**1.** American Academy of Pediatric Dentistry. Policy on transitioning from a pediatric-centered to an adult-centered dental home for individuals with special health care needs. The Reference Manual of Pediatric Dentistry. Chicago, III.: American Academy of Pediatric Dentistry; 2020:152-5.

2. Bayarsaikhan Z, Cruz S, Neff J, Chi DL. Transitioning from pediatric to adult dental care for adolescents with special health care needs: dentist perspectives-part two. *Pediatr Dent.* 2015;37(5):447-451.

3. Casamassimo PS, Seale NS, Ruehs K. General dentists' perceptions of educational and treatment issues affecting access to care for children with special health care needs. J Dent Educ. 2004;68(1):23-28.

4. Castillo C, Kitsos E. Transitions from Pediatric to Adult Care. Glob Pediatr Health. 2017;4:1-2. doi:10.1177/2333794X17744946

**5.** Chavis S, Canares G. The transition of patients with special health care needs from pediatric to adult-based dental care: a scoping review. *Pediatr Dent.* 2020;42(2):101-109.

**6.** Chi DL. Medical care transition planning and dental care use for youth with special health care needs during the transition from adolescence to young adulthood: a preliminary explanatory model. *Matern Child Health J.* 2014;18(4):778-788.

7. Commission on Dental Accreditation, American Dental Association. Accreditation Standards for Advanced Dental Education Programs in Pediatric Dentistry. Revised 2019. https://coda.ada.org/en/current-accreditation-standards/revised-accreditation-standards (Accessed May 30, 2021)

8. Commission on Dental Accreditation, American Dental Association. Accreditation Standards for Dental Education Programs. Revised 2020. https://coda.ada.org/en/current-accreditation-standards/revised-accreditation-standards (Accessed May 30, 2021)

9. Cruz S, Neff J, Chi DL. Transitioning from pediatric to adult dental care for adolescents with special health care needs: adolescent and parent perspectives-part one. *Pediatr Dent.* 2015;37(5):442-446.

**10.** Davidson LF, Doyle M, Silver EJ. Discussing Future Goals and Legal Aspects of Health Care: Essential Steps in Transitioning Youth to Adult-Oriented Care. *Clin Pediatr (Phila)*. 2017;56(10):902-908.

11. Espinoza K. Healthcare Transitions and Dental Care. In Health Care Transition 2018 (pp. 339-349). Springer, Cham.

**12.** Geenen SJ, Powers LE, Sells W. Understanding the role of health care providers during the transition of adolescents with disabilities and special health care needs. *J Adolesc Health*. 2003;32(3):225-233.

**13.** GL Borromeo, G Bramante, D Betar, C Bhikha, YY Cai, C Cajili; Transitioning of special needs paediatric patients to adult special needs dental services ; Australian Dental Journal 2014; 59: 360-365

14. IPSOS Research. The Canadian Dental Association Patient Understanding Study. March 2019. PowerPoint Presentation.

**15.** Kumar, R. & Chattu, V. K. (2018). What is in the name? Understanding terminologies of patient-centered, person-centered, and patient-directed care! Journal of Family Medicine and Primary Care, 7(3), 487-488. https://journals.lww.com/jfmpc/pages/default.aspx

**16.** Lotstein DS, Ghandour R, Cash A, McGuire E, Strickland B, Newacheck P. Planning for health care transitions: Results from the 2005-2006 national survey of children with special health care needs. Pediatrics 2009;123(1): e145-e152.

**17.** McManus MA, Pollack LR, Cooley WC, et al. Current status of transition preparation among youth with special needs in the United States. Pediatrics. 2013;131(6):1090-1097.

18. McTigue DJ, Fenton SJ. Educational issues workshop report. Pediatr Dent. 2007;29(2):146-147.

**19.** Nowak AJ, Casamassimo PS, Slayton RL. Facilitating the transition of patients with special health care needs from pediatric to adult oral health care. *J Am Dent Assoc.* 2010;141(11):1351-1356.

20. Nowak AJ. Patients with special health care needs in pediatric dental practices. Pediatr Dent. 2002;24(3):227-228.

**21.** Petrova EG, Hyman M, Estrella MR, Inglehart Mr; Children with Special Health Care Needs: Exploring Relationships between Patient's Level of Functioning, Their Oral Health, and Caregiver's Oral Health-Related Responses. *Pediatric Dent.* 2013;36(3) 233-239





22. Resources for Integrated Care. (2014). Integrating Behavioral Health Competency within Disability-Competent Teams [PowerPoint Slides]. Retrieved from https://resourcesforintegratedcare.com/sites/default/files/Presentation%20-%20Integrating%20BH%20 Comtetency%20within%20DCC%20Teams%20-%20Disability-Competent%20Care.pdf

23. Resources for Integrated Care. (2020). Using Person-Centered Language. Tip Sheet. Retrieved from https://www.resourcesforintegratedcare.com/

**24.** Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM; Society for Adolescent Medicine. Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. *J Adolesc Health*. 2003;33(4):309-311.

**25.** Scal P, Ireland M. Addressing transition to adult health care for adolescents with special health care needs. *Pediatrics.* 2005;115(6):1607-1612.

**26.** The University of Kansas Research and Training Center on Independent Living. (2013). Guidelines: How to Write and Report About People with Disabilities (8th Edition). Retrieved from http://rtcil.org/products/media/guidelines

**27.** Tyler Jr CV, McDermott M. Transitioning patients with developmental disabilities to adult care. THE JOURNAL OF FAMILY PRACTICE. 2021 Jul;70(6).

**28.** Waldman HB, Perlman SP, Rader R. The transition of children with disabilities to adulthood: What about dental care? J Am Dent Assoc 2010;141(8):937-8.

29. What Are You Willing to Change to Promote Your Patients 'Oral Health?. Ontario Dentist. June 2013. Volume 90: 20-23.

**30.** White PH, Cooley WC, Transitions Clinical Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics.* 2018;142(5); e20182587.

**31.** Williams A, Lewis DA. Models of transition of care for adolescents who require special care dentistry. J Disab Oral Health 2015;16(4):125-46.

