



Ontario Paediatric Diabetes Network

Transition to Adult Care Working Group Recommendations Report



February 2016

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Executive Summary

For youth living with diabetes, the transition from paediatric to adult healthcare services is an integral component of their transition to adulthood. Over the past decade, the need for an improved approach to this transition of care has become increasingly evident. Healthcare providers, patients and their families have reported that the issues they encounter during this period of transition are often not addressed in a timely or organized manner, and can have a significant impact on the provision and continuity of care. These issues include a lack of system integration and coordination of care and insufficient preparation for transition. Research has also shown that adolescents and young adults with diabetes transitioning to adult healthcare services are at a higher risk of developing diabetes-related complications and loss to follow-up care (Spaic, et al., 2013). The breadth and prevalence of these issues are further echoed in the published literature and in the Ontario Paediatric Diabetes Network's 2013 Current State Report.

The goals of effective transitions are to ensure high-quality, developmentally appropriate, psychologically sound healthcare that is continuous, comprehensive, patient-centered and coordinated, before and throughout a youth's transition from pediatric care to the adult healthcare system (Cooley & Sagerman, 2011; Adolescent Health Committee of the Canadian Paediatric Society, 2006). For optimal diabetes management, the transition from paediatric to adult diabetes care should therefore be a continuous and coordinated process that begins well before the actual transfer of patient care responsibilities and continues after the transfer has occurred. The transition process should focus on the patients and their families by providing them with the support and information they require to prepare for the transition. This includes enabling the attainment of diabetes knowledge and self-management skills, which is a process that takes time and involves children/youth, their families/caregivers and their healthcare providers. Youth with diabetes, their families, paediatric diabetes care providers, primary care providers and adult healthcare providers all have important roles to play in the shared responsibility of patient care prior to, during and following the transfer of care.

The Ontario Paediatric Diabetes Network established the Transition to Adult Care Working Group (TAC-WG) in December 2013 to effect change in the paediatric diabetes landscape by addressing the challenges and discrepancies associated with the transition from paediatric to adult diabetes care. The TAC-WG was tasked with developing a comprehensive set of recommendations for a more structured and consistent provincial approach to transitioning youth living with diabetes from paediatric to adult diabetes care. The recommendations made in this report address the needs of this patient population and how to leverage resources that currently exist within the Ontario healthcare system. Furthermore, this report explores the impact that transition has in the broader system on the long-term outcomes of the population they address. The TAC-WG makes the following recommendations to be implemented across the province:

1. Transition as a Process:

Recognizing that the attainment of knowledge and self-management skills leading to a mastery of diabetes management is a process that takes time and involves healthcare providers, parents/caregivers, and children/youth

AND

Recognizing that the roles of children, youth, parents, and the healthcare providers change over time

AND

Taking into consideration developmental, cognitive, and psychosocial issues as appropriate:

- A. Paediatric diabetes teams should begin, early in adolescence or at the appropriate developmental stage, the process of facilitating the following:

- Knowledge transfer related to diabetes management and the adult healthcare system

AND

- Skills development necessary for autonomy in the management of diabetes

- B. Once transferred to an adult diabetes education program, healthcare providers continue to foster knowledge acquisition and self-management skills within the young adult.

- Paediatric and adult diabetes teams communicate to ensure effective coordination of care for the duration of the young adult's transition to the adult diabetes education program.

2. **Standardized Transition Skills:** A standardized set of skills tailored to various ages and stages should be established and incorporated into standardized education for youth with diabetes.
3. **Readiness Assessment:** A transition readiness assessment should be utilized to identify youth with diabetes who would benefit from a more intensive approach to transition and to inform a plan of care.
4. **Formal Discharge Discussion:** A formal and planned discharge discussion should occur with every patient and/or family on or near their last appointment in the paediatric diabetes setting.
5. **Formal Discharge Meeting:** Paediatric diabetes teams should aim to identify high risk patients requiring a more intensive approach to transition early on, ideally in the year prior to transfer of care. If possible, a joint discharge meeting should occur in which the patient, family/caregiver(s) and members from paediatric and adult diabetes teams, as appropriate, are present.
6. **Patient Follow-up:** It is recommended that adult diabetes teams assume responsibility for tracking and follow-up of patients following receipt of an initial referral.
7. **Discharge Summary:** Every specialist involved in the provision of care to youth transitioning to an adult diabetes team should utilize a standardized formal discharge/transfer summary template that should be shared with:
 - The patient (and their family, as appropriate)
 - The patient's primary care provider
 - The adult diabetes team who will be involved in the patient's care including but not limited to endocrinologists, family physicians, nurse practitioners, diabetes educators and specialists
8. **Online Resource Centre:** A provincial online resource centre should be established that brings together relevant transition tools, templates and educational resources for patients, their families, paediatric diabetes care providers and adult diabetes care providers.
9. **Provincial Infrastructure:** The MOHLTC, LHINs, PDN, and other paediatric diabetes stakeholders should partner to ensure that there is provincial alignment and support for initiatives related to transitions to adult diabetes care, including but not limited to:
 - A. Supporting research to improve the transition to adult diabetes care and implementing evidence that emerges from clinical trials (such as the results of the Ontario Juvenile Diabetes Research Foundation funded Transition Trial).

B. Exploring opportunities to leverage an integrated, province-wide electronic medical record to support continuity of diabetes care.

10. Evaluation of Transitions: Paediatric and adult diabetes teams should collect information prospectively and conduct evaluations to ensure the ongoing effectiveness of their transition to adult care process, and make appropriate improvements where necessary.

11. Diabetes Education Program Funding: The 2010 Staff Funding Benchmark Review should be updated to accurately reflect 2015 patient volumes and case complexity, and dialogue should be opened with the MOHLTC toward the implementation of increased paediatric and adult diabetes education program FTEs to support the achievement of appropriate standards of care for these transitioning youth.

Prioritization of these recommendations, along with planning for their implementation and evaluation, will be forthcoming.

Acronyms and Glossary

Term	Definition
A1c	Glycated hemoglobin
Adult Diabetes team	For the purposes of this report, the adult diabetes team refers to adult DEPs and adult endocrinologists. In some circumstances, an adult endocrinologist may not work within an adult DEP.
Council	See PCMCH
DCPNS	Diabetes Care Program of Nova Scotia
DEP	Diabetes Education Program A DEP consists of a team that delivers diabetes education and management services funded (either in whole or in part) by the MOHLTC or LHIN. Funded adult DEPs consist of, at minimum, one registered nurse and one registered dietitian. Organizations may fund their own models of DEPs completely out of their own base or global funding.
eCHN	electronic Child Health Network
Endocrinologist	For the purposes of this report, endocrinologist is interchangeable with internist and diabetologist
FTEs	Full-time employees
JDRF	Juvenile Diabetes Research Foundation
LHIN	Local Health Integration Network
MOHLTC	Ministry of Health and Long Term Care
NOPDP	Network of Ontario Paediatric Diabetes Programs
OL-WG	Outreach Linkages Working Group
PCMCH	Provincial Council for Maternal and Child Health
PDEP	Paediatric Diabetes Education Program For the purposes of this report, PDEP is interchangeable with paediatric diabetes team. A PDEP is comprised of a multidisciplinary core team of, at a minimum, a registered nurse, a registered dietitian, and a registered social worker, who work closely with paediatricians, and/or paediatric endocrinologists, and/or primary care providers to provide comprehensive care to children and youth living with diabetes.
PDN	Paediatric Diabetes Network
TAC-WG	Transition to Adult Care Working Group

Background

Transition to adult healthcare

For adolescents and young adults living with a chronic health condition, transitioning from paediatric to adult healthcare is instrumental to both their transition to adulthood and to their journey as a patient navigating the healthcare system. During adolescence and young adulthood, individuals face a number of challenges while they establish their personal identity, sexual behaviors and gain increasing independence. The period of transition to adult care coincides with other significant life events, such as transition to post-secondary education or entering the workforce, separation from the family and changing residence. Due to the increasing influence of peers, combined with other contributing societal factors, this is a period of transition regardless of a person's health status. For anyone coping with the daily demands of managing a chronic disease, adolescence and young adulthood can be even more complex. Adolescents and young adults may have limited experience with basic tasks often routinely managed by parents, such as scheduling their own medical appointments and maintaining prescribed medications (Helgeson, et al., 2013). The transition from pediatric to adult care may also coincide with a loss of health insurance coverage and the emergence of new financial barriers to healthcare access (Willoughby, et al., 2007). As a result, youth, their families, and both paediatric and adult healthcare providers all have an important role to play in the shared responsibility of patient care prior to and following the transition from paediatric to adult medical care (American Academy of Pediatrics, 2011).

Transition to adult diabetes care

For adolescents and young adults with diabetes, transitioning from paediatric to adult medical care has been a challenging issue for decades. With the physiological, psychological, and developmental changes associated with adolescence, the transition to adult care is a highly vulnerable period for youth who also face the intricacies, demands and challenges of managing their diabetes (Nakhla, Daneman, To, Paradis, & Guttmann, 2009). A recent position statement from the American Diabetes Association highlighted that the transition from paediatric to adult diabetes care is a high risk period during which there is an increased rate of disengagement from care (Peters & Laffel, 2011). During this period, this heightened risk of leaving medical supervision leads to an increased risk of diabetes-related hospitalizations (Nakhla, Daneman, To, Paradis, & Guttmann, 2009). Diabetes control may also deteriorate significantly during this period due to many factors including: physiological insulin resistance associated with hormonal changes of puberty, psychosocial distress, risk taking behavior, intentional insulin omission for weight loss or attention, and eating disorders. Canadian studies have demonstrated that 13-56% of young adults with diabetes are lost to follow-up after having been transferred from pediatric to adult care, 31% reported gap of more than 6 months between visits and 11% reported a gap of more than 12 months (Frank, 1996; Scott, Vallis, Charette, Murray, & Latta, 2005; Pacaud, Yale, Stephure, Trussell, & Davies, 2005).

Loss to follow-up care

Loss to follow-up care can have a significant impact on the health of transitioning young adults, with suboptimal transitions being associated with higher risks of acute and chronic diabetes-related complications. Among those lost to medical follow-up care or those who receive fragmented follow-up

care, diabetic control is significantly worse, with a mean A1C on average 1.5% higher than in those who maintain medical follow-up (Sparud-Lundin, Öhrn, Danielson, & Forsander, 2008; Insabella, Grey, Knafel, & Tamborlane, 2007; Dyrlov, et al., 2000; Bryden, Peveler, Stein, Neil, Mayou, & Dunger, 2001). With loss to follow-up care, background retinopathy increases from 5% to 29% and nephropathy by 17% (Nakhla, Daneman, To, Paradis, & Guttman, 2009). The SEARCH for Diabetes in Youth Study reported that transfer to adult care was one of the significant predictors for suboptimal diabetic control (A1C >9%) for adolescents and young adults (Lotstein, et al., 2013). Another recent prospective study found that poor glycemic control was more likely for those who had left pediatric diabetes care or transitioned early as compared to those who remained in pediatric care one year after graduation from high school (Helgeson, et al., 2013).

Planned transitions

A transition to adult care that is continuous, planned, patient-centered and individualized is critical to ensuring optimal diabetes management and regular screening for microvascular complications, thereby mitigating the onset and progression of diabetes-related complications (Loche, et al., 1994; Jacobson, Hauser, Willett, Wolfsdorf, & Herman, 1997). In Ontario, pediatric diabetes programs as well as adult diabetes care providers continue to report transition to adult care as one of their greatest challenges to providing optimal diabetes care and an aspect of care that is not addressed in an organized, planned or timely manner. From the patient's perspective, the following barriers to successful transition have been identified: abrupt transfer of care, lack of accessibility of adult-care services, lack of coordination between different disciplines involved in the care and lengthy waiting periods (Busse, et al., 2006; Garvey, Beste, Luff, Atakov-Castillo, Wolpert, & Ritholz, 2014; Pacaud & Yale, Exploring a black hole: transition from paediatric to adult care services for youth with diabetes, 2005).

Transition to Adult Care Working Group

The Transition to Adult Care Working Group (TAC-WG) is a working group of the Ontario Paediatric Diabetes Network of the Provincial Council for Maternal and Child Health (PCMCH/Council).

PCMCH is an organization whose scope is primary, secondary, tertiary and quaternary maternal, newborn, child and youth health services, delivered in both community and hospitals settings, and includes responding to the needs of disadvantaged communities across Ontario. The Council's work reflects the importance of relationships and interfaces among providers and organizations across the continuum of care.

The Council's vision is: The Best Possible Beginnings for Lifelong Health

Its mission is to:

- **Be the provincial forum** in which clinical and administrative leaders in maternal and child health can identify patterns and issues of importance in health and health care delivery for system support and advice.

- **Improve the delivery** of maternal child health care services by building provincial consensus regarding standards of care, leading practices and priorities for system improvement.
- **Provide leadership and support** to Ontario’s maternal and child health care providers, planners and stewards in order to maximize the efficiency and effectiveness of health system performance.
- **Mobilize information and expertise** to optimize care and contribute to a high-performing system therefore improving the lives of individual mothers and children, providers and stewards of the system.

The Ontario Paediatric Diabetes Network (PDN) is a collaborative network comprised of the thirty-five specialized paediatric diabetes education programs (PDEPs) located in communities across the province of Ontario. The goal of this network is to ensure the best possible health outcomes for children and youth affected by diabetes across the province. To this end, PCMCH oversees the coordination of the PDN by fostering system improvement, providing opportunities for professional development, promoting linkages between the PDEPs, assisting with the development and dissemination of resources and guidelines, promoting consistency in standards of practice, and providing individual program support. The TAC-WG was convened as a working group of the PDN in December 2013 and committed to:

1. The completion of a report detailing a comprehensive set of evidence-based recommendations regarding a provincial approach for paediatric diabetes education programs to transition youth and their families living with diabetes to adult care.
2. The development of tools and knowledge transfer mechanisms to support the implementation of these recommendations by diabetes teams, patients and families, Local Health Integration Networks (LHINs), and the Ministry of Health and Long-Term Care (MOHLTC), as appropriate.

Refer to Appendix 1 for the TAC-WG terms of reference.

The membership of the TAC-WG covered different geographical regions across Ontario and comprised of representation from various paediatric and adult diabetes stakeholder groups including paediatric endocrinologists, adult endocrinologists, nurses, social workers, psychologists, program managers and LHIN representatives. Efforts were made to ensure representation from across the province, including both tertiary and community hospitals and healthcare centres. Refer to Appendix 2 for the TAC-WG membership.

The development of these recommendations was completed over a series of TAC-WG meetings that were held via teleconference, in addition to one in-person meeting that took place in November 2014. Based on the preliminary TAC-WG meetings, the recommendations were partitioned into the three themes and the following subgroups convened to address each theme:

- Preparing for Transition Subgroup
- Bridging the Gap Subgroup
- Supporting and Improving Transitions Subgroup

To foster collaboration and ensure alignment across the vast provincial healthcare system, the TAC-WG based the following set of recommendations on PCMCH’s Report of the Transition to Adult Healthcare

Services Work Group. The TAC-WG tailored, refined and expanded upon these recommendations in order to address the unique characteristics and needs of youth living with diabetes.

Recommendation 1: Transition as a Process

Recognizing that the attainment of knowledge and self-management skills leading to a mastery of diabetes management is a process that takes time and involves healthcare providers, parents/caregivers, and children/youth

AND

Recognizing that the roles of children, youth, parents, and the healthcare providers change over time

AND

Taking into consideration developmental, cognitive, and psychosocial issues as appropriate:

A. Paediatric diabetes teams should begin, early in adolescence or at the appropriate developmental stage, the process of facilitating the following:

- **Knowledge transfer related to diabetes management and the adult healthcare system**

AND

- **Skills development necessary for autonomy in the management of diabetes**

B. Once transferred to an adult diabetes education program, healthcare providers continue to foster knowledge acquisition and self-management skills within the young adult.

- **Paediatric and adult diabetes teams communicate to ensure effective coordination of care for the duration of the young adult's transition to the adult diabetes education program.**

Rationale

In acknowledging the significant challenges associated with transitioning youth to adult diabetes care, there is an opportunity for both paediatric and adult diabetes care providers to effect change in the current landscape and to optimize the provision of diabetes care. The purpose of this recommendation is to address this opportunity and to shape the overarching conceptual foundation for a more structured, supportive and consistent provincial approach to transition for adolescents and young adults living with diabetes. This recommendation is intended to align with and raise awareness about the goals and principles of effective transition. Within the literature, transition has been defined as the “purposeful, planned movement of adolescents with chronic medical conditions from child-centered to adult-oriented health care” (Blum, et al., 1993), whereas a transfer has been defined as a “one-time event that occurs at the time the youth is transferred out of the child health system” (Provincial Council for Maternal and Child Health, 2013). This recommendation emphasizes the continuous nature of transition, rather than considering it as a singular point in time.

In recent years, both the Canadian Paediatric Society and the American Academy of Pediatrics have released position statements indicating that the goals of effective healthcare transitions are to ensure high-quality, developmentally appropriate, psychologically sound healthcare that is continuous, comprehensive, patient-centered and coordinated, before and throughout a youth's transition from pediatric care into the adult healthcare system (Cooley & Sagerman, 2011; Adolescent Health Committee of the Canadian Paediatric Society, 2006). Planned transition to adult care is therefore an ongoing, patient-centered, multifaceted process that should begin early in adolescence and prior to the actual

transfer of youth to adult care services, and continue thereafter (Adolescent Health Committee of the Canadian Paediatric Society, 2006). Although not tailored specifically to adolescents and young adults living with diabetes, these goals and principles are pertinent to this recommendation and applicable to the transition to adult diabetes care.

Potential Impact

Adopting this more comprehensive, structured and supportive approach to transition has the potential to result in the following:

- PDEPs that are prepared for transition at both the individual patient and organizational levels.
- Collaboration and engagement with the patient and their families to ensure that the upcoming transition is tailored to the patient's evolving medical, developmental, cognitive and psychosocial needs (Peters & Laffel, 2011).
- Adult diabetes teams ensure that the patient continues to develop these self-management skills and knowledge of diabetes care following their transition to adult diabetes care.
- The occurrence of a fundamental shift in culture across the paediatric and adult diabetes landscape to support the effective and seamless transitions to adult diabetes care.
- Patients and their families are provided with the opportunity to learn how to advocate for themselves and use healthcare services effectively in order to ensure optimal management of their diabetes, maintain their health and prevent health complications (Adolescent Health Committee of the Canadian Paediatric Society, 2006).

Helpful Resources

PCMCH's Discharge Planning Implementation Tool was selected as a resource to support this recommendation. The tool is intended as a guide for care providers to implement discharge planning. It outlines specific activities to be conducted within discrete periods of time, beginning at a minimum of 24 months prior to the patient turning 18 years of age, and continues until after the patient has visited their adult healthcare providers. Although not specific to diabetes, this tool provides a comprehensive framework that can be used to guide the transition process for adolescents and young adults living with diabetes.

Discharge Planning Implementation Tool (See Appendix 3)

Recommendation 2: Standardized Transition Skills

A standardized set of skills tailored to various ages and stages should be established and incorporated into standardized education for youth with diabetes.

Rationale and Potential Impact

Building capacity in both youth and their families is an integral aspect of preparing patients for effective transition to adult healthcare, regardless of the health condition (Provincial Council for Maternal and Child Health, 2013). The Adolescent Health Committee of the Canadian Paediatric Society (2006) states

that one of the core principles of transition is to begin preparing for transition in early childhood and for the paediatric care providers to encourage the youth's parents or caregivers to be informed participants in their child's care. This recommendation focuses on building capacity in the youth with diabetes and their parents or caregivers. Despite there being a plethora of resources and tools pertaining to transition skills for youth living with diabetes and their families, a set of transition skills has not yet been standardized for use across the paediatric diabetes landscape in Ontario. Establishing a standardized set of transition skills that are tailored to specific ages and developmental stages and incorporated into PDEPs will help to ensure that youth with diabetes:

- Are equipped with appropriate transition skills.
- Acquire diabetes management skills and developmentally and age-appropriate knowledge.
- Gain independence and self-efficacy in managing their diabetes, to the extent possible.
- Enhance their autonomy to transition to adult diabetes services in an effective manner.

Helpful Resources

Several tools for standardized transition skills were reviewed by the Preparing for Transition Subgroup of the TAC-WG. The following two resources were selected to accompany this recommendation:

"Help Them Grow...so they're Good 2 Go" Timeline – Diabetes Program (See Appendix 4)

- Developed by the Good 2 Go Transition Program at the Hospital for Sick Children in Ontario.
- Provides age-appropriate activities for parents of youth living with diabetes and ideas for teens/youth to develop independence in many areas of one's life – socially, with family, education and in managing their diabetes ("Help Them Grow...so They're Good 2 Go" Timelines).
- In recommending this tool, the Subgroup identified opportunities for enhancement to further meet the needs of youth living with diabetes and their families. Some proposed modifications include rearranging the format to be visually pleasing and revising the content to ensure that there is adequate emphasis on the early diagnosis phase, later phases and other aspects of care.

Keys to Independence: Transitioning from the Pediatric to the Adult Health Care team (See Appendix 5)

- Developed by members of the University of Wisconsin-Madison Pediatric and Adult Diabetes Teams in Madison, Wisconsin, United States.
- Aims to help youth and their families learn more about diabetes and a formalized transition process to adult diabetes care.
- Divided into four stages that describe age-appropriate tasks, corresponding with the following age ranges: 8-10, 10-12, 13-15, 16-17.

Recommendation 3: Readiness Assessment

A transition readiness assessment should be utilized to identify youth living with diabetes who would benefit from a more intensive approach to transition and to inform a plan of care.

Rationale and Potential Impact

The Canadian Diabetes Association recommends that support and education are two key components of a planned, seamless transition to adult diabetes services (Canadian Diabetes Association Clinical Practice

Guidelines Expert Committee, Wherrett, Huot Mitchell & Pacaud, 2013). The purpose of a transition readiness assessment is to identify areas in which further education and support may be needed and to involve patients, their families and both their current and future care providers in proactively planning for the transition to adult diabetes care. This recommendation focuses on the importance of conducting a transition readiness assessment. The results of a transition readiness assessment should be shared with the healthcare providers who will be providing care to the patient prior to, during and following the transition to adult diabetes care. A transition readiness assessment can:

- Help to identify adolescents and young adults who may require more intensive counseling and more frequent visits.
- Serve as a means to identify gaps or miscommunications with regards to the youth's level of preparedness for transition to adult care.
- Inform youth, families and care providers about the patient's needs and the role providers can play in optimizing the patient's transition to adult diabetes care, including the primary care provider.
- Optimize the continuity of care and reveal what should be included in the plan of care.
- Identify and potentially provide the opportunity to mitigate the issues that arise prior to, during or after transition.

Helpful Resources

The Preparing for Transition Subgroup conducted a comprehensive review of a collection of readiness assessment tools, including those that had been put forth as part of PCMCH's Report of the Transition to Adult Healthcare Services Work Group, those collected through an additional environmental scan of diabetes-specific tools, and those being used by the PDEPs across Ontario. Based on this review, the Subgroup selected tools to accompany this recommendation specific to adolescents and young adults with diabetes, their parents and their healthcare providers in order to ensure that all three audiences agree upon the items in question with regards to preparing for transition.

For youth, adolescents and young adults:

Young Adult Transition Guide (See Appendix 6)

- Developed in 2006 by the Markham Stouffville Hospital in Ontario, through funding from the former Northern Diabetes Health Network.
- Designed to guide patients through the last two years of their paediatric diabetes care and address important issues prior to transitioning to the adult diabetes clinic.
- The Subgroup selected this tool as the preferred overall teaching guide. The Subgroup suggested that the guide is due for an update and that a small committee, with representation from the Markham Stouffville Hospital, could be convened to conduct this update.

"Moving On..." With Diabetes

Knowledge & Skills Self-Assessment (Ages 13-16 years) (See Appendix 7)

Adolescent Knowledge & Skills Checklist (Ages 17-18 years) (See Appendix 8)

- Developed by the Diabetes Care Program of Nova Scotia (DCPNS) in March 2012.
- Provide youth self-assessment of learning needs and identify areas in which the youth requires further education or skill development prior to transition.

- The Subgroup suggested that there were opportunities to make these tools more consistent and user-friendly. For instance, rather than using a Likert scale, the tool for 13-16 year olds could include the same scale used in the tool for 17-18 year olds.

For parents and caregivers:

“Moving On...” With Diabetes

Adolescent Knowledge & Skills Checklist (Ages 17-18 years) (See Appendix 8)

- See description above.

For healthcare providers:

“Moving On...” With Diabetes

Diabetes Educator Transition Checklist (See Appendix 9)

- Developed by the DCPNS in March 2012 together with the other “Moving On...” tools.
- Healthcare providers can use this to assess a patient’s readiness for transition.

Provider Assessment of Patient Skill Set (See Appendix 10)

- Developed by the Endocrine Society in Washington, D.C.
- Intended as an aide to assessing the readiness of adolescents and young adults in the transition and to be transferred from paediatric to adult diabetes care providers
- The Subgroup felt that this was a great tool for providers to refer to on an ongoing basis in order to track the areas of education that have been covered.

Recommendation 4: Formal Discharge Discussion

A formal and planned discharge discussion should occur with every patient and/or family on or near their last appointment in the paediatric diabetes setting.

Rationale and Potential Impact

This recommendation builds upon the recommendations previously described and focuses on both the importance of effective communication and the role of the paediatric diabetes care providers in coordinating a formalized discharge discussion with their patients. A formal discharge discussion aims to ensure that all adolescents and young adults living with diabetes have clear instructions and information regarding their transition to adult diabetes care. The timing of the formal discharge discussion should be determined by the patient’s needs, as identified in the transition readiness assessment. The formal discharge discussion should include the following key components:

- A review of differences in expectations and structure between pediatric and adult visits
- Discussion of age-related themes and concerns
- Summary of the patient’s diabetes history
- Details about the patient’s first visit with the adult diabetes care program
- Discussion about the importance of attending regular visits with their primary care provider in addition to their diabetes care team and/or endocrinologist.

Helpful Resources

The Bridging the Gap Subgroup reviewed a number of tools, checklists and guides pertaining to discharge discussions. The Subgroup selected the Transition Teaching Content Template developed by the London Health Sciences Centre as the preferred tool for formal discharge discussions. The Subgroup adapted the format and content of the tool to meet the needs of adolescents and young adults living with diabetes.

Modified Transition Teaching Content Template (See Appendix 11)

Recommendation 5: Formal Discharge Meeting

Paediatric diabetes teams should aim to identify high risk patients requiring a more intensive approach to transition early, ideally in the year prior to transfer of care. If possible, a joint discharge meeting should occur in which the patient, family/caregiver(s) and members from paediatric and adult diabetes teams, as appropriate, are present.

Rationale and Potential Impact

A staggering number of adolescents and young adults with diabetes are lost to follow-up care (Frank, 1996; Scott, Vallis, Charette, Murray, & Latta, 2005; Pacaud, Yale, Stephure, Trussell, & Davies, 2005) and do not receive diabetes care until they present to a diabetes program or emergency department with extremely poor glucose control or severe diabetes-related complications. Given the considerable impact that loss to follow-up care can have on the health of those living with diabetes, it is important for PDEPs to identify patients who are at a high risk of being lost to follow-up well before their transition to adult care. This way, an earlier, more intensive and supportive approach to transition can be devised. Adolescents and young adults who may be at high risk include those with co-morbid conditions, problems with compliance or attendance, poor glucose control and psychosocially vulnerable patients. It is recommended that if possible, a joint discharge meeting be held for these patients where the patient, their parents or caregivers, and members of both the PDEP and adult diabetes program are present. Ideally, this discharge meeting is held in-person; however in situations where distance, availability or other circumstances preclude an in-person meeting, the meeting may be conducted via teleconference or video-conference. The formal discharge meeting should entail:

- Discussing discharge and providing relevant resources, as outlined in Recommendation 4.
- Developing a plan of care to address the patient's needs that were identified in the transition readiness assessment, as outlined in Recommendation 3.
- Identifying which healthcare provider(s) will assume responsibility for functions related to the patient's overall care coordination and/or patient navigation between all healthcare providers.

The following components may also be considered as part of a more intensive approach for transition:

- Designating a liaison from the PDEP to communicate with the adult diabetes program and provide greater support to the patient for the transition to adult care. This role could be fulfilled by a social worker or diabetes nurse educator from the patient's PDEP. The responsibilities of this liaison would include making efforts to ensure that the patient attends their first appointment with the adult diabetes program. In circumstances where a joint discharge meeting with all stakeholders is not feasible, a liaison from the PDEP or Centre for Complex Diabetes Care (CCDC) where available, may be a viable alternative.

- Using other methods of communication such as email, phone, text message and websites to provide these patients with a more flexible approach to preparing for their transition.

Helpful Resources

The Bridging the Gap Subgroup of the TAC-WG identified hospital communications and email policies as appropriate resources to support this recommendation. Such resources outline the parameters for communication with patients via electronic or alternative means of communication. These methods of communication can be used by diabetes care providers to support those patients at higher risk of loss to follow-up in the adult care setting. One such resource is the communications policy developed and currently under review by the Markham Stouffville Hospital policy. Where possible, PDEPs are encouraged to refer and adopt their organization's communications policy as needed in order to support youth living with diabetes in effectively transitioning to adult diabetes care.

Recommendation 6: Patient Follow-Up

It is recommended that adult diabetes teams assume responsibility for tracking and follow-up of patients following receipt of an initial referral.

Rationale and Potential Impact

For adolescents and young adults with diabetes in Ontario, it is unclear whether the PDEP, adult diabetes education program (DEP), or adult endocrinologist is responsible for following up with them after an initial referral has been made. Given that patients do not typically see an adult endocrinologist for six months post-discharge, the PDEP often continues to provide post-discharge care, particularly for patients on insulin pump therapy who are required to be seen by a DEP or endocrinologist three times per year in order to meet the Assistive Devices Program's funding eligibility criteria. To further complicate matters, adult DEPs often have medical directives that preclude other members of the team (registered nurses, social workers and dietitians) from being able to see patients until they have been seen by an adult endocrinologist. These circumstances can lead to a loss to follow-up, with the PDEP and adult DEP both presuming that the patient is being cared for by the other team. This recommendation focuses on clearly identifying which diabetes care providers are responsible for following up with patients once the transition of care has been initiated. Efforts should be made to ensure that patients are seen within three months of being discharged from their PDEP and that care remains aligned with the Canadian Diabetes Association's guidelines for the number of recommended annual visits. Paediatric and adult diabetes care providers should also emphasize the importance of the patient seeing their primary care provider on a regular basis, in addition to their diabetes care team and/or endocrinologist, and encourage them to do so to ensure continuity of care. To mitigate issues of patient follow-up and help to ensure a seamless transition in care, the TAC-WG agreed that it would be most appropriate to assign the responsibility of patient follow-up to the adult diabetes care team. For the purposes of this recommendation, the adult diabetes team refers to adult DEPs and adult endocrinologists. In some circumstances, an adult endocrinologist may not work within an adult DEP. If this is the case, a separate referral to the adult endocrinologist is required.



To support this recommendation, the TAC-WG developed a pathway that outlines the recommended process for patient-follow up, from the point in time when the patient is discharged from the PDEP to when they are seen by the adult DEP. The pathway also provides details regarding communication with the patient, the referring PDEP and the patient's primary care provider. Refer to Appendix 12 for the full version of the pathway, contingencies and examples of communication tools.

Helpful Resources

There are a number of existing online resources that house information on the health

services available across Ontario, including those related to adult diabetes care. These resources have been selected to accompany this recommendation as they can help paediatric diabetes care providers and their patients learn about the services available in their community and therefore assist with these efforts to improve patient follow-up during the process of transition for adolescents and young adults with diabetes. One such resource is *Health Care Options*, which is an online portal developed by the government of Ontario that consists of centralized information on the different health care services that are offered in communities across the province, where they are located and how to access them. This portal includes information on the adult DEPs across the province, their referral criteria and the services they provide. For more information about this resource, see Appendix 13. Another relevant resource is *thehealthline.ca*, which is a website that provides users with access to information on health and social services in their community. Ontarians can search for information on health and social services by entering their postal code or selecting one of the fourteen LHINs' webpages. Each webpage is maintained by the LHIN's community care access centre and includes information on a variety of health topics, healthcare facilities, events, and social services, including diabetes education programs. For more information about *thehealthline.ca*, see Appendix 14.

The TAC-WG recommends that the creation of a comprehensive, standalone list of adult diabetes care teams and endocrinologists in Ontario could be considered in the future as another means to assist in these efforts to improve patient-follow-up for adolescents and young adults living with diabetes.

Recommendation 7: Discharge Summary

Every specialist involved in the provision of care to youth transitioning to an adult diabetes team should utilize a standardized formal discharge/transfer summary template that should be shared with:

- The patient (and their family, as appropriate)
- The patient's primary care provider
- The adult diabetes team who will be involved in the patient's care including but not limited to endocrinologists, family physicians, nurse practitioners, diabetes educators and specialists

Rationale and Potential Impact

This recommendation aims to facilitate the transition from paediatric to adult diabetes care by proposing a standardized means of providing members of the adult DEP team and primary care providers with access to pertinent and up-to-date information about the patient being referred. It entails the completion of a formal discharge summary template by the patient's current paediatric diabetes care provider, which is then reviewed by the patient and their family as appropriate and shared with both the patient and the adult diabetes team DEP team who will be providing diabetes care to the patient going forward. The referring paediatric diabetes care provider may also want to consider completing an additional document or section with sensitive psychosocial information that may be useful to the receiving adult diabetes team adult DEP and share exclusively with the adult diabetes care provider.

Having such a standardized process in place can help to:

- Equip the adult diabetes team and primary care provider with easy access to information about the patient's current health status, diabetes management and past medical records.
- Foster collaboration amongst paediatric and adult diabetes care providers.
- Decrease a sense of isolation felt by transitioning patients and adult diabetes care providers.
- Enhance communication amongst the care providers as well as with the patient and their family.

If the patient's primary care provider is a paediatrician, then the topic of who will assume the role of the patient's primary care provider after they turn 18 years of age should be discussed. To facilitate access and communication amongst diabetes care providers, a patient's formal discharge summary could be housed on an integrated, province-wide electronic medical record, which is described in further detail in Recommendation 9.

Helpful Resources

The Bridging the Gap Subgroup assessed several discharge summary templates specific to diabetes from the Endocrine Society, National Diabetes Education Program, Children's Hospital of Eastern Ontario, Hospital for Sick Children and Diabetes Care Program of Nova Scotia. The Subgroup selected the following template to accompany this recommendation due to its extensiveness and the fact that it can be easily adapted by a PDEP for their specific patient population and needs.

Clinical Summary for New Health Care Teams (See Appendix 15)

- Developed by the Endocrine Society in Washington, D.C.
- Used by the pediatric diabetes care provider to summarize a patient's medical record; this is then transferred to the adult diabetes care provider.
- The patient should receive a copy of the completed discharge template.

Recommendation 8: Online Resource Centre

A provincial online resource centre should be established that brings together relevant transition tools, templates and educational resources for patients, their families, paediatric diabetes care providers and adult diabetes care providers.

Rationale and Potential Impact

This recommendation addresses another strategy to build capacity amongst adolescents and young adults with diabetes who are transitioning to adult care, their families, paediatric diabetes care providers and members of the adult DEP teams. Currently, there is a multitude of resources available to both diabetes care providers and the general public that span various topics related to transitioning from paediatric to adult diabetes care. It is oftentimes difficult to determine the accuracy and validity of these resources, or their relevance to particular patient circumstances. Furthermore, these resources are not standardized across organizations, let alone across the province. The intention of this provincial online resource centre is to establish a standardized, web-based space where tools, templates, educational resources and information relevant to transition to adult diabetes care can be housed and easily accessed by diabetes care providers, patients and their families. This will help to make information more easily accessible and reduce duplication of efforts across the province. This online resource centre should be easy to navigate, well-organized and populated with both the resources recommended throughout this report, those that had been reviewed but not selected to accompany a specific recommendation and those from different jurisdictions. Furthermore, the TAC-WG recommends that the provincial online resource centre include links to adult DEP websites and encourages adult diabetes teams and endocrinologists to include information about transitioning to adult diabetes care on their websites. This online resource centre should be maintained by the PDN and housed on the PCMCH website, with links to relevant external websites. Appendix 16 includes a list of additional resources and websites for this online resource centre, as recommended by the members of the TAC-WG.

Recommendation 9: Provincial Infrastructure

The MOHLTC, LHINs, PDN, and other paediatric diabetes stakeholders should partner to ensure that there is provincial alignment and support for initiatives related to transitions to adult diabetes care, including but not limited to:

- A. Supporting research to improve the transition to adult diabetes care and implementing evidence that emerges from clinical trials (such as the results of the Ontario Juvenile Diabetes Research Foundation funded Transition Trial).**
- B. Exploring opportunities to leverage an integrated, province-wide electronic medical record to support continuity of diabetes care.**

Rationale and Potential Impact

There are various stakeholder groups involved in the oversight, delivery, accountability and integration of paediatric diabetes care across the province, including but not limited to the MOHLTC, the fourteen LHINs, the PDN and the 35 PDEPs themselves. Primary care providers are also an important stakeholder

group since they provide care throughout the patient's life and at times when there is a delay in or limited access to adult diabetes care. Each of these stakeholder groups has significant roles to play when it comes to transitioning adolescents and young adults with diabetes to adult diabetes services. Collaborative efforts need to be made amongst all stakeholders to ensure that there is alignment across the province and support of initiatives that impact youth who are transitioning to adult diabetes care. Two such initiatives currently underway are the Ontario Juvenile Diabetes Research Foundation (JDRF) funded Transition Trial. There may also be opportunities to leverage existing infrastructure, such as provincial electronic medical records or systems, to support transitions to adult diabetes care.

In 2012, the Transition Trial was initiated with collaboration between PDEPs and adult DEPs in London, Ottawa and Mississauga, and support from the JDRF and the Federal Economic Development Agency of Southern Ontario. This multicentre study is the first randomized controlled trial to examine a structured transition program that incorporates a dedicated coordinator to help in the process of transitioning youth to adult diabetes care. This study aims to improve clinic attendance and health outcomes by closing the gap in the care of this patient population at a vulnerable time. The Transition Coordinator, a Certified Diabetes Educator, provides continuity of care between paediatric and adult diabetes services and supports youth during their last six months of paediatric diabetes care and the first twelve months of adult diabetes care. The results of this trial, anticipated for 2017, may serve to inform clinical practice guidelines and may be applicable to young adults with other chronic health conditions at the time of transition.

As part of the provincial infrastructure, the TAC-WG also recommends exploring opportunities to support transition by leveraging an integrated, province-wide electronic medical record or system that currently exists. Although this portion of the recommendation extends well beyond the scope of this project, a province-wide electronic medical record would help to enhance continuity of care and support effective transitions to adult diabetes services as it could house existing clinical information and patient demographics that could be accessed by and shared amongst paediatric and adult diabetes care providers. Pertinent health information, such as a patient's formal discharge summary, relevant clinic notes, and lab results could be made available as part of a module on the electronic medical record prior to a paediatric diabetes patient's transition to adult diabetes care. Such a province-wide resource is of particular importance given that many transition-aged youth are moving out of their region for post-secondary education or employment.

One existing system that could potentially be leveraged to provide paediatric and adult diabetes care providers with access to existing patient information is the electronic Child Health Network (eCHN). eCHN is a secure web-based network that offers authorized healthcare providers from across Ontario to access health information about paediatric patients, instantly, from multiple different sources (ECHN, 2015). The paediatric patient information is consolidated into a single health record that can be accessed online at any time by healthcare organizations or accredited healthcare providers anywhere in the province who have registered as members of eCHN (ECHN, 2015). The eCHN portal holds records of over 1,800,000 patients, from newborn to 19 years of age (ECHN, 2015). eCHN is already being used by many health care professionals across the province and membership is not limited to paediatric health care providers. Currently, 101 hospitals, 82 Community Care Access Centres, 37 Children's Treatment Centres and

numerous independent clinics and offices have become eCHN member sites (ECHN, 2015). There are no costs associated with registering as a member of eCHN.

Strong support, involvement and buy-in from paediatric diabetes stakeholders, adult diabetes care providers, the PDN, the LHINs and the MOHLTC will be necessary to ensure successful and timely implementation of these current initiatives and in considering future endeavours related to transition to adult diabetes care.

Recommendation 10: Evaluation of Transitions

Paediatric and adult diabetes teams should collect information prospectively and conduct evaluations to ensure the ongoing effectiveness of their transition to adult care process, and make appropriate improvements where necessary.

Rationale and Potential Impact

The purpose of this recommendation is to encourage diabetes care providers to conduct some form of formal evaluation from both the program-level to ensure that the approaches, strategies and interventions in place to transition adolescents and young adults with diabetes to adult care are effective and continually improved upon as necessary. This evaluation should entail mechanisms to capture both the patient and provider perspectives on the effectiveness of transitions. Due to the nature of transitioning from paediatric to adult diabetes care, the paediatric program-level outcome measures would differ considerably from those of the adult DEPs. To evaluate transitions, the Supporting and Improving Transitions Subgroup suggests the following:

- Small patient focus groups: For PDEPs, these would be comprised of graduated patients at some time period after their transition, whereas for adult DEPs, these would focus on current patients at some time period following transition. It would be important to ensure that the focus groups capture not only the perspectives of patients who are keen to participate, but those who are struggling with transitioning to adult care.
- Patient surveys: These could also provide valuable narrative feedback to teams in a more confidential way. Attaining an adequate sample size to ensure that the results of a patient survey are not misleading may be difficult for some teams.
- Outcome measures: The crucial outcome measures of successful transition are initial contact with an adult diabetes care provider and continued attendance at an adult DEP. Therefore, the Subgroup suggest that the minimal measures that should be tracked include:
- For PDEPs:
 - % of patients discharged who request re-referral or referral to an alternate adult diabetes care provider (knowing why would be important)
 - % of referrals for whom confirmation of first visit is received from the adult diabetes care provider.
- For adult diabetes teams:
 - % of patients referred who present for initial visit.

- % of patients referred who remain with provider after a certain time period (e.g. 1 year, or tied to individual centres' re-referral period (which is the amount of time a patient can not show up for before they need to get re-referred).
- % of patients who had a 2nd visit within their first year.
- % of patients who had a 3rd visit within their first year.

Outcomes measures from the JDRF-funded Transition Trial could also be considered as ways to evaluate transitions to adult diabetes care (Spaic, et al., 2013).

Recommendation 11: Diabetes Team Funding

The 2010 Staff Funding Benchmark Review should be updated to accurately reflect 2015 patient volumes and case complexity, and dialogue should be opened with the MOHLTC toward the implementation of increased paediatric and adult diabetes education program FTEs to support the achievement of appropriate standards of care for these transitioning youth.

Rationale and Potential Impact

Despite increasing patient volumes, advancements in clinical technology requiring increased time for patient education, and enhancements in standards of care for paediatric diabetes and evidence-based lower clinical targets as outlined in the 2013 Canadian Diabetes Association Clinical Practice Guidelines, staffing benchmarks for PDEPs have remained unchanged since they were established over a decade ago. In 2010, the former Network of Ontario Paediatric Diabetes Programs (NOPDP) completed a Staff Funding Benchmark Review, which made recommendations for updated staffing ratios for the core members of paediatric diabetes teams – registered nurses, registered dietitians and social workers – in PDEPs across the province. The findings of this review revealed that PDEP staffing levels were insufficient to meet the clinical targets for optimal care and for improving the quality of life for youth living with diabetes. Based on these findings, the NOPDP Advisory Committee recommended that staffing benchmarks for registered nurses, registered dietitians and social workers be increased by 25%, 40% and 50% respectively. Given the growing fiscal constraints in the Ontario healthcare system, these recommendations have not yet been implemented. The TAC-WG recognized that revisiting the issue of PDEP funding is outside the scope of this project; however, they agreed to put this recommendation forth to emphasize the importance of human resource capacity as it can have a considerable impact on the paediatric diabetes care providers' ability to support the recommendations proposed and ultimately enable youth living with diabetes to have a successful and seamless transition to adult diabetes care.

Next Steps

The next steps for the TAC-WG include proceeding to the second phase of the project – implementation of the recommendations - and subsequently conducting a formal evaluation of the degree to which youth transitions to adult diabetes care have been impacted by the implementation of the recommendations.

Implementation

Following the release of this recommendations report, the TAC-WG will proceed to the second phase of the project by conducting a prioritization exercise to determine which recommendations should be implemented by paediatric and adult diabetes stakeholders across Ontario. In order to do so, the TAC-WG may use the Pareto model, which provides a validated approach to prioritization that is transparent, open and less prone to biases (Provincial Council for Maternal and Child Health, 2013). By using this model, each recommendation would be ranked and scored independently, based on factors such as its perceived value, ease of implementation, potential to enable system improvement, ability for system change, time constraints and cost implications (Provincial Council for Maternal and Child Health, 2013). The scores would then be averaged and recommendations placed into tiers, with preference assigned to those that received high scores for both importance and ease of implementation (Provincial Council for Maternal and Child Health, 2013). A modified Delphi approach is another methodology that may be considered in order to prioritize the recommendations.

Once the prioritization exercise has been completed, the TAC-WG will develop an implementation strategy for the recommendations that have been identified as high priority. Toolkits and knowledge transfer mechanisms will be developed to support the implementation of the recommendations by diabetes teams, patients and families, LHINs, and the MOHLTC, as appropriate. Furthermore, the implementation strategy will include an approach to stakeholder engagement that will foster collaboration, ensure that the necessary allocation of human, financial and capital resources are available, and help to raise awareness about the implementation of these recommendations across the province.

Evaluation

In addition to evaluating transitions from a program level, it is important to conduct a formal evaluation from a provincial perspective to determine whether the degree to which the implementation of the prioritized recommendations is impacting patients and the system of diabetes care across Ontario. Establishing an evaluation framework can also help to uncover gaps that may not have been identified by the TAC-WG or emerging issues related to transitions to adult diabetes care that were addressed in the recommendations report. One approach to evaluating the implementation of the recommendations might be to determine the rate of loss to follow-up care prior to and following the implementation. Other evaluation methods may focus on patient satisfaction with their experience transitioning from paediatric to adult diabetes care. Furthermore, opportunities to link or leverage health administrative data, such as those held by the Institute for Clinical Evaluative Sciences, can be explored as a means to track outcomes across the transition process, evaluate the implementation of interventions or assess certain patterns of care related to transition to adult diabetes care. The TAC-WG has not yet embarked on the development of this evaluation framework.

Conclusion

The transition from paediatric to adult diabetes care is a multifaceted process that begins prior to transferring patient care responsibilities and continues thereafter. Across the province of Ontario and abroad, this process continues to bring about significant challenges for paediatric care providers, adult

care providers and most importantly patients and their families. With these challenges comes the opportunity for diabetes stakeholders to effect change by collaborating to provide a more structured and consistent provincial approach to transitions from paediatric to adult diabetes care. As outlined in this recommendations report, this approach has the potential to cultivate a positive impact on the provision of diabetes care and the health and quality of life of adolescents and young adults living with diabetes.

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Appendix 1 – Transition to Adult Care Working Group Terms of Reference



Provincial Council for Maternal and Child Health Paediatric Diabetes Network

Transition to Adult Care Working Group Terms of Reference

Background:

Due to the complex physiological, psychological, and developmental changes associated with adolescence, transition to adult care is a vulnerable period for youth living with diabetes. Following transfer to adult care, patients often feel a sense of desertion with the conclusion of their paediatric patient-provider relationship and find this a negative experience. During this period, there is an increased risk of diabetes-related hospitalizations, and adolescents are at increased risk of leaving medical supervision.

Seamless transition to adult care is essential to ensure regular screening for microvascular complications and optimized glycemic control, thereby mitigating the onset and progression of diabetes-related complications. With both the increasing case complexity and technological advancements faced in managing diabetes, the need for a planned approach to transition to adult care has become more pressing over the past decade. Both the Canadian Paediatric Society and the American Academy of Pediatrics state that the goals of planned healthcare transitions are to ensure high-quality, developmentally appropriate, psychologically sound healthcare that is continuous, comprehensive, and coordinated, before and throughout the transfer of youth into the adult system. In doing so, youth and their families can learn to advocate effectively for themselves, maintain good health behaviors, and use healthcare services to maintain their health and prevent secondary disability. Transition to adult care services is a process that begins prior to the actual transfer and does not stop once the transfer has occurred. Youth, their families, paediatric healthcare providers, and adult healthcare providers all have an important role to play in the shared responsibility of patient care prior to and following the transfer of care.

Despite the importance of this interval in the transition to adult life for youth and their families living with diabetes, reports from families indicate transition is often not addressed in an organized, timely, and planned manner. In addition, paediatric diabetes programs across Ontario report that the transition of patients to adult care encompasses their greatest challenge in supporting quality diabetes management for their patient populations.

Purpose:

The Transition to Adult Care (TAC-WG) will make a comprehensive set of recommendations regarding a provincial approach for paediatric diabetes programs to transition youth and their families living with diabetes to adult care. Recommendations will be tailored to patients and families, paediatric and adult diabetes teams, Local Health Integration Networks, and the Ministry of Health and Long-Term Care, as appropriate. The recommendations put forward will be generic so that they can be adapted to each patient, patient population, and the unique characteristics of an organization or the health system as a whole.

Objectives:

- To identify current issues in transition to adult care, both from a paediatric and an adult care perspective
- To identify current best practices in transition to adult care
- To identify and clarify the roles of paediatric and adult teams over the period of transition to adult care

- To recommend strategies to ensure a seamless interface between paediatric and adult care providers
- To gain consensus regarding a framework for transition to adult diabetes care
- To prioritize strategies based on both importance and cost/ease of implementation
- To make recommendations regarding knowledge transfer to paediatric and adult health care providers, patients, and families
- To look at opportunities for partnering with and/or leveraging existing technologies
- To make recommendations regarding a plan for implementation of the recommendations
- To make recommendations regarding evaluation of the impact related to implementation of the recommendations

Accountability:

The TAC-WG will report to the Paediatric Diabetes Network Working Group (PDN-WG) of the Provincial Council for Maternal and Child Health (PCMCH).

Membership:

In order to ensure a comprehensive approach, TAC-WG members will be chosen from both paediatric and adult care, balanced by profession and organizational type.

Members:

- Paediatric Endocrinologists (2 - preferably at least 1 with involvement in ongoing transition clinical trials)
- Paediatric program Registered Nurses/Dietitians/Social Workers from a mix of secondary and tertiary centres (5)
- Adult program Endocrinologist/Registered Nurse/Dietitian/Social Worker (2)
- Representatives from established transition programs an adult settings (1)
- LHIN-based and/or MOHLTC-based representative(s) (1-2)

Given the focused nature of the group’s work, alternates will not be permitted. The PCMCH Paediatric Diabetes Network Coordinator will provide support to the TAC-WG.

Decision Making Process:

Members share accountability for decisions. There should be open and direct communication based on honesty, respect and transparency, to ensure that all perspectives are heard. Decisions should be evidence or most-promising practice based. Decisions will be made by consensus whenever possible. If voting is required, all members will have one vote.

Conflict of Interest:

Members of the TAC-WG shall disclose, to the chair of their group, without delay, any actual or potential situation that may be reasonably interpreted as either a conflict of interest or a potential conflict of interest.

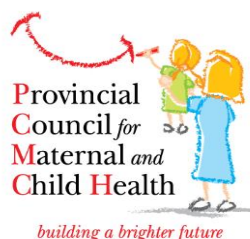
Communication and Confidentiality:

TAC-WG material should be treated as confidential. It will be clearly stated when TAC-WG material is no longer confidential.

Meeting Schedule:

October 2013 – March 2013

Appendix 2 – Transition to Adult Care Working Group Membership



Provincial Council for Maternal and Child Health Paediatric Diabetes Network

Transition to Adult Care Working Group Membership

Name	Profession	Organization	LHIN
Cheril Clarson (Co-Chair)	Paediatric Endocrinologist	London Health Sciences Centre - Children's Hospital	South West (2)
Zubin Punthakee	Endocrinologist (Paediatric and Adult)	Hamilton Health Sciences Centre - McMaster Children's Hospital	Hamilton Niagara Haldimand Brant (4)
Angelo Simone	Paediatric Endocrinologist	Paediatric Diabetes Services, Trillium Health Partners (Mississauga)	Mississauga Halton (6)
Cheryl Osborne	Clinical Manager	Paediatric Diabetes Education Program, Markham Stouffville Hospital	Central (8)
Ana Artiles	RN, CDE	Sick Kids (Toronto)	Toronto Central (7)
Kathy Parker	RN, CDE (Paediatric and Adult)	Diabetes Education Centre, Brant Community Healthcare System	Hamilton Niagara Haldimand Brant (4)
Annie Garon-Mailer (Co-Chair)	RN, CDE (Paediatric and Adult)	North Bay Diabetes Education Centre	North East (13)
Janine Malcolm	Endocrinologist (Adult)	The Ottawa Hospital	Champlain (11)
Suela Cela	MSW, RSW	Diabetes Comprehensive Care Program & Mobility Program St. Michael's Hospital (Toronto)	Toronto Central (7)
Leah Drazek	RN, MN, CDE	Women's College Hospital (Toronto)	Toronto Central (7)
Penny Frederick / Janet Harris	RN, CDE / RD, CDE	Peterborough Regional Health Centre	Central East (9)
Kirstin Yates	MPH, Psy.D, Clinical Health Psychologist	Hamilton Health Sciences Centre - McMaster	Hamilton Niagara Haldimand Brant (4)
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Appendix 3 – Discharge Planning Implementation Tool



Developed by the Provincial Council for Maternal and Child Health
July 2015

Discharge Planning Implementation Tool

	- 24 months Process Initiation	- 24 months	- 3 months	After Handoff
Transition Team				
Assess				
Design				
Implement				
Monitor				
Evaluate				

The following recommendations will guide your care of youth who will transition to adult health services at 18 years of age. This plan if fully implemented in your care setting will help you meet Accreditation Canada's transition standards published in Medical Services required organizational practices (ROPs) February 2015 for inclusion in 2016 accreditation surveys. Please note that while the plan identifies discrete time periods, they are a guide for activities which will in fact be iterative and on a continuum over the 24 months leading up to the patient's 18th birthday and transition to adult health services.

At an organizational level, consider the current workflow, policies and procedures, decision support analyses and IM/IT enablers which could be used, modified or developed to enable discharge planning implementation. Consider the following:

- Is there a policy or procedure in our organization regarding discharging an adolescent from paediatric care to adult services?
- Would it be possible to create a clinic visit called discharge consultation, in order to track the number of patients who were provided a formal discharge planning discussion?
- How can the information management system (electronic medical record) support the discharge summary development?
- Provide the discharge summary to the patient and or family so they can be informed and inform adult providers who may for some reason not have the discharge summary immediately available for the patient visit?
- Can we create or do we have a space within the discharge summary for patients to identify their goals for health and social development?

1

Guidance Timeline

Process Initiation: 24 months before transition discharge (< or = 16 years old)	
Transition team	<ul style="list-style-type: none"> Although plans begin as soon as a person becomes a paediatric patient, a minimum of 24 months before the person's 18th birthday, a series of decisions must be taken: Which program within an organization is responsible for managing the patient's transition Who is responsible for transition within a program Who in the regular health care team is the primary transition lead or facilitator for the patient If the patient attends other organizations, establish a lead organization (likely the organization where the most care is received)
Assess current state and gaps	<p>Identify:</p> <ul style="list-style-type: none"> a primary care provider (not a paediatrician) primary medical supports (specialists) <ul style="list-style-type: none"> community supports; regional and or provincial Supports <ul style="list-style-type: none"> financial social educational document transition assessment in chart document discussion with patient and family <p>Determine if there are:</p> <ul style="list-style-type: none"> organizational transition policies are in place to guide transition processes transition clinics of this diagnostic group, or general youth transition If there is no transition clinic in the organization, schedule a clinic visit to discuss and the initiation of transition; every HCP needs to discuss the transition – in addition the HCP may be supported by a transition clinic community services (such as CCAC, community organization coordinators) should be engaged in the process have a discussion about consent and capacity; start to prep child and family for the difference between family centered and patient centered care. Begin to encourage independence / autonomy.... At this point it should be a discussion. <p>Identify Gaps and issues between:</p> <ul style="list-style-type: none"> patient readiness¹ family readiness current paediatric services versus available adult services develop a plan to address readiness gaps for patient and for family

¹ A readiness for transition tool has been developed and validated by McMaster researchers and the use of this tool, or a similarly validated readiness tool is recommended. The development of a risk assessment tool to help identify those adolescents most at risk of encountering difficulty after transitioning from paediatric services is in development and will also be made available when it is ready on the CanChild website.

Process Initiation: 24 months before transition discharge (< or = 16 years old)																									
Design individualized state	<p>At every point of contact with the child and family assess readiness using readiness tools:</p> <ul style="list-style-type: none"> ▪ parent ▪ patient ▪ Link patient and family to resources <ul style="list-style-type: none"> ▪ developmental ▪ chronic disease <p>Develop a service mirror-example</p> <table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th colspan="2" style="text-align: center;">Paediatric</th> <th colspan="2" style="text-align: center;">Adult</th> </tr> </thead> <tbody> <tr> <td style="text-align: center;">X</td> <td>Primary care MD</td> <td style="text-align: center;">√</td> <td>Primary care MD</td> </tr> <tr> <td style="text-align: center;">√</td> <td>Respirologist</td> <td style="text-align: center;">X</td> <td>Respirologist</td> </tr> <tr> <td style="text-align: center;">√</td> <td>Endocrinologist</td> <td style="text-align: center;">X</td> <td>Endocrinologist</td> </tr> <tr> <td style="text-align: center;">√</td> <td>Mental health clinician</td> <td style="text-align: center;">√</td> <td>Mental health clinician</td> </tr> <tr> <td style="text-align: center;">√</td> <td>Paediatrician</td> <td style="text-align: center;">X</td> <td>Paediatrician</td> </tr> </tbody> </table>	Paediatric		Adult		X	Primary care MD	√	Primary care MD	√	Respirologist	X	Respirologist	√	Endocrinologist	X	Endocrinologist	√	Mental health clinician	√	Mental health clinician	√	Paediatrician	X	Paediatrician
Paediatric		Adult																							
X	Primary care MD	√	Primary care MD																						
√	Respirologist	X	Respirologist																						
√	Endocrinologist	X	Endocrinologist																						
√	Mental health clinician	√	Mental health clinician																						
√	Paediatrician	X	Paediatrician																						
Implement	<ul style="list-style-type: none"> ▪ Help patient complete "Good to Go Passport", an on line tool developed at SickKids to document key health information on a form that can be printed and folded into a wallet sized document; it includes the three sentence summary of health condition ▪ If multiple care organizations, collaborate to determine lead organization for transition preparation; most likely organization providing the most service ▪ If patient does not have a family doctor, patient and or family supported in finding one. ▪ Health update sent to (new) family doctor 																								
Monitor																									
Evaluate																									

12 months before transition discharge (< or = 17 years old)	
Transition team	
Assess	
Design	<ul style="list-style-type: none"> ▪ Develop "a Transition to adult health services document" that will provide an overview of the : <ul style="list-style-type: none"> ▪ transition process, issues and mitigation strategies ▪ social, educational, developmental status and supports ▪ a comprehensive discharge summary with standard elements provided by all disciplines currently involved in care <ul style="list-style-type: none"> ▪ all currently treating specialists to contribute standardized elements ▪ standard formatting recommended to improve clarity of communication for reader ▪ discharge summary sent to all adult providers and copy given to patient and/ or family (if patient gives permission to share with family). Exceptions only for components that are sensitive and have been identified as confidential ▪ Identify who will provide case management (may be primary care provider / service or may be community organization)
Implement	<ul style="list-style-type: none"> ▪ Start sending referrals for adult services ▪ Include a comprehensive summary that includes recommended elements ▪ Document activity and confirm plans for adult services: <ul style="list-style-type: none"> ▪ Name of provider / service ▪ Contact information for provider / service ▪ Location address ▪ Transportation to get to provider / service
Monitor	
Evaluate	




3 months before transition discharge (< 18 years old)	
Transition team	
Assess	
Design	
Implement	<ul style="list-style-type: none"> ▪ Primary case manager to conduct transition visit and include adult providers as appropriate and possible; if in person attendance is not possible, yet warm handover preferred, consider videoconference, or teleconference option for adult provider ▪ Ensure written documentation of transition visit in chart and given to patient and or family ▪ Ensure family knows of coordinator to contact if problems arise. ▪ Give written and verbal information to patient and family confirming all adult providers and services arranged: <ul style="list-style-type: none"> ▪ name of provider / point of contact at service ▪ date and time of appointment ▪ location of provider ▪ As availability and care complexity requires, link clinician types between paediatric and adult teams: nurse to nurse, social work to social work, physician to physician (by specialty, or ensure primary care adult doctor has contact information for paediatric specialist) ▪ Document and confirm to patient and or family where to seek care if required before first contact with adult provider
Monitor	
Evaluate	

After Handoff	
Transition team	To ensure smooth transition let the patient and family know that the pediatric providers can be contacted if problems arise prior to establishing the relationship / first visit with the adult provider
Assess	
Design	
Implement	
Monitor	<ul style="list-style-type: none"> ▪ Contact patient within three months after discharge to confirm first visit to adult provider(s) has taken place. Based on the phone call consider whether further action is required.
Evaluate	<ul style="list-style-type: none"> ▪ Plan to gather feedback from patients and family on transition process benefits and gaps (organization level) ▪ Further provincial evaluation activity will be considered within the context of PCMCH strategic work review and strategic planning

Appendix 4 – “Help Them Grow...so they’re Good 2 Go” Timeline – Diabetes Program

Help them grow... so they’re Good 2 Go!

DIABETES PROGRAM

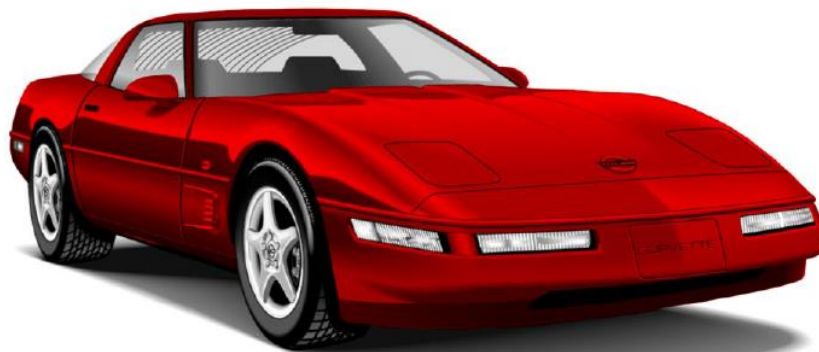
	For parents			For teens/youth	
	Birth to 3 years old	4 to 7 years old	8 to 11 years old	12 to 15 years old	16 years and up
General	<ul style="list-style-type: none"> Remember, your child’s diabetes is not who they are; expect normal childhood experiences Be a part of your child’s health-care team Take breaks to renew your energy and learn to accept help from others Encourage healthy eating habits for your child by setting a good example 	<ul style="list-style-type: none"> Praise your child for their efforts and accomplishments Encourage your child to make food choices, but continue to promote healthy eating Teach your child that behaviour has consequences and be consistent Limit screen time e.g. TV, video games, computer 	<ul style="list-style-type: none"> Recognize your child’s increasing need for independence Talk to your child about what they want to be when they grow up Encourage your child to express needs and wants Support your child’s involvement in activities to develop their interests 	<ul style="list-style-type: none"> Ask questions and keep the lines of communication open with your parents and diabetes team Talk to friends about your diabetes and how they can help you out Ask about bodily changes you are noticing 	<ul style="list-style-type: none"> Look for positive role models Keep exploring your interests in different activities Think about what you would like to do after high school and how to prepare for this Find out if you will be covered by your parents’ drug plan when you turn 18
Social	<ul style="list-style-type: none"> Take your child to playgrounds and community activities Set limits for your child to develop positive behavior Connect with other families who have a child with diabetes e.g. JDRF and CDA 	<ul style="list-style-type: none"> Explore with your child their feelings about having diabetes and, if they’re ready, talk about simple ways to tell others When your child visits friends, give the host parents a basic understanding about diabetes Try to control your own stress as children are sensitive to this and may try to hide things to avoid upsetting you Gradually assign your child more responsibilities e.g. cleaning up toys 	<ul style="list-style-type: none"> Coach your child on how to talk to their friends about having diabetes Think about registering your child for a session at the CDA’s Camp Huronda Prepare your child to safely perform diabetes care so they can visit friends on their own Introduce your child to positive role models with diabetes 	<ul style="list-style-type: none"> Meet new friends by joining activities that interest you Plan ahead for being away from home by showing that you can safely carry-out your diabetes care Take part in the Teen Day at SickKids to meet with other teenagers and talk about what it is like to have diabetes 	<ul style="list-style-type: none"> Talk about relationships and sexuality with someone you trust <ul style="list-style-type: none"> If you’re dating, decide when you are ready to talk about your diabetes When away from home, make sure that someone you’re with knows about your diabetes and what to do if you need help
Self-care	<ul style="list-style-type: none"> Let your child participate in their diabetes as appropriate e.g. putting the strip in the meter Carry out insulin injections and blood sugar checks in a calm matter-of-fact manner and praise your child for being co-operative Share responsibility for routines by making sure at least two adults can perform diabetes care Keep a logbook of your child’s blood sugar readings and insulin doses 	<ul style="list-style-type: none"> Provide reassurance, but don’t delay blood sugar checks or insulin injections Use distraction to help your child relax before diabetes routines e.g. singing, blowing bubbles and reward your child with incentives for co-operating Allow your child to have some control and involvement in their care e.g. choosing a finger for the blood sugar check, reading numbers from the meter Speak with the Child Life Specialist if your child is anxious about their diabetes treatments Make sure your child’s meter and low sugar treatment is always with you 	<ul style="list-style-type: none"> Encourage your child to wear a MedAlert bracelet Set realistic expectations by helping your child to not focus on every blood sugar reading Provide guidance to your child about the least painful way to do diabetes routines Promote healthy eating and encourage your child to take part in meal planning and preparation 	<ul style="list-style-type: none"> Ask for help from your parents with your diabetes care when you need it e.g. during stressful times or when you need a break Be honest if you make a mistake around your diabetes and treat it as a chance to learn Meet with the dietitian on your own to review carb counting and tips for healthy eating Work out a plan with your parents on how to keep your logbook up-to-date Make sure you have extra diabetes supplies and low sugar treatment stored at your school 	<ul style="list-style-type: none"> Create a plan with your diabetes team to make sure you are safe while driving <ul style="list-style-type: none"> Talk to someone you trust when you are feeling stressed by school or social/family pressures Plan ahead to fit your diabetes care into your life so you don’t miss out on anything e.g. keep a supply of insulin at your best friend’s house Learn how smoking, drugs and drinking will affect your blood sugars and overall health
Education	<ul style="list-style-type: none"> Use play activities and books to talk to your child about their diabetes Inform all caregivers about your child’s diabetes care in a simple and direct way Be honest when explaining a procedure to your child, even if it will hurt Talk to your child about upcoming clinic visits and bring a favourite toy for comfort 	<ul style="list-style-type: none"> Ask your diabetes team for a school resource package and discuss what to tell teachers Make sure your child knows the name of their medical condition Help your child to recognize low blood sugar symptoms and praise them for communicating these to others Learn that blood sugar highs and lows are not bad or good and will happen Find out about resources, such as the Diabetes Playbox and the Just for Kids diabetes website 	<ul style="list-style-type: none"> Teach siblings about diabetes, but limit the amount of responsibility you give to them Communicate with your child’s school to develop a plan that ensures safety Look at age appropriate websites with your child Remember, as your child develops, they can start learning more about their diabetes by participating in teaching sessions 	<ul style="list-style-type: none"> Learn a simple way to explain diabetes to teachers and other people in your life Become your own diabetes expert by increasing what you know e.g. understand what an A1c test is Speak to your diabetes team about the different types of insulin routines and which one is best for you Talk about birth control, drugs, alcohol and smoking with your diabetes team 	<ul style="list-style-type: none"> Consider volunteer work or a part-time/summer job Take more responsibility for your diabetes by emailing or phoning your nurse or dietitian with your questions Look into applying for a Diabetes Hope Foundation Scholarship if you are planning to go to college/university Attend the Transition Day offered at SickKids to help you prepare for adult care when you turn 18 Be involved in choosing your adult diabetes team and learn how your care will change
Medical	<ul style="list-style-type: none"> Work with your diabetes team to adapt treatments and meal times to your child’s usual patterns Learn why your child’s blood sugar target range and insulin regimen is unique for their age When your child is having a low blood sugar, describe the signs and symptoms to help them become more familiar with these feelings in the future Plan ahead for vacations by taking extra diabetes supplies and, if flying, get a travel letter 	<ul style="list-style-type: none"> Set new blood sugar targets with your diabetes team as your child becomes more predictable in their eating and can recognize low blood sugars Meet with the dietitian to review your child’s school schedule to create a more regular meal plan Prepare for diabetes management what if’s by talking with your team e.g. what to do if an insulin injection is forgotten Speak with your child’s doctor about the flu shot 	<ul style="list-style-type: none"> Help your child to speak directly to their diabetes team members at clinic appointments Learn how exercise affects blood sugars and how you can plan ahead to try to limit activity-related highs and lows Remember that some high and low blood sugars are due to things you cannot control, such as growth and stress Make sure you have a glucagon kit at home and ask for a refresher if you forget how to use it 	<ul style="list-style-type: none"> Find out when you need to start seeing an ophthalmologist and have regular complication screening tests performed Talk to your diabetes team about why your insulin doses need to increase as you grow and how hormonal changes can affect your blood sugars Create or update your own MyHealth Passport by visiting www.sickkids.on.ca/myhealthpassport Make sure you take extra supplies with you on vacation and bring a travel letter if you’re flying 	<ul style="list-style-type: none"> Be in charge of your clinic appointment! Meet with diabetes team members on your own, take responsibility for knowing your A1c result and book your future appointments. Make sure you have an updated MyHealth Passport by visiting www.sickkids.on.ca/myhealthpassport Let your SickKids team know if you have any problems attending your first adult appointment Celebrate your graduation from SickKids!

As your child grows, continue with the suggestions from earlier years and add new activities and responsibilities as appropriate. Consider your child’s unique developmental course and use this as a guideline.



Keys To Independence...

*Transitioning from the Pediatric
to the Adult Care Team*



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A Special Note to You and Your Family:

As a way to help make a smooth transition from pediatric to adult care, we have created this booklet to help you learn more about diabetes and to take charge of your diabetes and health.

The age at which you were diagnosed with diabetes will determine how much help you need in managing your diabetes. This book will serve as a tool for you and your family along with your health care team to help you reach your goals. As time goes on, we hope that you will start to use this booklet on your own. This is a great way to build confidence in yourself, and also to let your parents know that you are learning to take care of yourself.

As you grow and develop, you may find it helpful to refer back to the “Pink Panther” Understanding Diabetes book*. This is a great source for information about diabetes, ketones, standards of care, and long-term complications. Chapter 18 explores responsibilities of children at different ages.

As you learn more about diabetes, you can take charge of your life and your health.

We wish you well on your journey...

* H. Peter Chase, M.D.
11th edition ©2006



What Is Transition?

To get started, we look to our “Old friend” Webster’s dictionary. According to Webster, transition is “the passage from one state, stage, or place to another.” At the University of Wisconsin Diabetes Program, we see it as moving from pediatric to adult care in a way that feels safe and smooth to you and your family.

What Is Our Philosophy Regarding Transition?

We are committed to caring for people with diabetes across their lifespan. Helping young adults and their families move to the adult care team is a big part of our commitment. We believe transition is a rite of passage or a milestone that you and your family will experience. This is a big change. We want you to know that you are not alone and we will be here to help you with this change. We’ll help you throughout your journey and promise to take good care of you along the way.

Just like school prepares children for the future, we hope our pediatric diabetes program prepares you and your family for life as an independent, healthy adult. Our goal for all young adults is to learn about and manage their diabetes effectively and successfully.



What Is The Diabetes Care Team's Policy On Transition?

The diabetes care team has a policy that states that all young adults under the age of 18 will be cared for in the Children's Hospital. It also states that we can provide care up to the age of 21. Both the pediatric and adult diabetes care teams expect that you will transition by the age of 21. To help you make a smooth transition, we have developed a program to help you learn more about how to manage your diabetes as you move from pediatric to adult care.

Stages Of Transition

Just as you had to roll over before crawling, crawl before walking, and walk before running, there are times when you are ready to learn new things and take on more responsibilities. Your diabetes management is built on skills you will learn along the way. We have broken down these skills into five stages. We have given you an overview of what to expect during each stage.

Our philosophy is that your parents need to be involved in your diabetes management at least until you are 16 years old. We choose the age of 16 based on the fact that you can't drive a car until you are 16 years old. We also realize that not everyone is ready to be independent at the age of 16 and some may require more family involvement.

We included a checklist to help you learn more about diabetes. Learning the specific skills in each list will help you to take charge of your life and your health.

Our experience shows most young adults are successful when they have help from their parents throughout their adolescence.



Stage 1

Ages 8-10

The diabetes team begins to ask you (instead of your parents) questions about your health. We help you understand how food, insulin, and exercise affect your blood sugars.

Checklist

- Explain what it means to have diabetes.
- Understand why some people have diabetes and others do not.
- Begin to learn how your body uses the food you eat.
- Understand why checking your blood sugar is important, and learn to check your blood sugar.
- Begin to learn how to give yourself insulin.
- Begin to identify foods that contain carbs. (Carbohydrates)
- Begin to learn how to make healthy food choices that are part of your food plan.
- Begin to understand the causes, symptoms, and treatment for low blood sugars. (Hypoglycemia)
- Understand that insulin is going to be part of your daily life even when you are sick.
- Name insulin types and simple reasons for taking them.
- Begin to understand how sports, play, and exercise affect your blood sugar levels and insulin sensitivity.
- Begin to understand how your school day affects diabetes.



Stage 2

Ages 10-12

We continue to ask you questions about your health and diabetes. Try to answer questions about your health on your own. We will help you to understand your diabetes and how to recognize changes in your control. When you begin to notice these changes, you can start to take charge of your own care. This helps you be more independent.

Checklist

- Continue steps from stage 1.
- Remember (most of the time) to check blood sugars on your own.
- Choose foods that are healthy for you and fit your meal plan.
Discuss ways to make healthy choices at school, eating out with friends, and other special occasions.
- Begin to understand how an illness like a cold or flu can affect your body and blood sugar.
- Begin to answer questions in clinic.
- Understand why you come to clinic every three months.
- Begin to understand the importance of A1C values and target goals.
- Begin to name insulin types (use proper names), reasons for taking them, and the proper doses.
- Continue to understand how sports, play, and exercise affect your blood sugar levels and insulin sensitivity.
- Continue to understand how diabetes affects your school day.
- Begin to make choices about friends, drinking, and smoking that keep you healthy.
- Discuss effects of growth, puberty, and sexual development on diabetes.



Stage 3

Ages 13-15

The diabetes care team gives you and your family the option of seeing you alone for a portion of the visit. We will ask your parents to join you for the remainder of the visit to review information, talk about the health care plan, and answer any questions or concerns. This helps you to be more independent and to build confidence that you can take care of your health.

Checklist

- Continue with steps from the previous stages.
- Answer questions independently in clinic.
- Mix insulin and give all injections with minimal reminders.
- Parents review blood sugar logs, help you to think through and double check insulin doses.
- Let parents know when you need medications or supplies.
- Understand the significance of A1C, how the choices you make affect it, and how you can change the numbers of your A1C.
- Introduce the option of attending a teenage clinic.
- Begin to understand ketones, what they are, what they do, and how to check them.
- Begin to understand the tests that we do each year and why.
- Discuss effects of growth, puberty and sexual development, sexual activity, and reproduction on diabetes.
- Begin to understand the impact of diabetes on driving and the importance of checking blood sugar levels prior to driving.



Stage 4

Ages 16-17

This is a time when you, instead of your parents, begin to talk directly with the diabetes team over the phone when there are changes in your health. We will begin talking about your plans for after high school and how your career choice or school may impact you and your health. We will talk about when to transition to the adult care team. You and your family will have a chance to meet with adult team members during a clinic visit. (See more detail about this clinic visit under, “Common Questions And Concerns About Transition.”) You may have already done this if you have attended the “Teenage Clinic” held throughout the year.

Checklist

- Continue with steps from the previous stages.
- Independent with monitoring and recording blood sugars.
- Independent with all insulin doses without parents reminding you.
- Begin to call the diabetes team and speak directly with staff if there are changes in your health. (See Keys to Independence Resource Roadmap.)
- Understand the impact of diabetes on driving and the importance of checking blood sugar levels prior to driving.
- Know your health history including major illness, surgeries, allergies, and health care providers.
- Begin to think about the impact of college, work, and career choices on diabetes management.



Stage 5

Ages 18-21

We expect you to call the diabetes team independently if there are changes in your health. You will manage your own insulin and diabetes related medications and supplies and call when refills are needed. We will continue to talk about how school, work and lifestyle choices impact your health. We will talk about and help facilitate transition and link you with the adult diabetes care team.

Checklist

- Continue with steps from the previous stages.
- Routinely call the diabetes team and speak directly with staff if there are changes in your health.
- Understand reproductive choices and the impact on your diabetes and overall health.
- Understand Advanced Directives and complete if desired.
- Discuss long-term complications of diabetes, the need for routine follow up and tests, and the importance of glucose control into adulthood.
- Review the American Diabetes Association guidelines for managing and controlling diabetes. (See Keys to Independence Resource Roadmap.)
- Explore “Off to College” course offered by the Pediatric Diabetes Team.
- Establish care with an internist or family practice physician and with an adult diabetes team.



How to Prepare for Transition What adult family members can do...

1. When your child is age 8, begin talking to him/her about the changes that will happen in clinic. Explain that we will start to ask questions directly to him/her. This will allow your child to get comfortable answering questions while they have a “safety net” of a parent in the room.
2. Work with your child at home to take an active role in his/her care. You can use the checklist that we have provided as a guide. Gently encourage independence, but know that it will take time.
3. When your child is 14, encourage him/her to see the Diabetes team independently for the majority of the visit. You can join your child and care providers at the end of the visit to review information and ask any questions or concerns you may have. This will help your child become independent and form a relationship with his/her health care providers. This can also help him/her learn how to form future relationships with the adult care team. You may also encourage your child to attend the teenage clinic as a way to increase independence.
4. Find out about the age limit and terms of coverage under your health insurance policy.
5. Find out how your insurance company handles referrals to an adult diabetes care team.
6. If it would be helpful to you, ask to speak to another parent who has a child who has transitioned to the adult care team.
7. Remember, you are not alone and we will be here to help you with this change.



How to Prepare for Transition What adolescents / young adults can do...

1. As you get older, take on more responsibility for your diabetes.
2. Keep a list of your health care providers and other information about how you manage your diabetes.
3. Keep a log of blood sugars, insulin doses, and other medications.
4. Learn how to obtain and maintain an appropriate weight through good nutrition and exercise.
5. If it would be helpful to you, ask to speak to another young adult who has recently transitioned to the adult care team.
6. Find out how your health insurance coverage works.
7. Make a list of questions to ask your future health care practitioner.
8. Work through the checklists for each of the five transition stages.
9. Remember you are not alone... your parents, and the pediatric and adult care teams will help you with this change.

How to Prepare for Transition What the health care team can do...

1. Encourage you to meet the adult care team.
2. Encourage you to come to clinic prepared to talk about your health, medication and supplies.
3. Remind you that you are not alone and will help you with the move to the adult care team.
4. The adult care team will answer your questions and ease you into their system.



How Do You Know When It Is Time to Transition?

1. Do you take responsibility for your diabetes most of the time? Are you independent with your blood sugar testing and medication administration? Do you choose and make your own meals? Do you know how these choices affect your diabetes?
2. When you give the diabetes team your health history, does it sound the same as what your parents tell the team? Does your health history match with the diabetes team's view of your health and diabetes control?
3. Do you speak directly with the diabetes team?
4. Do you know when you need refills for your medication and supplies? Do you call the pharmacy?
5. Do you have a plan for your future, such as college or work?
6. Have you met the goals in each checklist?

If the answer to all the questions is "YES," then you are ready for transition.

If the answer to any of the questions is "NO," then a plan will be made to help you be more independent with that part of your diabetes management. However, answering no to any of the above does not stop you from transitioning to adult care. The adult care team is experienced in helping young adults become independent.



How Does Your Information Transfer To The Adult Care Team?

- A Medical Summary Transfer Form
- Medical Records will be sent upon your request
- Release of Information Forms to allow medical records to be sent to adult providers
- Bring patient and Family Notes to the Adult Care Team



Patient And Family Notes To The Adult Care Team

What would you and your family like the adult care team to know about you?

Lined area for patient and family notes. An illustration of an orange sports car is positioned over the lower portion of the lines.



Glossary

“Off to College” class – A one day course offered at the UW for high school graduates planning to attend college. It provides information regarding meal planning with college cafeterias, insulin adjustments, exercise on campus, sick days, and special accommodations available to students.

Annual labs/tests – Blood and urine tests done once a year to detect early signs of diabetes complications. These tests generally include thyroid studies, cholesterol screening, and urine microalbumin screening.

Diabetic Ketoacidosis (DKA) – What happens in the body when not enough insulin is available. The blood sugar is usually high at this time but can be normal. Moderate or large ketones are present in the urine and then build up in the blood. The ketones make the blood acidic resulting in total body acidosis.

Family Practice Physician – A doctor who specializes in the general care of children and adults.

Ketones – Acids that build up in the blood. They appear in the urine when the body doesn't have enough insulin. Ketones can poison the body. They are a warning sign that the diabetes is out of control or that a person is getting sick.

Ketostix – Test strips which are dipped into the urine to detect ketones.

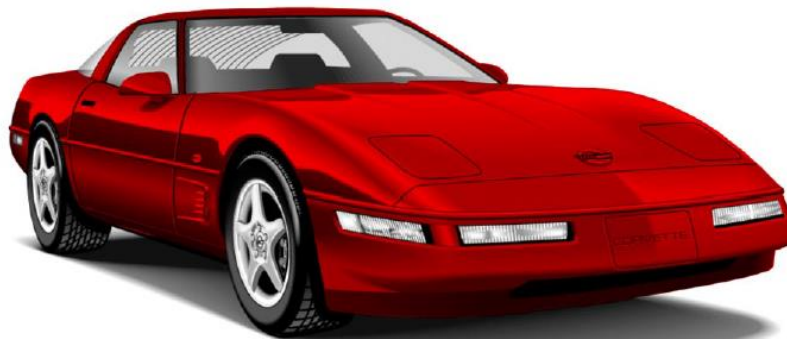
Medical records – Documents that contain one's health history, medical diagnoses, and treatments; cannot be shared without the individual's written permission.



Medical Release form – the document that provides permission to release all or a designated portion of the medical record. The individual or legal guardian must sign it.

Medical summary transfer form – a document outlining a person’s health history; utilized to ease his or her transition to another provider.

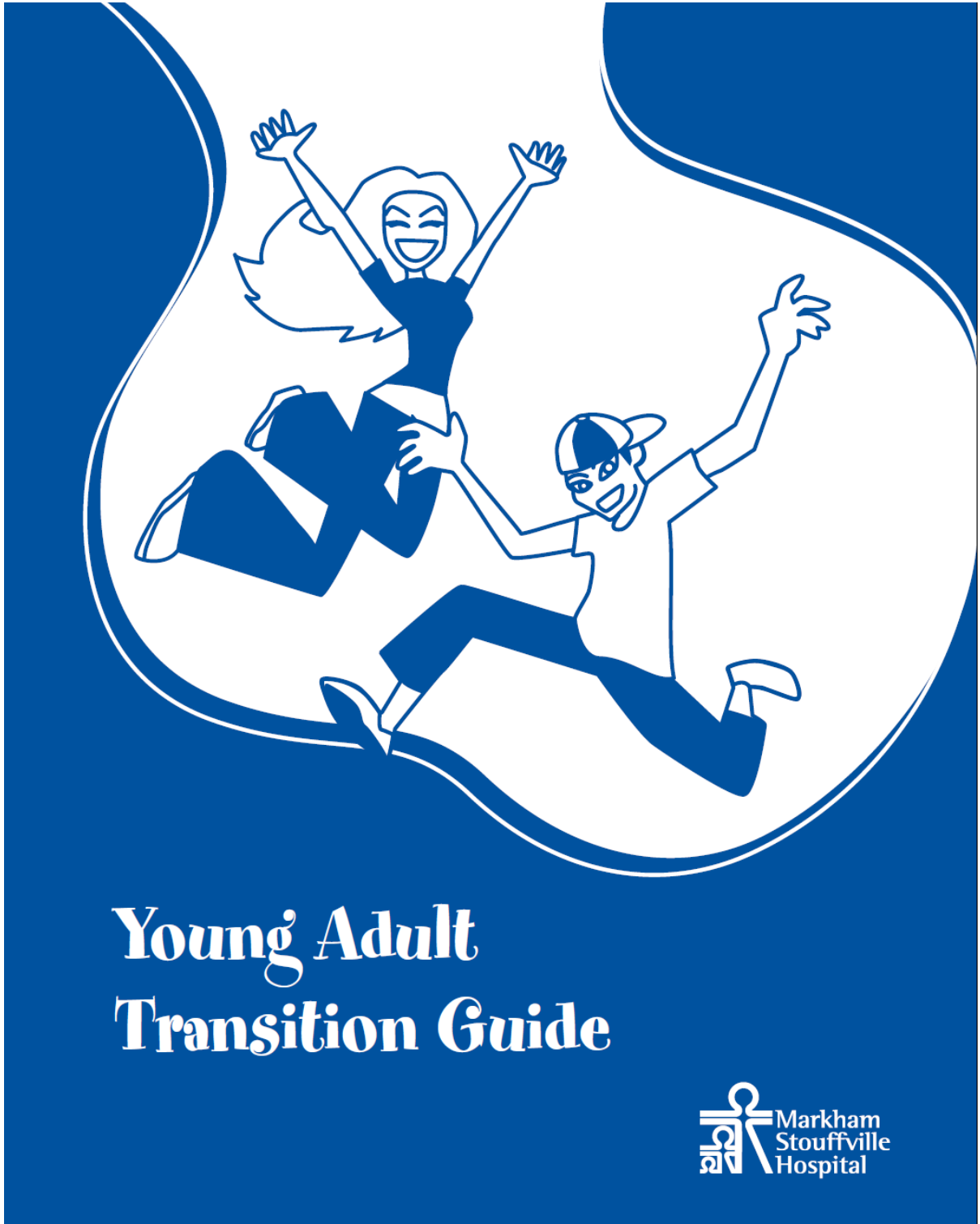
Teenage clinic – a UW pediatric diabetes clinic offered specifically for teenagers with the goal of assisting teens to become more independent in the care of their diabetes. The clinic focuses on issues of particular interest to teens.



Phone call “cheat sheet” for sick days or high blood sugars

1. What is your glucose reading right now?
When did you last check it?
Is this outside of your normal range?
2. Have you been nauseated, vomited or had diarrhea in the past 24 hours? What are you doing to manage your symptoms?
3. When was the last time you took any insulin?
What type was it?
How many units did you take?
If you are using a pump, what are your settings?
4. How old is the insulin you have been using?
Is it older than one month?
5. How do you usually correct a high sugar?
Do you use a correction scale?
Did you do this?
6. Do you have urine ketone sticks?
Have you checked your urine ketones?
7. Do you rotate your injection sites or do you use the same site all the time?
8. What pharmacy do you use?
What is the phone number and/or the fax number of the pharmacy?





Young Adult Transition Guide



THE YOUNG ADULTS GUIDE TO TRANSITION

In your eighteenth year you will be leaving our Paediatric Diabetes Clinic and will be moving on to an adult diabetes clinic for your diabetes care. This resource is to help guide you through the last two years of your paediatric care.

There are many issues that are important to discuss before you leave the paediatric clinic and this booklet has been developed to assist you. The responsibility of recording your own important health information helps prepare you for independence in your diabetes management.

Over the course of the next 4–6 clinic visits, different topics from the booklet will be discussed with you. There will also be several interactive handouts for you to keep. By your final visit all of the included documents will have been reviewed and discussed. The completed booklet is for you to keep. Please feel free at any appointment to ask questions or give comments on the material reviewed.



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INTRODUCTION

This initial section is designed to help you keep track of what you should expect at future clinic visits. It also provides a way to keep track of the skills and information that you will be talking about with the team.

Tracking Sheet for each visit

Date									
HbA1C (<.07)									
Meter									
lab									
Ht									
Wt									
BMI (20-25)									
TSH (0.34-5.6mu/L)									
Cholesterol (3.2-4.4 mmol/L)									
Eye Exam									
Other									
Albumin/ Creatinine ratio (<3.0mg/mmol)									

Young Adult's Checklist

Topics Covered	Signature of team member
<input type="checkbox"/> Adult Diabetes Clinic Terminology	
<input type="checkbox"/> A review of insulin action	
<input type="checkbox"/> Relationship of HbA1C to average blood sugar	
<input type="checkbox"/> Meal planning	
<input type="checkbox"/> Use of glucagon for severe hypoglycemia	
<input type="checkbox"/> Use of glucagon for illness	
<input type="checkbox"/> When you are sick	
<input type="checkbox"/> Alcohol	
<input type="checkbox"/> Smoking	
<input type="checkbox"/> Drugs	
<input type="checkbox"/> Driving	
<input type="checkbox"/> Personal Matters	
<input type="checkbox"/> Heading off to College or University	
<input type="checkbox"/> What to tell your roommate	
<input type="checkbox"/> Traveling	
<input type="checkbox"/> Employment	
<input type="checkbox"/> Financial	
<input type="checkbox"/> Complications	

Adult Diabetes Clinic: Terminology

The main goal of diabetes management is to achieve blood sugars that are as close to normal as possible without causing too many low blood sugars. Now that you are older and moving into an adult health care setting, you will be expected to achieve lower blood sugar readings than you did when you were younger. More aggressive and intensive treatment of your diabetes may be necessary to achieve these targets. Remember that the lower your HbA1C over time the less likely you are to develop complications. (pg. 25 on complications)

When you attend an adult program you may be asked to change your insulin dose or routine. The following are some of the terms that you may hear in the adult clinic.

Multiple daily injections (MDI)—4–5 insulin injections of fast acting insulin per day combined with 1–2 injections of a long acting insulin. Fast acting insulin is taken prior to each meal and insulin dose is based on the amount of carbohydrate that is to be eaten at that time. The benefit of MDI is flexibility in timing and amount of food. Properly used MDI has been proven to lower HBA1C.

Basal and Bolus Insulin— Basal insulin refers to your long acting insulin Lantus and Levemir when you are on MDI. If you are on a pump, it refers to the continuous flow of background insulin. Basal insulin covers your non food insulin needs.

Bolus doses of insulin are given prior to the mealtime intended to cover your food needs.

Correction dose—insulin given to account for blood sugar levels that are above the target range. For example:

Actual blood sugar target range 4–8

Actual blood sugar 12mmol/L

A correction is given to bring blood sugar back down the target range. The correction dose is individualized by your physician.

Carbohydrate counting—determining the amount carbohydrate you plan to eat at each meal using food labels and nutrient tables.

Insulin to carbohydrate ratio—the amount of Carbohydrate you eat determines how much insulin you need to cover a meal. Protein and fat that you eat are absorbed more slowly and have little effect on your blood sugar level. Your insulin to carbohydrate rates will cover your usual amounts of protein and fat, as well as your carbohydrate in that meal.

A typical ratio of 1 unit of insulin per 10 g of Carbohydrate, you would need 6 units of insulin for a 60g carbohydrate meal.

What to expect from the adult diabetes team visit

There will be some changes in your care moving from the paediatric to the adult care setting. The following are some of the new expectations:

1. The responsibility is shifted to you to make sure you check your blood sugars regularly and record readings in your log book. You need to take control of your care, if you have not already. You may not be reminded to do these things and you may need to learn how to ask questions of your provider instead of them asking you all of the questions. For example asking about the latest advances in diabetes management.
2. The team will most likely speak to you instead of your parents during your visit.
3. The focus will be on maintaining good control of your blood sugars with possibly lower target values.
4. Expectations will be to achieve an Hba1C to be less than 7%.
5. Insulin regimens may be changed.
6. When you are in the adult setting you may not have a diabetes nurse on call. Find out what your adult diabetes team wants you to do.
7. Your feet will be checked to make sure you don't have any early signs of complications.
8. See your eye doctor at least once a year.
9. Your family doctor will continue to be your primary care giver. He/she will continue to provide on-going medical support for all of your other health care.



MANAGEMENT

This section identifies and provides information about important aspects of your diabetes care that you need to know as you begin to take on more responsibility for your health.

A Review of Insulin Action Profiles

PROFILE	ONSET	PEAK	DURATION
Humalog/Novorapid	5–15 min	60–90 min	2–3 h
REGULAR	30–60 min	2–4 h	6–8 h
NPH	4–6 h	8–12 h	18–24 h
Lantus/Levemir	1 ½ h	none	18–24 h



The Relationship of Hemoglobin A1C (HbA1C) to Average Blood Sugar

The HbA1C is a test that correlates with the average blood sugar over the past 3 months. Hemoglobin is the part of the red blood cell that carries oxygen from the lungs to the rest of the body. Sugar sticks to hemoglobin and stays there for the lifespan of the red blood cell — approximately 3 months. HbA1C reflects the average blood sugar level during that period. The HbA1C should be measured every 3 months.

How does the average blood sugar measured translate to HbA1C?

Average Blood Sugar (mmol/L)	% HbA1C
15.5 – 19 mmol/L	12%
14 – 17 mmol/L	11%
12.5 – 15 mmol/L	10%
11 – 13 mmol/L	9%
9.5 – 11 mmol/L	8%
8 – 9 mmol/L	7%
6.5 – mmol/L	6%

Canadian Diabetes Association Guidelines For Glycemic Targets For Adolescents

Age (years)	A1C (%)	Blood sugar target range
13–18	<7.0	4.0–7.0
Adult	≤6	if safely achieved

Meal Planning

Many changes may be occurring in your life such as, going away to school, moving out on your own, starting a career and taking on full responsibility for all your diabetes management. At times your diet and exercise routine may not be a priority; However, to perform your best keeping your diabetes under control is essential. Management of your diabetes must include healthy eating and regular meals. This requires planning. Here are some simple suggestions for meal planning.

Some simple suggestions for eating and exercise.

- ◆ try to choose at least 3 out of the 4 key food groups at each meal
 - ◆ starch
 - ◆ fruits & vegetables
 - ◆ milk
 - ◆ protein foods
- ◆ choose portion sizes that will help you reach or maintain a healthy weight
 - ◆ by now you probably have stopped growing taller and do not need as much food as you did before.
 - ◆ if you are in the habit of filling up on protein choices as “free” foods consider the extra calories they are adding to your diet.
- ◆ try to include high fibre foods such as whole grain breads and cereals, fresh fruits, vegetables and legumes, and grains (pasta, rice)
- ◆ make lower fat choices (e.g. use skim milk, lean meat and use smaller amounts of added fat such as butter and salad dressings)
 - ◆ this can be challenging if you are eating out frequently.
 - ◆ have lower fat snacks available like yogurt and fruit instead of chips and granola bars.
- ◆ try to get some physical activity on most days of the week
 - ◆ build time in your routine to get some exercise, walk or ride a bike, go skating, take up a new activity.



** For more specific dietary advice speak to a dietitian.*

** Adapted from Canadian Diabetes Association 2003 Clinical Practice Guidelines.*

When you are sick

In the past, your parents have probably managed your diabetes for you while you were sick. When you are on your own managing an illness can be quite challenging. Here are some guidelines for you to follow.

During an illness:

- ◆ Check your urine for ketones every 4 hours and blood sugars every 2–3 hours or even more frequently if you are vomiting.
- ◆ Most of the time you should take your usual amount of insulin even if you are unable to eat your usual meals. **However**, if you are vomiting or your blood sugar is **low** you may need to decrease your overall insulin by 20% of your total daily dose. If you need help to adjust the insulin dose contact your diabetes team for advice. If you are both low and vomiting please follow the guidelines for using low dose glucagon.
- ◆ Check blood sugar and urine ketones every 4 hours to assess the need for more insulin. If blood sugar is higher than 13mmol/L and ketones are present give 10-20% of your total daily dose as extra insulin. To do this add up the amount of all of the insulin that you take in a day (fast acting and long acting) and take 10% of that as fast acting insulin right away. If the next blood sugar is not lower than 13mmol/L give 20% extra the next time your insulin is due. Add the extra insulin to your usual dose.
- ◆ Be sure to drink lots of fluids to prevent dehydration and help flush out any ketones. If blood sugars are high drink sugar free fluids and if they are low use sugar-containing fluids.

Also use The Sick Day Guidelines Pamphlet you will be provided with as an additional resource.



The Use of Glucagon for Severe Hypoglycemic Reactions

Glucagon is a hormone made by the alpha cells of the pancreas. It raises the blood sugar level by stimulating the liver to release some of its store of carbohydrate (glycogen) into the blood as sugar.

Glucagon is packaged as a kit with one vial containing 1 milligram (mg) of glucagon as a dry powder, and a syringe preloaded with 1cc sterile diluent. It is to be used when there is a **severe hypoglycemic reaction** and you are unconscious, or having a seizure, or so uncooperative that juice or other concentrated sugar is not safe to be given by mouth. Glucagon should be given by someone else like a roommate.

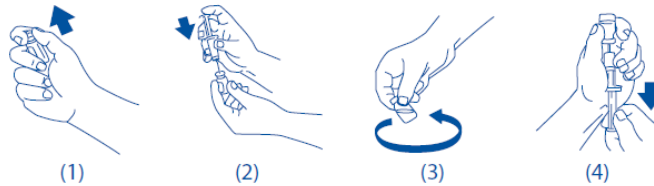
Review these guidelines with a roommate or living companion as you will not be able to administer the Glucagon yourself.

Glucagon cannot be given by mouth. If someone has a seizure call 911.

Once unconscious you should be turned on your side.

To use the kit*

1. remove the cap
2. inject the diluent directly from the loaded syringe into the dry powder vial
3. roll gently to dissolve
4. withdraw the fluid.
5. Inject the entire syringe as you would an injection



It may take a little time to respond fully, possibly 10–20 minutes. Once alert, it is very important that you be given some juice or fast acting sugar, followed by a long acting carbohydrate source. Nausea and vomiting are common side effects and can last up to 24 hours. Your family physician or diabetes team should be contacted, as you may need to adjust in your insulin dose.

**Adapted from the BC Children's Hospital handout "Glucagon for Severe Hypoglycemic Reactions"*

The use of Glucagon during Intercurrent Illness

Rationale:

During a time of illness, especially with vomiting and diarrhea, your blood sugar may fall to dangerously low levels. This often requires that you may need to go to the emergency room to be put on an IV with glucose. Tiny amounts of glucagon given like insulin can keep the blood sugar up without causing vomiting and may be able to prevent a trip to the hospital.

How to use Glucagon

1. Dilute the glucagon in the usual fashion.*
2. Using an **insulin syringe** draw up 15 units.
3. Inject the glucagon under the skin like insulin.
4. Check the blood sugar in 30 minutes. It should have risen.
5. You may repeat the injections every 2 hours if the blood sugar falls too low again.
6. If after 3 injections the blood sugar drops too low, go to the nearest hospital emergency room for an I.V.
7. If you are not nauseated, continue to drink small amounts of sugar containing fluids.

**Once prepared glucagon may be stored in the refrigerator for up to 12 hours.*



LIFESTYLE

This section covers some of the challenges that you can encounter as a teenager having diabetes. Here is information and tips on how to safely enjoy your growing independence and freedom.

Alcohol

What is happening to my body?

When you drink alcohol it is absorbed very quickly into your body. The alcohol travels from the bloodstream to the liver. The liver's function is to remove the alcohol from your body as fast as possible. It is important to drink slowly because the liver can only remove 1 drink per hour from your body. When you drink more than this, alcohol builds up in your bloodstream, which leads to the symptoms of being drunk. Also, when you have been drinking or are drunk, it is easy to miss the early signs of a low blood sugar because they both appear similar. It is important that at least one friend knows you have diabetes.

It is important to be careful when drinking when you have diabetes because there is a high risk for getting a low blood sugar. Usually when someone with diabetes has a low blood sugar, the liver produces emergency sugar, but when you are drinking, the liver is too busy processing the alcohol that it is unable to make the emergency sugar. As a general rule, pure alcohol lowers your blood sugar while a mixed drink with juice or regular pop may raise your blood sugar. It is important to bring your glucometer with you so you can catch your "highs and lows" It is also important to carry juice, candy or something to treat your blood sugar in case your blood sugar drops too low.

Getting ready for a night out

- ◆ Stick to your usual meal plan. Drinking should never replace your meals.
- ◆ Check your blood sugar before you go out, but don't leave your meter at home. You will need to check your sugars throughout the night.
- ◆ Make sure at least one friend knows that you have diabetes. This is so they can help you in case you have a low blood sugar reaction. Sometimes it's easy for friends to think you may be acting "different" because of the alcohol instead of a low blood sugar.
- ◆ Carry a snack with you.
- ◆ Carry a fast acting sugar with you. (juice, candy, glucose tablets, anything to treat your lows)

At the party

- ◆ Always choose the sugar free option. So instead of a rum and coke, go for the rum and diet coke.
- ◆ Remember to drink slowly. Your liver can only clear one drink an hour from your system. Don't let that liver of yours work overtime!
- ◆ Never drink on an empty stomach. Since you have followed your regular meal plan you should have already had your dinner by now and if not what are you waiting for? You need to eat!
- ◆ Eat extra snacks for extra activity. If you are dancing at the party you will use extra energy, so you need to eat extra starch or fruit for each 1/2 hour of extra activity.
- ◆ Watch for low blood sugars. Having a low blood sugar and drunkenness can sometimes feel the same. It's important you test your blood sugar to know what is really going on.

Time to Go home

Okay its has been a fun night and now you are home.... now what??

- ◆ Check your blood sugar again and have a snack. Alcohol can cause unexpected changes in blood sugar levels. Blood sugars may rise initially when drinking, and then may drop several hours later. Alcohol has delayed effects on lowering blood sugars, even up to 14 hours.

To sleep in or not to sleep in... that is the question.

- ◆ Although it may be tough, it is important to take your insulin and have breakfast at the usual time. Not following your regular routine can be very dangerous to your health. If you are still tired, you can go back to sleep for a few hours.



Smoking

Most people know that smoking causes cancer and breathing problems. But it can also cause other problems, especially if you have diabetes. Smoking and diabetes is a dangerous mix. Smoking decreases the way blood flows through your body, therefore increasing the chance of getting long term complications of diabetes including heart disease and amputation.

Here are the facts:

- ◆ When you smoke, less oxygen flows inside your body. This can cause a heart attack or a stroke.
- ◆ Smoking damages your blood vessels, which makes it harder for your body to heal. This can lead to infections in your legs and feet which can lead to amputation.
- ◆ If you smoke and you have diabetes, you are more likely to get nerve damage and kidney disease.
- ◆ Smokers are more likely to get colds and respiratory infections.
- ◆ Smoking can lead to impotence.
- ◆ Children are more likely to start smoking if their parents smoke.

No matter how long you have smoked it is never too late to quit. Your health will start to improve right after you quit or cut down a lot on the amount that you smoke. Kicking the habit is hard to do — but is worth it.

You benefit in important ways when you have diabetes and quit smoking.

When you quit smoking, you have:

- ◆ less resistance to insulin
- ◆ less chance of eye damage
- ◆ less chance of kidney damage and kidney failure
- ◆ less chance of nerve damage

Results of your blood tests may improve when you quit smoking.

Possible effects on your blood test results are:

- ◆ lower A1c levels
- ◆ lower glucose levels
- ◆ lower cholesterol levels
- ◆ lower LDL (bad) cholesterol levels
- ◆ lower triglycerides (fats) levels
- ◆ higher HDL (good) cholesterol levels

Drugs

The biggest risk of using street drugs is that it is illegal. Also, what you've been told you are getting may not be really be what you get. If you want to take this risk, you may change your mind after reading the facts below.

Marjuana

- ◆ **Will impair your judgment** so it is likely you will not make the best decisions about food, insulin, activity, sexuality, etc. Because drugs influence the brain there is a higher chance of dosage errors, mistakes about how to respond to blood sugar results and perhaps also timing errors.
- ◆ **Causes problems with memory**, concentration, sensory and time perception, coordinated movement and problem solving, which may effect control.
- ◆ **Increases appetite:** and can cause overeating, which can lead to hyperglycemia.

Opiates/Heroin

- ◆ Can change eating habits, which can affect your blood sugar
- ◆ Alters perception which can affect the ability to manage diabetes.
- ◆ Highly addictive

Cocaine

- ◆ Can increase blood sugars and change eating habits
- ◆ Can cause high bloodsugar as a result of increased liver glycogen breakdown
- ◆ Alters perception which can affect the ability to manage diabetes
- ◆ Highly addictive

Reference: Campbell K. et al (2003). Effects of legal and illegal substances on diabetes control Diabetes Interview.

Driving

For anyone who is planning to get their driver's license, it is important to remember that driving is not a right, but a privilege. All people who intend to drive must prove that they will be responsible behind the wheel. When you have diabetes you have to make sure that your diabetes is well managed and take certain precautions when you drive.

Precautions while driving

Diabetes is a condition that has the potential to make driving unsafe. Hypoglycemia is your greatest risk when driving, because it can slow your response and reaction time for up to 45–60 minutes. This not only puts you in danger but it puts pedestrians, other drivers and your passengers in danger. It is recommended that you take the following precautions when driving:

- ◆ Check your blood sugar prior to driving and approximately every 4 hours thereafter if you are on a long trip.
- ◆ If your blood sugar is below 4 mmol/L treat with 15 grams of fast-acting carbohydrate (glucose tablets or regular pop) followed by a snack before driving.
- ◆ Always have a source of fast-acting glucose within easy reach while driving. As well, keep your blood glucose meter with you in the car, along with plenty of snacks in the glove compartment.
- ◆ If you feel like you are having a low blood sugar reaction while driving, **immediately** stop driving and treat with fast-acting glucose followed by a snack. Resume driving only when your blood sugars have returned to normal (above 6 mmol/L).
- ◆ Always wear your diabetes ID when driving.



Personal Matters

Now that you are approaching adulthood issues of sexual activity, birth control and eventually pregnancy planning must be considered. Decisions on these matters are personal but will have an impact on your diabetes. You should be aware of your options.

If you are planning to be sexually active and do not want to get pregnant, it is important to start on a birth control method. There are many options available including birth control pills, the patch and depo shots etc. It may be a good idea to speak to your doctor about the best option for you. The most important thing to remember is the choices for birth control methods are the same for those with or without diabetes.

Key point: Birth control options are the same for those with or without diabetes.

Pregnancy and Diabetes

Having children is a big decision for anyone. If you are a woman who has diabetes, however, it is a decision that requires much more thought and careful planning. Many women who have diabetes have healthy pregnancies and healthy babies. But this isn't to say that it's an easy experience — it requires a lot of work and dedication.

Importance of planned pregnancies

Poor **control of blood sugars** before conception and through the first eight weeks of pregnancy greatly increases the chances that your baby will develop problems. That is why it is very important to have a planned pregnancy.

You can increase your chances of delivering a healthy baby by keeping your blood sugar in good control before conception and throughout your pregnancy. The first eight weeks are particularly important for the physical development of your baby.

If you plan to get pregnant discuss it with your diabetes team.

Cut down or cut out alcohol

Drinking too much alcohol during pregnancy can harm your baby. It also affects your blood sugar levels and can increase your risk of hypos. 'Less is best' when it comes to alcohol and, ideally, stop drinking altogether until after your baby is born.

Try to stop smoking

Smoking while pregnant can harm your baby. The effects it has on your child can last well into childhood and can be permanent. The potential problems caused by diabetes can make smoking even more unhealthy for you.

Heading off to College or University

Trying to find the right balance between diabetes and school life can be quite challenging. Here are some hints to help you transition from living at home to living on your own more smoothly.

Student tips for Special Arrangements/Housing Plans

During the enrolment process:

- ◆ Mark the "disability" box on the application form. This notifies the school that you have a medical condition that may require special attention. This will make things easier once you start.
- ◆ Register at the disabilities office/resource center. Diabetes is not a physical disability, however by registering at the office, you may be allowed special/preferred housing, parking and meal plans. This allows for the support you may need.
- ◆ Try to get housing that has an open kitchen, or is near a 24-hour food source. A dorm with a late night cafeteria, or housing near a fast food places, or eating spots on campus.
- ◆ Get a small fridge for your dorm room. This is for storage of emergency snacks or light meals (milk yogurt, cheese, juice) and insulin.
- ◆ Get a meal plan. This is so you will have easy access to food.

Dorm set-up:

- ◆ Have your diabetes supplies easily accessible.
- ◆ Have food available for snacks and easy weekend meals.

It is important to let the people around you know that you have diabetes, what it means to have a low blood sugar, what symptoms you may have and how to treat it.

Take advantage of any resources that may come your way.

Many schools offer people registered with diabetes a note-taker for any class you may have missed for medical reasons. The school must allow you to make up any exams that you may have missed for that same reason. Some schools may also have affirmative action programs for students with diabetes. Don't use diabetes as an excuse, but it is nice to know that these services are available if you need them.

Not all schools are able to offer all of these services/benefits because of limited resources. Most campuses have some form of support teams in place to help students if they need it. Informing as many offices and people at school that you have diabetes as you can may help the transition from living at home to living away as smooth as possible. Some schools have financial resources available for supports and supplies.

Exams

- ◆ Have extra food or snacks available when taking major exams.
- ◆ Inform your test supervisor of your diabetes, and any need you may have.
- ◆ Remember to 'graze': strenuous brain activity may affect your blood glucose (sugar) similar to physical activity.
- ◆ If your blood sugar is low during the test, inform your supervisor.
- ◆ Let the supervisor know that your meter may "beep" if you need to check your blood glucose (sugar) level. Or if your pump may "click" when you need to give yourself insulin.

What to Tell Your Roommate

Moving away from home and living on your own—whether it is away at school or in an apartment with friends—can be both exciting and scary. There are many new experiences to face. Having diabetes can make things even more challenging. It is especially important that your roommates are aware that you have diabetes, and what that means.

We suggest that you discuss the following with your roommate.

- ◆ A simple explanation about what diabetes is, what you need to do each day (for example, blood glucose testing, insulin injections, eating meals and snacks on time).
- ◆ Explain what hypoglycemia is and list your symptoms:
Confusion Glassy stare Shakiness Irritability
Moodiness Incoherence Dizziness
- ◆ Tell your roommate that if you need assistance with treating a low blood sugar how they can help.
 - ◆ Giving 125mL regular pop, juice or glucose tablets.
 - ◆ Tell them that if you should refuse to cooperate, it is still important that they make sure that you eat something with sugar in it.
 - ◆ If you aren't feeling better after 10–15 minutes, they should insist you take more carbohydrate.
 - ◆ If your roommate ever finds you unconscious or having a seizure, at any time, even after partying, or they cannot wake you up, they should call 911 immediately.
 - ◆ to use glucagon if they have been shown how and are comfortable using it.
- ◆ Have a list of emergency contact numbers readily available. Know where the local hospital is.
- ◆ Have a supply of food somewhere specific in your room, and explain the importance of it being your 'emergency food,' and that it cannot be shared.
- ◆ Provide opportunities for your roommate to ask questions about your diabetes. It may be totally familiar to you, but not necessarily for your roommate, and it may take time for him/her to adjust to it.

**Adapted for the BC Children's Hospital handout*

Traveling

Your diabetes should not prevent you from traveling anywhere in the world. However, before you set off you need to plan ahead carefully and consider the following information.

Preparing for your trip:

- ◆ If you know that you will be traveling through several time zones you will need to adjust your insulin doses. For example flying East to Europe will shorten your day so you may need less insulin while flying West to Hawaii will lengthen your day so you may require more insulin. Ask your diabetes team for advice.
- ◆ You should also travel with a letter from your diabetes clinic confirming the fact that you have diabetes and that you need to carry syringes, needles, insulin and testing equipment and may be wearing an insulin pump.
- ◆ Make sure that you have an ample amount of insulin and diabetes supplies just in case of loss or accidental breakage. A good guide is to double up on what you would usually require if you were not traveling.
- ◆ Air Canada recommends that you advise the airline when you are booking your ticket that you use insulin and will be traveling with diabetes supplies. You also have to advise the ticket agent at check-in as well as security.

Most airport x-ray machines will not affect insulin pumps or blood glucose monitors.

- ◆ Always carry your diabetes supplies in your hand baggage. You are less likely to become separated from your carry-on bags and insulin that travels in the baggage hold of an airplane is subject to extremes of temperature.
- ◆ Obtain proof of prescription for your medications and syringes. Make sure you have a prescription label on your insulin vials or cartridges.
- ◆ Look into buying travel insurance.



Diabetes Supplies checklist

- Diabetes ID (medic alert bracelet or necklace)
- Insulin or medications to last the whole trip
- Blood sugar meter and extra battery
- Strips for meter
- Syringes or pen needles
- Proof of prescription for supplies (box with original label)
- Alcohol wipes
- Glucose tables or candies
- Lancets
- Non perishable snacks
- Travel letter
- Glucagon emergency kit

Other helpful hints

- ◆ Your hand baggage should include food supplies in case of flight delays and a supply of glucose tablets and/or whatever food or drink you usually use to treat low blood sugars.
- ◆ Double the amount of insulin, lancets, strips, syringes/pen, needles, etc. necessary for your whole trip.
- ◆ Take a glucagon kit with you especially if your destination is off the beaten track. Make sure to instruct a traveling companion on when and how to use the glucagon injection.
- ◆ At home or abroad, it is always a good idea to wear some form of diabetes identification such as a medic alert.
- ◆ Travel insurance is available to all members of the Canadian Diabetes Association. For further information, please contact:

Canadian Diabetes Association
15 Toronto St., Suite 800
Toronto, Ontario M5C 2E3
(416) 363-3373
Or 1-800-BANTING (226-8464)
Visit www.diabetes.ca

Employment:

Things to Consider:

When considering a part time job, people may worry about discrimination if their diabetes is revealed at the time of employment.

A person's medical information is confidential and therefore unless health related questions are directly related to a specific job requirement, a person with diabetes is not required to report diabetes on their employment application or in an interview. The decision is yours.

The employer does not need to be provided medical information after employment begins unless the employee wishes to disclose it. However, you may wish to consider this for safety reasons.

The employer needs to make provisions allowing the employee to have time or space for meals or other aspects of diabetes management.

If any extra information is needed to address these concerns then see "The Human Rights Commission" for "A Guide to Creating an Inclusive Workplace".



Financial

As you are aware, there are some costs associated with your diabetes care. They may include: insulin, syringes, blood glucose (sugar) monitor, blood and urine test strips and trips to hospital appointments. There are a number of programs listed that may be able to assist you. There are some Universities and Colleges that are now covering medical supplies for their students so please inquire at your school as to whether this is an option.

Name of Program	Coverage	Documentation Required	Application Process
Monitoring for Health	Must be insulin dependent and/or gestational diabetes. Reimbursement of up to 65% of the cost of strips and bloodletting devices up to \$500/ year.	Ontario resident Health Card Monitoring for Health Claim form completed by physician.	Contact Canadian Diabetes Association 1-800-361-0796.
Trillium Drug Program	Assistance for medical supplies for managing your diabetes as well as drug costs for your entire family.	Income tested outline in the application package.	Ministry of Health and Long Term Care 416-326-1558.
Income Tax		You are advised to keep track of all expenses associated with your diabetes and general health.	You may be eligible for a deduction of medical expenses.
If you are receiving assistance from Ontario Disabilities Support Program	Drug Card to cover diabetes supplies	Income tested Tax Return Medical Letter	Contact Ministry of Community, Family and Children's Services 1-877-669-6658.
If you are receiving assistance from Ontario Works Regular Benefits	Ongoing benefits including coverage for medical supplies	Income tested Medical Letter Social Insurance Number	Ontario Works 1-877-464-9675.

Complications & How to Avoid Them

People with diabetes are at risk to develop problems with your eyes, kidneys and nerves. In addition, people with diabetes are at greater risk for early heart attacks, strokes and poor circulation to the feet. The longer you have diabetes the greater your risk. The risk of complications can be greatly reduced by having good control of your blood sugar. The lower your Hba1c the lower the risk.

The following is a brief description of each of the complications:

Eye Disease: Retinopathy

Poor control of diabetes can lead to damage of the small blood vessels of the eyes. This is why we look in your eyes at clinic visits and why formal eye examinations are necessary every 1-2 years.

Kidney Disease: Nephropathy

Poor control of diabetes can lead to kidney damage. This is why we check your urine for protein, the first sign that there may be a kidney problem. High blood pressure accelerates kidney problems. This is why we check your blood pressure regularly and recommend treatment if it is elevated.

Nerve Disease: Neuropathy

This affects mainly the nerves to the legs and sometimes the arm. The usual symptom is pain. This pain can be severe. Also, there may be loss of sensation, tingling and in men impotence—the inability to maintain an erection. Again, good control of blood sugar will reduce the risk of this occurring.

Heart Disease and Stroke

Persons with poorly controlled diabetes may have early heart attacks and strokes. Research has clearly shown that good diabetes control will reduce the risk. Also persons with diabetes are at risk for circulation problems. It usually occurs in the feet, which could lead to amputation.

Complications & How to Prevent Complications

- ◆ Control your blood sugar
- ◆ Treat high blood pressure
- ◆ Have regular eye examinations
- ◆ Take care of your feet— avoid going barefoot
- ◆ DO NOT SMOKE
- ◆ See your Diabetes Health Care Team regularly

Resource List

www.diabetes.ca (*Canadian Diabetes Association*)

www.diabetes.org (*American Diabetes Association*)

www.diabetes-children.ca (*The Diabetic Children's Foundation*)

www.jdrf.org (*Juvenile Diabetes Research Foundation International*)

www.diabetes-exercise.org (*Diabetes Exercise and Sports Association*)

www.ezdiabetes.com (*Kids health: dealing with diabetes*)

www.diabetes.org/diabetes-forecast.jsp (*Diabetes Forecast*)

www.bcchildrens.ca (*BC Children's Hospital*)

www.diabetescareguide.com (*Canadian Diabetes Care Guide*)

www.kidswithdiabetes.org (*Kids with Diabetes*)

www.hc-sc.gc.ca (*Health Canada: Nutrient value of some common foods*)

www.nal.usda.gov (*USDA National nutrient database*)

www.ndhn.com (*Listing of Ontario Diabetes programs*)

www.sickkids.ca (*click> on about kids health*)

For a complete list of diabetes resources go to :
www.bcchildrens.ca
(*Search for department of Endocrinology and diabetes; for families then look for handouts.*)

Important Telephone Numbers

Markham Stouffville Hospital

Main Number: (905) 472-7000

Your New Health Care Team

Phone Number: _____

Contact Name: _____

Diabete Nurse: _____

Dietitian: _____

Adult Endocrinologist: _____

Appointment Date: _____





Young Adult Transition Guide



381 Church Street, P.O. Box 1800
Markham, Ontario, L3P 7P3
Tel: (905) 472-7000
www.msh.on.ca

3248-06-2006

Appendix 7 – “Moving On...” With Diabetes: Knowledge & Skills Self-Assessment (Ages 13-16 years)

“MOVING ON...” WITH DIABETES

KNOWLEDGE & SKILLS SELF-ASSESSMENTS (AGES 13-16 YRS)

DIABETES EDUCATOR/TEAM USER GUIDE

PURPOSE

- Evaluates knowledge and skill level related to **diabetes management**.
- Directs further education/skill development prior to transition.
- Provides adolescent self-assessment of learning needs.
- Used by pediatric designate/team to work through topics.
- Topics color-coded for ease of use.

INSTRUCTION

- Complete during the **preparation phase** of the transition process (**ages 13-16 years**).
- Document name, age, and year completed and keep on chart.
- Mail out prior to appointment or have completed while adolescent waiting to be seen.
- Use all topic sheets intermittently through ages 13-16 years.
- Use individually or in a group session.
- Review and assess actual knowledge and skill level of topic on a regular basis.

Transition from pediatric to adult diabetes care is a purposeful, progressive process.

The pediatric team members should continuously review and re-assess actual knowledge and skill level of the adolescent through active discussion of answers circled on the topic sheets, problem solving (using their own data, situations, etc.), and what the adolescent is actually doing on a day to day basis.

It is important to verify that the adolescent is at the level he/she thinks, with regard to self-management skills, to identify any gaps that need further education/skill development prior to transition.

“Moving On...” With Diabetes

The following self-assessment will help you and your diabetes team understand what you already know about your diabetes and where you need more information.

Name: _____ Age: _____ Month/Year Completed: _____

BLOOD GLUCOSE CHECKS

In the sections listed below, circle the number that best describes how well you know each topic (1 means you know nothing about the topic, and 5 means you know everything about the topic).

I know ...

How to take care of my blood glucose meter	1	2	3	4	5
How to do a lab comparison test with my meter	1	2	3	4	5
How to keep a record of my blood glucose readings	1	2	3	4	5
How to look for patterns in my blood glucose readings	1	2	3	4	5
Why it is important to wash my hands before testing	1	2	3	4	5
What my target blood glucose is before and 2 hours after meals	1	2	3	4	5
How often I should check my blood glucose	1	2	3	4	5
How to upload blood glucose readings from meter	1	2	3	4	5

“Moving On...” With Diabetes

The following self-assessment will help you and your diabetes team understand what you already know about your diabetes and where you need more information.

Name: _____ Age: _____ Month/Year Completed: _____

INSULIN

In the sections listed below, circle the number that best describes how well you know each topic (1 means you know nothing about the topic; 5 means you know everything about the topic).

I know...

The name and type of my insulin(s)	1	2	3	4	5
How and when my insulin(s) works	1	2	3	4	5
How to choose insulin injection or pump site(s)	1	2	3	4	5
Why I should rotate my sites	1	2	3	4	5
The best way to inject my insulin	1	2	3	4	5
How to use my insulin pen (or insulin syringe)	1	2	3	4	5
How to adjust (change) my insulin dose	1	2	3	4	5
How to store my insulin at home	1	2	3	4	5
How to store my insulin when travelling	1	2	3	4	5
What to do with my used needles and sharps	1	2	3	4	5

“Moving On...” With Diabetes

The following self-assessment will help you and your diabetes team understand what you already know about your diabetes and where you need more information.

Name: _____ Age: _____ Month/Year Completed: _____

FOOD

In the sections listed below, circle the number that best describes how well you know each topic (1 means you know nothing about the topic; 5 means you know everything about the topic).

I know how to...

Choose healthy meals/healthy portions	1	2	3	4	5
Space my meals and snacks	1	2	3	4	5
Choose healthy snacks	1	2	3	4	5
Read food labels	1	2	3	4	5
Count carbohydrates	1	2	3	4	5
Adjust my insulin dose for the number of carbohydrates that I eat	1	2	3	4	5
Manage my diabetes during parties and special occasions	1	2	3	4	5

“Moving On...” With Diabetes

The following self-assessment will help you and your diabetes team understand what you already know about your diabetes and where you need more information.

Name: _____ Age: _____ Month/Year Completed: _____

EXERCISE AND PHYSICAL ACTIVITY

In the sections listed below, circle the number that best describes how well you know each topic (1 means you know nothing about the topic; 5 means you know everything about the topic).

I know...

- | | | | | | |
|--|---|---|---|---|---|
| How physical activity can affect my blood glucose | 1 | 2 | 3 | 4 | 5 |
| When to check my blood glucose when I am physically active | 1 | 2 | 3 | 4 | 5 |
| How much extra food (carbohydrate) to take for different types of activity | 1 | 2 | 3 | 4 | 5 |
| How to make changes to my insulin dose when I am physically active | 1 | 2 | 3 | 4 | 5 |
| How to fit 30 minutes of physical activity into my day | 1 | 2 | 3 | 4 | 5 |
| Why physical activity is important for people with diabetes | 1 | 2 | 3 | 4 | 5 |

“Moving On...” With Diabetes

The following self-assessment will help you and your diabetes team understand what you already know about your diabetes and where you need more information.

Name: _____ Age: _____ Month/Year Completed: _____

PUMPS

In the sections listed below, **circle** the number that best describes how well you know each topic (1 means you know nothing about the topic; 5 means you know everything about the topic).

I know...

How to set up and start my insulin pump	1	2	3	4	5
How to insert my pump infusion set	1	2	3	4	5
How and where to rotate sites	1	2	3	4	5
My plan for keeping a written copy of all my pump settings	1	2	3	4	5
How to set a temporary basal and can list examples of times to use it	1	2	3	4	5
How to use an extended wave bolus and dual/combo bolus and can list examples of times to use these	1	2	3	4	5
How to do a correction bolus	1	2	3	4	5
How and when to check for ketones	1	2	3	4	5
When to give a correction bolus by syringe instead of the pump	1	2	3	4	5
How to use my insulin-to-carb ratio	1	2	3	4	5
How to use my pump calculator	1	2	3	4	5
How the pump calculator can help me prevent insulin “stacking”	1	2	3	4	5
How to test to see if my insulin-to-carb ratio is working	1	2	3	4	5
When and why to carry extra pump supplies with me	1	2	3	4	5
What to do if my pump stops working	1	2	3	4	5
When I would need to start a longer-acting insulin (basal) for pump failure	1	2	3	4	5
How to calculate basal insulin doses for pump failure	1	2	3	4	5

“Moving On...” With Diabetes

The following self-assessment will help you and your diabetes team understand what you already know about your diabetes and where you need more information.

Name: _____ Age: _____ Month/Year Completed: _____

LOWS

In the sections listed below, circle the number that best describes how well you know each topic (1 means you know nothing about the topic; 5 means you know everything about the topic).

I know...

What low blood glucose is	1	2	3	4	5
What can cause low blood glucose	1	2	3	4	5
How to tell when I am having a low blood glucose	1	2	3	4	5
What to do when I am having a low blood glucose	1	2	3	4	5
What to carry with me to treat a low blood glucose	1	2	3	4	5
Why I need diabetes identification (ID)	1	2	3	4	5
What to tell my friends to do if I have a low blood glucose	1	2	3	4	5
What glucagon is used for	1	2	3	4	5
How to avoid low blood glucose	1	2	3	4	5
The guidelines for driving and diabetes	1	2	3	4	5
The guidelines for alcohol and diabetes	1	2	3	4	5

“Moving On...” With Diabetes

The following self-assessment will help you and your diabetes team understand what you already know about your diabetes and where you need more information.

Name: _____ Age: _____ Month/Year Completed: _____

HIGHS

In the sections listed below, circle the number that best describes how well you know each topic (1 means you know nothing about the topic; 5 means you know everything about the topic).

I know...

What high blood glucose is	1	2	3	4	5
What causes a high blood glucose	1	2	3	4	5
The signs of a high blood glucose	1	2	3	4	5
How and when to check for ketones	1	2	3	4	5
How and when to change my insulin dose to lower my high blood glucose	1	2	3	4	5

“Moving On...” With Diabetes

The following self-assessment will help you and your diabetes team understand what you already know about your diabetes and where you need more information.

Name: _____ Age: _____ Month/Year Completed: _____

WHEN I AM SICK

In the sections listed below, **circle** the number that best describes how well you know each topic (1 means you know nothing about the topic; 5 means you know everything about the topic).

I know...

How often to check my blood glucose	1	2	3	4	5
When to take my insulin	1	2	3	4	5
When to check for ketones	1	2	3	4	5
How to adjust my insulin and food	1	2	3	4	5
How to adjust my insulin for correcting a high blood glucose with ketones	1	2	3	4	5
To take lots of water/sugar-free drinks	1	2	3	4	5
I have a plan to tell someone when I am sick, so they can help me if needed	1	2	3	4	5
When to contact my diabetes care team	1	2	3	4	5

**Appendix 8 – “Moving On...” With Diabetes: Adolescent Knowledge & Skills Checklist
(Ages 17-18 years)**

“MOVING ON...” WITH DIABETES

ADOLESCENT KNOWLEDGE & SKILLS CHECKLIST (AGE 17-18 YRS)

**DIABETES EDUCATOR/TEAM
USER GUIDE**

PURPOSE

- Provides adolescent self-assessment of learning needs prior to transition.
- Provides parent(s)/guardian(s) assessment of adolescent’s learning needs prior to transition.
- Directs further education/skill development prior to transition

INSTRUCTION

- **Adolescent and parent(s)/guardian(s) to complete during the last year at the pediatric centre (age 17-18 yrs).**
- Mail out prior to appointment or have completed while adolescent waiting to be seen.
- Review and assess actual knowledge and skill level of topic.
- Send copy to adult diabetes team with *Transition* package.

Successful transition from pediatric to adult diabetes care requires the adolescent to have the knowledge, skills, and motivation to actively participate in diabetes self-management.

The pediatric team members should continuously review and re-assess the knowledge and skill level of the adolescent through:

- Active discussion of how he/she has scored himself/herself on the checklist.
- Problem-solving (using their own data, situations, etc.).
- What the adolescent is actually doing on a day-to-day basis.

It is important to verify that the adolescent is at the level he/she thinks, with regard to self-management skills, to identify any gaps that need further education or skill development to assist with independence as he/she transitions to adult care.

“MOVING ON...” WITH DIABETES ADOLESCENT KNOWLEDGE & SKILLS CHECKLIST

(TO BE COMPLETED BY THE ADOLESCENT AND BY THE PARENT)



Use this checklist to help you evaluate your knowledge and skill level in **managing** your diabetes. It will help you to identify those areas where new information or a review is needed. If you have questions about any area, talk to your Diabetes Health Care Team. They are always available to help.

Name: _____ Age: _____ Month/Year Completed: _____



PART ONE

DIABETES MANAGEMENT



a) Blood Glucose Monitoring

Knowledge/Skill	Got it Covered 	Need Update 	Not Applicable
Using my blood glucose (BG) meter			
Taking care of my meter			
Comparing my meter reading with the lab result			
Recording my BG/uploading BG from meter			
Looking for patterns of high or low readings			
Taking appropriate action if glucose is high or low			

b) Insulin Management

Knowledge/Skill	Got it Covered 	Need Update 	Not Applicable
Identifying my insulin(s) name/type			
Stating the action/timing of my insulin(s)			
Using and rotating appropriate injection sites			
Using proper injection technique			
Using the following injection devices:			
• Insulin Pen			
• Syringes			
• Pump			
Knowing what to do if my insulin pump stops working			
Adjusting my insulin/figuring out correction doses			
Uploading pump data to computer			
Safely disposing of my needles and sharps			

c) Nutrition

Knowledge/Skill	Got it Covered 	Need Update 	Not Applicable
Eating healthy meals/snacks			
Spacing my meals			
Controlling food portions			
Carbohydrate counting			
Adjusting insulin for the number of carbohydrate that I eat			
Making appropriate food choices when eating out			

(see other side)

d) Physical Activity/Exercise

Knowledge/Skill	Got it Covered 🧐	Need Update 🧐	Not Applicable
Benefits of physical activity			
Effect of different types of exercise on my BG			
Adjusting insulin/food for extra activity			
Monitoring BG before, during, and after exercise and know what to do with results			

SHORT TERM COMPLICATIONS

e) Hypoglycemia

Knowledge/Skill	Got it Covered 🧐	Need Update 🧐	Not Applicable
Identifying signs and symptoms of a low BG			
Identifying causes of a low BG			
Appropriately treating low BG			
What to carry with me to treat a low BG			
Why I need to wear a medic-alert ID or other identification			
What glucagon is used for/expiry date			
Dangers of driving with a low BG and how to avoid this			
What it means to have hypoglycemic unawareness			

f) Sick Day Management

Knowledge/Skill	Got it Covered 🧐	Need Update 🧐	Not Applicable
How often to check my BG when I am sick			
When to take my insulin when I am sick			
How to adjust my insulin and food when I am sick			
Why I should drink lots of water and glucose free drinks			
When and how to check for ketones			
What to do to prevent diabetic ketoacidosis (DKA)			
When to call my diabetes care team			

LONG TERM COMPLICATIONS

g) Prevention and Screening

Knowledge/Skill	Got it Covered 🧐	Need Update 🧐	Not Applicable
Diabetes and Eye Disease (Retinopathy)			
Need for yearly eye exam (dilated pupils)			
Diabetes and Kidney Disease (Nephropathy)			
Need for urine testing for protein (every 6-12 months)			
Diabetes and Nerve Disease (Neuropathy)			
Need for yearly foot assessments			
Diabetes and Heart Disease and Stroke			
Need for regular blood pressure and cholesterol checks			

If there are things you are confused/unsure about, make a list below; talk to your Diabetes Care Team.

**“MOVING ON...” WITH DIABETES
ADOLESCENT KNOWLEDGE & SKILLS CHECKLIST**

(TO BE COMPLETED BY THE ADOLESCENT AND BY THE PARENT)



Use this checklist to help you evaluate your knowledge and skill level in **managing** your diabetes. It will help you to identify those areas where new information or a review is needed. If you have questions about any area, talk to your Diabetes Health Care Team. They are always available to help.

Name: _____ Age: _____ Month/Year Completed: _____

PART TWO



LIVING WITH DIABETES

a) Lifestyle

Knowledge/Skill	Got it Covered 	Need Update 	Not Applicable
Sexual Health and Birth Control			
Planned Pregnancy			
Smoking and Diabetes			
Alcohol and Diabetes			
Drug Use and Diabetes			
Dating and Diabetes			
Travel and Diabetes			
Driving and Diabetes			
Diabetes and Eating Disorders			
Diabetes and Depression/Anxiety			



TAKING RESPONSIBILITY FOR MY HEALTH CARE

b) Routine Follow-Up

Knowledge/Skill	Got it Covered 	Need Update 	Not Applicable
Making and Keeping Appointments			
Flu Vaccine and Other Immunizations			
Filling Prescriptions/Who Can Renew Prescriptions			
Ordering Diabetes Supplies			
Drug Plans and Tax Credits			
Insurances			
Contacting Other Health Care Professional/Resource People			

LIVING ON MY OWN

c) Living On My Own

Knowledge/Skill	Got it Covered 	Need Update 	Not Applicable
Grocery Shopping			
Cooking/Meal Preparation			
University/College Life			
Apartment/Residence Living			
Finances and Budgeting			
Finding Reliable Diabetes Information/Resources			
Emergency Situation/Contact #s			

(see other side)

If there are things you are confused/unsure about, make a list below; talk to your Diabetes Care Team.

Appendix 9 – “Moving On...” With Diabetes: Diabetes Educator Transition Checklist

“MOVING ON...” WITH DIABETES
DIABETES EDUCATOR TRANSITION CHECKLIST

USER GUIDE

PURPOSE

- Topics covered help the adolescent acquire the knowledge and skills necessary to self-manage his/her diabetes.
- The checklist helps to assess readiness for transition and highlights knowledge/skills at time of transition.

INSTRUCTION

- Place on chart when the child turns 13 years old. If older than 13 years of age, place on chart when diagnosed. This will initiate the formal transition process (*The Preparation Phase*).
- Place an asterisk (*) by the topic to indicate a knowledge/skill deficit at time of transition (*see example below*).
- Use in conjunction with “Moving On...” Knowledge & Skills Self-Assessments (13-16 yrs) and “Moving On...” Adolescent Knowledge & Skills Checklist (17-18 yrs).
- Send a copy to the Adult Diabetes Team with Transition package.

Example:

Age	Topics
13-15 yrs	Diabetes Management
*	<input checked="" type="checkbox"/> Blood Glucose Monitoring
	<input checked="" type="checkbox"/> Insulin Management
	<input checked="" type="checkbox"/> Nutrition/Healthy Choices/CHO Counting
	<input checked="" type="checkbox"/> Physical Activity/Exercise
*	<input checked="" type="checkbox"/> Hypoglycemia
	<input checked="" type="checkbox"/> Glucagon
*	<input checked="" type="checkbox"/> Sick Day Management

(see other side)

DIABETES EDUCATOR TRANSITION CHECKLIST

Place on chart when the child turns 13 years old. If older than age 13, place on chart when diagnosed. The Diabetes Educator is to sign and date when the adolescent verbalizes/demonstrates acquisition of knowledge and skill related to the following:

Age	Topics	Signature/ Date	Signature/ Date
13-15 yrs	Diabetes Management		
	<input type="checkbox"/> Blood Glucose Monitoring		
	<input type="checkbox"/> Insulin Management		
	<input type="checkbox"/> Nutrition/Healthy Choices/CHO Counting		
	<input type="checkbox"/> Physical Activity/Exercise		
	<input type="checkbox"/> Hypoglycemia		
	<input type="checkbox"/> Glucagon		
	<input type="checkbox"/> Sick Day Management		
	Adolescent Issues		
	<input type="checkbox"/> Puberty/Hormones		
	<input type="checkbox"/> Sexual Health/Contraception		
	<input type="checkbox"/> Planned Pregnancy		
	<input type="checkbox"/> Smoking/Drugs/Alcohol		
	<input type="checkbox"/> Driving		
	<input type="checkbox"/> Travel		
	<input type="checkbox"/> Mental Health/Stress/Depression		
15-17 yrs	Long-Term Complications/Screening		
	<input type="checkbox"/> Retinopathy/Eye Exams		
	<input type="checkbox"/> Nephropathy/Albumin Creatinine Ratio		
	<input type="checkbox"/> Neuropathy/Sensation Loss/GI/Sexual Health		
	<input type="checkbox"/> Foot Inspections		
	<input type="checkbox"/> Heart Health Risk Factors		
	<input type="checkbox"/> Recommended A1C target		
	Health Care		
	<input type="checkbox"/> Recommended Frequency of Follow-up Visits		
	<input type="checkbox"/> Flu Vaccine/Immunizations		
	<input type="checkbox"/> Role of Family MD/Allied Health Professionals		
	<input type="checkbox"/> Filling Prescriptions/Ordering Supplies		
	<input type="checkbox"/> Health Plan/Insurances		
17-18 yrs	Transition		
	<input type="checkbox"/> Adolescent Knowledge & Skills Checklist		
	<input type="checkbox"/> College/University/Career Plans		
	<input type="checkbox"/> Living on Own/Moving Away		
	<input type="checkbox"/> Provided Transition Handbook		
	<input type="checkbox"/> Adult Diabetes Centre: What to Expect		
	<input type="checkbox"/> Introduction to Adult Diabetes Centre/Team		
	<input type="checkbox"/> Complete/Forward Transition Summary		
	<input type="checkbox"/> Appointment Date for Adult Diabetes Centre		

(Place an asterisk (*) by the topic to indicate knowledge/skill deficits at time of transfer).

Appendix 10 - Provider Assessment of Patient Skill Set

Provider Assessment of Patient Skill Set



This form is suggested to help assess the teen/emerging young adult's knowledge and skills regarding diabetes and its management. The tool is intended as an aide to help assess the readiness of older teens/emerging young adults in the transition and to be transferred from pediatric to adult diabetes care providers. Note that some questions may not apply to patients with type 2 diabetes or other forms of diabetes.

At the end of this document, please write your name along with discipline and initials, then provide the date along with your initials when each item is assessed.

Basic knowledge of your diabetes:

Type 1 Type 2 Other Forms

	DATE	INITIALS
<input type="checkbox"/> Describe what insulin does	_____	_____
<input type="checkbox"/> If you take oral medications, describe how they keep blood glucose in range	_____	_____
<input type="checkbox"/> Describe what happens if you don't take your medications	_____	_____
<input type="checkbox"/> Describe the meaning of HbA1c	_____	_____
<input type="checkbox"/> Describe the link between HbA1c level and the risk of diabetes complications	_____	_____
<input type="checkbox"/> Describe how nutrition/diet affects blood glucose and cardiovascular (heart and blood vessel) health	_____	_____
<input type="checkbox"/> Describe the effect of exercise on blood glucose (right after exercising and overnight)	_____	_____
<input type="checkbox"/> Describe how to drive safely	_____	_____
<input type="checkbox"/> Describe how to drink alcohol responsibly and reduce risk of low blood glucose levels	_____	_____
<input type="checkbox"/> Describe importance of excellent blood glucose control before & during pregnancy to support the development of a healthy baby	_____	_____
<input type="checkbox"/> Describe risk for other autoimmune diseases and symptoms to look for (for type 1 patients)	_____	_____
<input type="checkbox"/> Describe the need for and recommended frequency of routine check-ups	_____	_____
<input type="checkbox"/> Describe the need for annual lab work to assess kidney, eye, and cardiovascular health	_____	_____
<input type="checkbox"/> Describe the need for routine dental care exams	_____	_____

Experience in the following skills:

DATE INITIALS

- Accurately measure and give yourself insulin injections (even if you're on insulin pump therapy) _____
- Calculate correct dose of insulin according to both blood glucose level and carbohydrate intake _____
- Monitor blood glucose _____
- Monitor ketone levels (urine or blood) during illness, stressful times or when blood glucose levels are persistently elevated _____
- Log or download blood glucose readings _____
- Be able to state target blood glucose levels/range and goal HbA1c level _____
- Show how to program date/time into blood glucose meter and any other devices you may use _____
- Be able to count/estimate carbohydrates _____
- For those on fixed dosing, state number of carbohydrates to eat at each meal/snack _____
- Describe the reasons for changing/rotating injection/infusion sites _____
- Wear a medical alert identification _____

For those on insulin pump therapy/continuous glucose meter:

- Demonstrate how to insert infusion set _____
- Demonstrate how to check diabetes supplies and when it's time to order new supplies _____
- Demonstrate how to access insulin pump basal and bolus settings and how to alter them _____
- Demonstrate how to download pump/glucose monitor information _____
- Demonstrate how to share pump/glucose monitor information with the diabetes care provide _____
- Demonstrate how to program the pump (date, time, correction dose, carb dose, insulin on board, types of boluses, basal rates and temporary basal rates) _____
- Demonstrate when to use insulin injections and monitor for ketones to prevent diabetic ketoacidosis (DKA) _____

Show ability to arrange for medical care:

- Be able to make appointment _____
- Identify what insurance you have now _____
- Identify what insurance you will have when you are over 18 years of age _____
- Be able to keep track of insurance claims and co-pays _____
- Be able to maintain prescriptions and obtain medications/supplies before you run out _____
- Identify the name and phone number of pediatric endocrinologist _____
- Identify the name, phone number, and office location of adult endocrinologist _____
- Confirm contact information for urgent issues after office hours, weekends, holidays _____

Describe what to do in emergency situations or when ill:

DATE INITIALS

- Create a list with names and numbers of people who should be contacted _____
- Describe how to reach your doctor's office _____
- Describe when you should be calling your doctor's office _____
- State what information you will need to tell the diabetes care provider _____
- Identify a nearby emergency room/hospital if ever needed _____
- Create an emergency plan for high blood glucose, low blood glucose, and illness _____
- State how to manage high blood glucose levels (insulin, glucose, ketone monitoring, drinking sugar-free liquids/water) _____
- State how to manage low blood glucose levels (carbohydrate intake, low dose glucagon) _____
- State how to manage diabetes when sick (monitoring glucose, insulin adjustments) _____
- Review the significance of vomiting and the need to check glucose and ketone levels, give insulin, and call healthcare team. _____

NAME	INITIALS	DISCIPLINE
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____



Appendix 11 – Modified Transition Teaching Content Template

(Adapted from the Modified Transition Teaching Content Template developed by the London Health Sciences Centre)

This content is to be covered in the 6 months prior to transfer of diabetes care.

1. The importance of transitioning well	
<ul style="list-style-type: none"> • Patient’s future health and well-being, as well as the importance of chronic disease management 	
<ul style="list-style-type: none"> • Risks involved in not connecting with an adult diabetes centre 	
<ul style="list-style-type: none"> • Consider a tool to deal with change 	
2. Differences between expectations and structure between pediatric and adult visits	
<ul style="list-style-type: none"> • Philosophy of family centred care vs autonomy of young adult, parents/family members may attend but you are in charge, take responsibility for knowing A1C 	
<ul style="list-style-type: none"> • Team approach vs. separate appointment with DEC 	
<ul style="list-style-type: none"> • Difference in appointment schedule: 3mth vs 6-9 months (outside the study period) (as compared to 4 times per year as a paediatric patient) 	
<ul style="list-style-type: none"> • Be in charge of your clinic appointment: no reminder letters or calls, if you miss appointment- you are responsible for re-scheduling (may take up to 6 months for next appointment) 	
<ul style="list-style-type: none"> • Length of appointment (30-90 minutes for first visit) 	
<ul style="list-style-type: none"> • Access to healthcare team and information by family members (parents need to know that they will need their young adults patients permission to contact their health care team) 	
<ul style="list-style-type: none"> • Do you wear a Medic Alert? 	
<ul style="list-style-type: none"> • Housekeeping tips at Adult Centre: location, parking areas and costs, etc. 	
<ul style="list-style-type: none"> • Think about setting goals for yourself!!! 	
3. Differences in medical expectations for clinic visits	
<ul style="list-style-type: none"> • Review of diabetes regime (is this the best for you?), *bring record log, glucometer, and any medications you are taking endocrine appointment, will have physical including BP, heart lungs, injection sites and foot exam. 	
<ul style="list-style-type: none"> • Greater focus on complication screening - Discuss micro (eyes, kidney, lower extremity nerve damage, foot problems) and macro (stroke, heart disease, high BP and foot problems) complications of diabetes 	
<ul style="list-style-type: none"> • Greater focus on tighter control-A1C <7 	
<ul style="list-style-type: none"> • Greater emphasis on carb counting vs. sliding scale 	
<ul style="list-style-type: none"> • Focus on control of blood sugars but also greater focus on control of BP, cholesterol and weight. 	
<ul style="list-style-type: none"> • Assess patient’s knowledge and understanding of long term complications associated with diabetes and how to avoid them 	
4. Age-related themes and concerns	
<ul style="list-style-type: none"> • Driving “5 to Drive” assess patient’s diabetes habits with driving (i.e. checking BG before driving, access to treatment for lows etc.) 	
<ul style="list-style-type: none"> • Smoking- does patient smoke? Is he aware of health risks? 	

<ul style="list-style-type: none"> • Uses of alcohol - does patient consume alcohol? How often? How many drinks? Binge drinking? Assess patient's knowledge of effect of alcohol and diabetes, review safety practices around drinking 	
<ul style="list-style-type: none"> • Sex, birth control, pregnancy-assess patient's knowledge and possible need for prescription 	
<ul style="list-style-type: none"> • Drugs, tattoos, body piercing 	
<ul style="list-style-type: none"> • Leaving home, living in residence (what to tell your roommate), work and future careers, financial issues (insurance coverage – how to access help) 	
<ul style="list-style-type: none"> • Making sure you know how to access health care or help for diabetes when away at school 	
<ul style="list-style-type: none"> • Travelling/Vacations 	
<ul style="list-style-type: none"> • Importance of having a primary care provider (family MD) for general health 	
<p>5. Information that should be provided to the young adult at the last visit to their paediatric diabetes program</p> <p><i>Please note: The patient's last visit to their paediatric diabetes program should be labelled and identified to the patient that this is the last transfer meeting and care should be taken to ensure that the key topics above have been reviewed. This is a summary and formal ending to the pediatric diabetes care.</i></p>	
<ul style="list-style-type: none"> • Laboratory form and map for external laboratory 	
<ul style="list-style-type: none"> • Bio-sketch of adult endocrinologist given 	
<ul style="list-style-type: none"> • Directions to adult diabetes clinic 	
<ul style="list-style-type: none"> • Adult appointment should be made at the penultimate pediatric visit (so patient leaves with date, time, name and place for adult endo appointment (adult clinic should notify the patient as well as the peds clinic of the date/time of the first appointment to adult care) 	
<ul style="list-style-type: none"> • Tool(s) for the patient that including (at a minimum): <ul style="list-style-type: none"> ○ Short summary of diabetes diagnosis (date) ○ Last A1c ○ Current therapy ○ If screened for complications (may have a copy of flow sheet) <p>Recommended tool: The Endocrine Society's Clinical Summary for New Health Care Team - https://www.endocrine.org/~media/endosociety/Files/Education/Practice%20Management/Type%201%20Updated%20March%2012%202014/Clinical_Summary.pdf</p>	

Appendix 12 – Patient Follow-up Care Pathway



***The adult diabetes team consists of adult diabetes education programs (DEPs) and adult endocrinologists. In some circumstances, an adult endocrinologist may not work within an adult DEP. If this is the case, a separate referral to the adult endocrinologist is required.**

Examples and Contingencies

Step #2: Example of an introductory letter, from St. Michael's Hospital

St. Michael's
Inspired Care.
Inspiring Science.

Date: _____

We have received a referral for you to attend the **Young Adult Diabetes Clinic** at St. Michael's Hospital for an appointment with Dr. Andrew Advani (Endocrinologist) and the Health Care Team. The clinic is located in the St. Michael's Health Centre across from the main hospital at 61 Queen Street East, 7th floor.

Your appointment is schedule for: Date: _____ Time: _____

If you cannot attend this appointment, please call our booking office at 416 867-3679. You will need to complete fasting blood work at least two weeks before you see the Endocrinologist. For your first time to our clinic, we request that your blood work be done at our lab. Please contact us at 416 867-3679 if there are extenuating circumstances that would make it difficult for you to come down to our hospital for the blood tests so that alternative arrangements can be made.

PLEASE READ THE FOLLOWING INSTRUCTIONS CAREFULLY:

1 WEEK BEFORE YOUR APPOINTMENT, YOU SHOULD HAVE A FASTING BLOOD TEST:

- A requisition for your blood work is enclosed with this letter.
- You should fast (nothing but water) for 12 hours before the test. Bring a snack or breakfast to eat after you have had your blood taken at the lab.
- The lab is located on the ground floor of St. Michael's Health Centre, 51 Queen Street East and is open from 7:30 am to 3:30 pm. Please bring the enclosed lab requisition. This requisition cannot be used at an outside lab.
- You should bring your health card with you.

ON THE DAY OF YOUR APPOINTMENT:

- Bring your Ontario Health Card
- Eat breakfast and lunch and take your medications as usual.
- It is helpful if you bring all of your medications with you and if you test your blood sugar levels at home, please bring both your meter and your log book/records.
- You may want to bring a snack in case your appointment is longer than expected. While it is likely to be shorter, the total time for your first visit may be 2-3 hours.


WE LOOK FORWARD TO SEEING YOU FOR YOUR APPOINTMENT

Step #2: Example of a brochure, from St. Michael's Hospital





St. Michael's
Inspired Care.
Inspiring Science.

YOUNG ADULTS CLINIC


St. Michael's Hospital
61 Queen Street East, Toronto, ON



OUR TEAM

-  **Dr. Andrew Advani**
Endocrinologist
-  **Jane Mason**
Diabetes Nurse
-  **Sandi Williams**
Registered Dietitian
-  **Suela Cela**
Social Work

ALSO AVAILABLE

-  **Psychiatrist**

Our goal is to help you learn to live realistically with diabetes.


Welcome to St Michael's Hospital. We understand that turning 18 is both an exciting and challenging time in your life. It is a time when there are changes in school, work and your diabetes care.

One of these changes is transitioning to a Young Adult Diabetes Clinic. Our goal is to make the transition smooth, and at the same time encourage and empower you to manage your diabetes.

You have the right to:	We encourage you to:
<ul style="list-style-type: none"> • Make your own decisions • Meet with your healthcare provider on your own and • Ask questions so that you understand your diabetes and treatment options 	<ul style="list-style-type: none"> • Attend your appointments • Bring your blood sugar records with you • Have your blood-work done as requested • Share with the team any issues and concerns you have that may or may not impact on your diabetes care

How will our clinic be different?

Transition is an opportunity for young adults to establish independence from family. While we welcome family members to be involved in your care, our aim is to help you learn to manage your diabetes on your own. Information about your health, your appointments and your care is confidential and only available to you.




We will ensure that you have a primary contact within the clinic with whom you can communicate by email or phone.

Booking Line:
416 867-3679

We have regular clinic days and are also available in between clinic visits. Our hours are 8:00 am to 4:30pm.

Our Location and Visit Specifics



We are close to Ryerson University, George Brown and University of Toronto. We are next door to the Eaton Centre and the Queen Street Subway.

On your first visit you will meet with the endocrinologist and the rest of the team.

Follow Up Visits are scheduled every 3-4 months with the endocrinologist. You can schedule individual appointments with the Diabetes Nurse, Dietitian, Social Worker or Psychiatrist at any time outside of the clinic and between your visits with the endocrinologist. Your Health Care Team can help you work on improving your diabetes management and fitting diabetes into your busy life.

St. Michael's Health Centre is located at 61 Queen Street East, across from the main hospital.

We look forward to working with you to help you manage your diabetes and act as a resource for you as you move along the journey into adulthood.

Step #6 – Consider the following contingencies when access to an adult endocrinologist or adult diabetes education program (DEP) is difficult:

- Send referral earlier to ensure the patient can access an adult provider in the recommended time frame following their paediatric discharge.
- Paediatric diabetes teams can see the patient for an extra visit if necessary until a visit with the adult diabetes team can be scheduled.
- Pending models of the PDN Outreach Linkages Working Group, patients may be able to see an adult endocrinologist over OTN until they can be attached to a more local endocrinologist.
- An interim solution for diabetes management is for the patient to be seen by their primary care provider. However, many patients may not have a primary care provider and some primary care providers may not be comfortable with the management of type 1 diabetes. (Asking whether or not the patient has a primary care provider should be included as part of the discharge planning).
- Adult diabetes teams should try to be welcoming to patients lost to follow-up regarding the need for re-referral. Some centres require re-referral after one or two years, yet consideration should be given to not introduce unnecessary barriers.

Appendix 13 – Health Care Options

Website: <http://www.ontario.ca/locations/health/>

Ontario

Contact Français

Menu

This website is not for medical emergencies. If this is a medical emergency, call 911 now.

Home / Health Care Options

Health Care Options near you

Find health care services in your community.

Find

e.g., Walk-in clinic, hospital, or pharmacy

Note: You cannot find a doctor through Health Care Options. Learn how to find a family doctor or nurse.

Near

Search

Enter a city, address or postal code then select a location from the list.

Learn more about

- Aboriginal Health Access Centres
- Breast Screening Centres
- Breast Screening Programs
- Community Care Access Centres
- Community Health Centres
- Community Support Services
- **Diabetes Education Program**
- Emergency Rooms
- Exercise and Falls Prevention Programs
- Family Health Teams
- Immunization Clinics
- Nurse Practitioner-Led Clinics
- Pharmacies
- Physiotherapy Clinics (OHIP funded)
- Public Health Units
- Seniors Centres
- Sexual Health Clinics
- Urgent Care Centres
- Walk-In Clinics

Understanding health care in Ontario

- Get medical advice : Telehealth Ontario
- Find a family doctor or nurse
- EatRight Ontario
- HIV/AIDS tests and treatment
- Get an Ontario health card
- Mental health services
- How to quit smoking
- Flu clinics

Tags

Health and wellness

Health care options

Location and service information is maintained by Community Care Access Centres and their community partners and made available through thehealthline.ca. Contact thehealthline.ca with updates or questions.

Contact us

Follow us

twitter

Topics

- Arts and culture
- Business and economy
- Driving and roads
- Education and training
- Environment and energy
- Government

Appendix 14 – thehealthline.ca

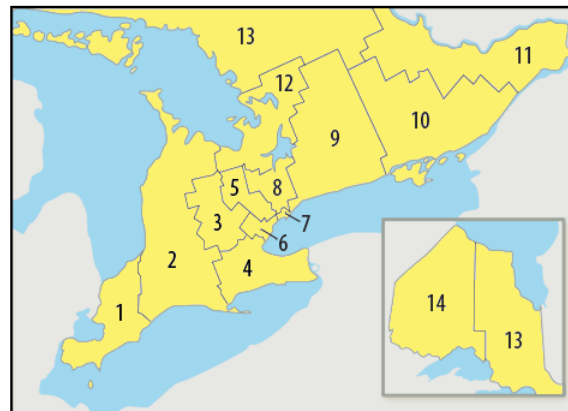
Website: <http://www.thehealthline.ca/>



RESIZE TEXT | FRANÇAIS

Enter your community name or a postal code to find health and community services in Ontario.

1. **Erie St. Clair**
ErieStClairhealthline.ca
2. **South West**
SouthWesthealthline.ca
3. **Waterloo Wellington**
wwhealthline.ca
4. **Hamilton Niagara
Haldimand Brant**
hnhbhealthline.ca
5. **Central West**
CentralWesthealthline.ca
6. **Mississauga Halton**
MississaugaHaltonhealthline.ca
7. **Toronto Central**
TorontoCentralhealthline.ca



8. **Central**
Centralhealthline.ca
9. **Central East**
CentralEasthealthline.ca
10. **South East**
SouthEasthealthline.ca
11. **Champlain**
Champlainhealthline.ca
12. **North Simcoe Muskoka**
nsmhealthline.ca
13. **North East**
NorthEasthealthline.ca
14. **North West**
NorthWesthealthline.ca

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Appendix 15 – Clinical Summary for New Health Care Teams

**Clinical Summary for
New Health Care Team**



*Form to be completed, signed, and dated on last page by referring provider and patient.
Patient and family to review and give completed form to new adult health care provider.*

Patient Name _____ **Date of Birth** _____

Diabetes Type

Type 1 Type 2 Other _____
 Antibodies: Positive Negative Not Performed
 Date Diabetes Diagnosed _____

Problem List and Date of Onset

Type of Insulin Therapy

If applicable, please also attach pump settings/specific insulin regimen.

Pump Therapy	Type of Pump:	Insulin:	
Total Average Daily Dose	Units/kg/day	Total/% Basal	Insulin Brand
Ins: Carb ratio	Sensitivity Factor (CF)	Target Sugar	
1 U: grams	1 U: mg/dL		

Basal/Bolus Therapy		Average Units/kg/day
Rapid/Short Acting Insulin	Long Acting Insulin	
<input type="checkbox"/> Humalog	<input type="checkbox"/> Lantus _____ units <input type="checkbox"/> AM <input type="checkbox"/> PM	
<input type="checkbox"/> Novolog	<input type="checkbox"/> Levemir _____ units <input type="checkbox"/> AM <input type="checkbox"/> PM	
<input type="checkbox"/> Apidra	<input type="checkbox"/> Humulin R U-500 _____ unit <input type="checkbox"/> AM <input type="checkbox"/> PM	
<input type="checkbox"/> Regular	<input type="checkbox"/> NPH _____ unit <input type="checkbox"/> AM <input type="checkbox"/> PM	
Ins: Carb ratio	Sensitivity Factor (CF)	Target Sugar
1 U: grams	1 U: mg/dL	

Patient Name Date of Birth

Other Insulin Regimens	Insulin Name	Dosage and Schedule	
Pre-mixed Insulin		Units <input type="text"/>	Time <input type="text"/>
		Units <input type="text"/>	Time <input type="text"/>
Long Acting Insulin	<input type="checkbox"/> NPH	Units <input type="text"/>	Time <input type="text"/>
<input type="checkbox"/> Syringe <input type="checkbox"/> Pen	<input type="checkbox"/> Lantus	Units <input type="text"/>	Time <input type="text"/>
	<input type="checkbox"/> Levemir	Units <input type="text"/>	Time <input type="text"/>
Rapid Acting Insulin	<input type="checkbox"/> Humalog	Units <input type="text"/>	Time <input type="text"/>
<input type="checkbox"/> Syringe <input type="checkbox"/> Pen	<input type="checkbox"/> Novolog	Units <input type="text"/>	Time <input type="text"/>
	<input type="checkbox"/> Apidra	Units <input type="text"/>	Time <input type="text"/>
	<input type="checkbox"/> Regular	Units <input type="text"/>	Time <input type="text"/>

All Other Medications	Dosage	Schedule	Date
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>

Allergies/Alerts:

Self-Monitoring (check all that apply)

Blood Glucose Frequency Prescribed Frequency 0-1/day 2-3/day 3-4/day >5-6/day
Performed Frequency 0-1/day 2-3/day 3-4/day >5-6/day
Meter

Continuous Glucose Monitoring? No Yes, Currently Yes, In the Past
If currently: Sometimes? Most of the Time?
If in the past: When:
Device:

Ketones Blood Urine

Recent Clinical Exam/Test Results

Blood Pressure (Date)	Dilated Eye Exam (Date)	Sensory Foot Test (Date)
<input type="text"/>	<input type="text"/>	<input type="text"/>
Current Weight (Date)	Height (Date)	BMI (Date)
<input type="text"/>	<input type="text"/>	<input type="text"/>

Patient Name _____ Date of Birth _____

Other Concerns

Hypoglycemia Unawareness No Yes
Fear of Needles No Yes
Fear of Hypoglycemia No Yes

Participation in Clinical Research? No Yes Current Past

Which study? _____

Patient/Family Comments _____

Most Recent Diabetes Education Consult _____

Most Recent Nutrition Consult _____

Are there additional issues that you would like to discuss about this patient? No Yes

If yes, please call Referring physician _____
Phone Number _____

Notes _____

Has this information been reviewed with the patient? No Yes

Pediatric Providers: Please attach a clinical summary with any relevant additional clinical information, family and social history, etc.

Patient Signature and Date

Referring Physician Signature and Date

Contact Information

Attach Business Card Here



Appendix 16 – Additional Resources and Websites for the Online Resource Centre

Resource	Website
Canadian Diabetes Association (Canada)	http://www.diabetes.ca/
The Diabetes Hope Foundation - Transition Resource Guide (Canada)	http://diabeteshopefoundation.com/content/transition-resource-guide-0
Diabetes Care Program of Nova Scotia (Nova Scotia)	http://diabetescare.nshealth.ca/
The Maestro Project (Manitoba)	http://www.maestroproject.com/
On Trac (British Columbia)	http://ontracbc.ca/#
Endocrine Society - Managing the Transition of Care for Patients with Type 1 Diabetes (United States)	https://www.endocrine.org/education-and-practice-management/quality-improvement-resources/clinical-practice-resources/transition-of-care
National Diabetes Education Program (United States)	http://ndep.nih.gov/index.aspx
Florida Health and Transition Services (HATS) (United States)	http://www.floridahats.org/
Pediatric Endocrine Society - Transition Toolkit (United States)	https://www.pedsendo.org/patients_families/transition_toolkit/index.cfm
Got Transition (United States)	http://www.gottransition.org/