

## MOVING ON...WITH DIABETES

### PEDIATRIC TO ADULT DIABETES CARE TRANSITION EVENT GUIDE

#### HOW TO USE THIS GUIDE

The *Pediatric to Adult Diabetes Care Transition Event Guide* provides the materials to plan and deliver an event for youth/young adults ages 15-18 years. It is intended to guide facilitators with ideas about how to structure a learning process for youth/young adults with diabetes who are transitioning from pediatric to adult care services.

The *Guide* contains a step-by-step approach to facilitating an event.

#### WHO SHOULD DELIVER THIS SESSION

Ideally, the facilitator delivering this session shall have experience with diabetes care transition (i.e., Transition Project Consultant) or be a health care provider supported with first voice experiences (young adult with recent transition experiences). If delivered by the Transition Consultant, an educator from the local Diabetes Centre should be in attendance.

#### EVENT OBJECTIVES

Teens/young adults participating in this event will:

- Meet other teens/young adults with diabetes experiencing the transition to adult diabetes care process.
- Understand the concept of transition and the importance of gradually preparing oneself.
- Understand the ways their diabetes team will help them gradually prepare for transition to adult diabetes care.
- Understand the importance of successful transition from pediatric to adult diabetes care.
- Receive advice/lessons learned from a young adult who has successfully transitioned from pediatric to adult diabetes care.
- Explore and discuss topics relevant to teens/young adults with diabetes with the aid of the **Moving on...with Diabetes Transition Handbook**.
- Discuss typical questions/answers that arise for many teens/young adults as they prepare for their first adult appointment.
- Know where to find and access additional information, support, and education to ease the transition process.

## PARENTS

You may decide to invite parents. The benefits of inviting parents include:

- They will learn more about the transition process to adult care and the role they play to encourage self-care in preparation.
- They will have a better understanding of what their teen may need for support before, during, and after transitioning from pediatric to adult diabetes care.
- They feel included in the process.

**NOTE:** If you do invite parents to your event, it is important to separate them from the teens when it is time to have participants navigate the handbook. It is important that the teens can ask questions and engage in dialogue on topics that they may not be comfortable discussing in the presence of parents.

One staff member could stay with the teens and another could take the parents to another room/location. Ask the parents what topics they are interested in learning more about and discuss the identified topics of interest.

Parents can regroup with the teens for discussion on community supports and for the remainder of the event.

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## TRANSITION EVENT PLANNING PROCESS

### PLANNING PROCESS

- Identify youth in your area with type 1 diabetes between the ages of 15-18 years.
  - Patients in your Diabetes Centre (DC)
  - DCPNS Registry (generate a list using the Advanced Clinical Indicator Report)
- Identify 2 staff members to attend (RN & Pdt) so that any medical questions can be answered.
- Book an informal location outside of the DC or hospital setting during evening hours.
  - Wellness Centre
  - Library
  - Community Room (Sobeys, Superstore, etc.)
- Secure a “1<sup>st</sup> voice person.” This person should be someone ~19-21 years-of-age with type 1 diabetes, has successfully transitioned to adult diabetes care, and can share his/her experiences.
- Invite the identified youth via:
  - Letters
  - Phone calls
  - Posters in DC, hospital, schools
  - PA announcement at schools
  - Diabetes Canada/JDRF (inform them of the event)
  - Social media outlets (posting on website, use of twitter, etc.)
- Content on the poster:
  - **Title:** In Transition: Moving on... with Diabetes
  - **Who:** Youth/Young Adults (15-18 years old) with type 1 diabetes. Encourage them to bring a friend/sibling of similar age.
  - **What:** Opportunity to meet others with type 1 diabetes and discuss adult diabetes care and living with diabetes as a young adult
  - **When:** Date & time of event
  - **Where:** Location of the event
  - **RSVP:** Date and contact information to RSVP
- Keep track of the RSVPs (*see sample*):
  - Name
  - Phone number
  - E-mail address
  - Food allergies?
  - Guest?
- Confirm attendance of RSVPs (via phone). Send reminder 1-2 days prior to event date.
- Purchase food/snacks for the event (e.g., pizza, beverages, fruit/veggie tray, granola bars, juice boxes, etc.).

## TRANSITION EVENT SAMPLE AGENDA

Transition events are guided by the session lead and intended to be interactive and engaging, with time for questions and discussion among the participants. It should not be instructional or scripted but follow the lead of participants.

**6:00 p.m.**      **Set-up room** (arrange chairs/tables, food/beverages).

**6:30 p.m.**      **Event starts - Introductions and Ice-Breaker Activity**

- Introduce staff hosting the event and 1<sup>st</sup> voice young adult.
- Icebreaker activity; e.g., name, length of time with diabetes, something random about self.

***Remember**, participants may be shy initially and should be given the opportunity to become comfortable with each other. Icebreakers help to serve this purpose, so use your icebreaker to not only serve as an introduction but to set the stage.*

**6:45 p.m.**      **What is transition? Why is it important?**

**1. Discuss the transition process from pediatric to adult diabetes care and its importance.**



**Ask the attendees what they think transition is and why it is important.**

- Acknowledge views and tell them/confirm that transition is a planned and purposeful movement of adolescents/young adults from child-centered to adult-oriented health care.
- Discuss how transition from pediatric diabetes care to adult diabetes care generally occurs during the last year of high school but that it is important to begin planning for transition from age 13 so that they can gradually prepare.
- Gradually preparing for transition will help them feel more confident and comfortable in their ability to self-manage their diabetes. It will also help the transition process feel less overwhelming.
- What does the interaction look like? Are there questions that should be posed 1<sup>st</sup>?

**2. Discuss the ways their team will help them gradually prepare:**

- Assessing what knowledge and skills they have in managing their diabetes and what they and their team can work on together during their visits leading up to transition.



**Ask attendees why they think this is important.**

- Validate their answers and share other examples:
  - Builds their self-confidence in their ability to self-manage their diabetes.
  - Allows for a gradual shift in responsibility from parent/caregiver to them.
  - They feel better prepared for adult diabetes care.
  - Provides an opportunity to refresh or learn new skills

**3. Spending time alone with them for some of their appointment time.**



**Ask attendees why they think this is important.**

- Validate their answers and share other examples. This helps them:
  - Get used to speaking on their own with the diabetes care team.
  - Encourages them to answer questions for themselves.
  - Gives them a chance to ask questions without their parents present.
  - Helps build their confidence in their ability to self-manage their diabetes.

**4. Discuss their future plans (university/college, job, moving away...).**



**Ask attendees why they think this is important.**

- Validate their answers and share other examples.
  - A proper referral can be made to an adult diabetes specialist/team (depends where they are going after high school).
  - Ability to discuss important topics such as: insurance options, informing roommates, professors, etc. about diabetes, living on own, etc.

**5. Provide them with more information about adult diabetes care (*Moving on... with Diabetes Handbook*, handouts, provider profile (if available), etc. Have copies on hand to share.**

**6. Refer them to an adult diabetes team and/or adult diabetes specialist.**

**7:10 p.m. Engage the group in talking about why successful transition is important - what we/they know. This may require prompts:**

- Thinking about your current connection to the health care system, why would continuing this be important?
- What risks do you face without access to a diabetes specialty team?
- What benefits can a team bring to you?

**Jot these responses on a flip chart for ease of reflection and to return to later in the discussion as needed.**

**7:15 p.m. Invite the 1<sup>st</sup> voice person to share his/her transition experiences.**

- What went well?
- Not so well?
- What were his/her greatest worries?
- What surprised him/her?

**7:25 p.m. Introduce the Handbook/APP and distribute to participants.**

- Before inviting the group to review the *Handbook* on their own, take a couple of minutes to:
  - Show them the Table of Contents and the breadth of the topics in the book. For example, under “Living on My Own” there is information around college life, residence living, finances/budgeting, and even grocery shopping.
  - Show them the types of materials in the appendices (sample letter to roommate, Transitioning Out of Province, etc.).
  - Flip to a specific section that you know has information of interest to most groups - alcohol, insurance, driving, sick day management, etc. You will be able to see from your “read” of the group if they are “with you” and understand what they are seeing.

**7:30 p.m. Give participants 10 minutes to navigate the Handbook. *Remember, if parents are included in this event, please separate them from the teens/young adults at this time.***

- As they are reviewing, ask them to make note of the things that they would like to chat about in more depth.
- If they are a particularly shy group, you could gather their responses of topics they wrote down and read the topics out loud - having participants remain anonymous.

***Remember, it is important to have a few key discussion points in your back pocket to spark the discussion if participants are hesitant.***

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- 7:40 p.m.**      **Have participants read out the topics that they are interested in learning more about (or read out their anonymous responses).** As a group, find the information in the *Handbook* and have a discussion about it.
- Depending on what you hear, you could add information about preparing for the first adult visit (as this is very important and comes up a lot among teens). Direct them to this section of the book (pages 4-6). Also, ask the 1<sup>st</sup> voice person to add his/her thoughts on this and what worked/did not work.
  - You may also want to share the work DCPNS and the Transition Project Consultant did with adult specialists to have them better understand young adult needs/concerns. Some providers have done “physician profiles” which has made these physicians appear less intimidating and provides specifics about what they expect for a first visit.
- 8:10 p.m.**      **Discuss community supports available (e.g., JDRF, Diabetes Canada). If parents are included in this event, they can rejoin the teens/young adults at this time.**
- 8:15 p.m.**      **Fill out Evaluation Form and take a group photo (optional).**
- 8:30 p.m.**      **Event Ends**