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FIGHTING DIABETES
PRESERVING A LEGACY

Understanding Transition

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The mission of SFBLF is to Fight Diabetes and Preserve a Legacy

Our focus is on disease prevention and disease self-management through education, clinical innovation and sustained support with an emphasis on youth.

Minimizing the transition challenges faced by youth living with diabetes as they navigate from the paediatric to the adult healthcare system is a key priority.

The SFBLF Diabetes Management and Education Centre (DMEC) is located in Alliston, Ontario, Canada at the Banting Homestead Heritage Park, birthplace of Sir Frederick Banting, co-discoverer of insulin and Canada's first Nobel Laureate.

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Understanding Transition

Learning Objectives

This tutorial provides an overview to help parents of youth living with diabetes to prepare for the move of their youth from pediatric to adult health care.

The content should not be used as medical advice. It is essential that you consult with qualified healthcare professionals to identify and assess the needs appropriate for your family.

Are you ready for 'transition'?

Successful transition means not just that the teen has acquired the essential knowledge, skills and confidence but also that specific post-transfer links, follow-up and evaluation processes have been established and shared with all involved.

* Are 'we' (teen and parents) 'ready' for transition?
* Do we have a common set of expectations for the next stage?
* Can our teen:
    1. Self-manage their condition reliably?
    2. Advocate for their health care needs on their own or with support from others?
    3. Maintain health-promoting behaviours?
    4. Utilize adult health care services appropriately and successfully?
* Have the following needs been met:
    5. Adult healthcare provider identified and a date set for a first appointment?
    6. An up-to-date, 'condition status' record of the patient provided to all?
    7. Schedule for progress review sessions with both pediatric and adult providers?
    8. Contact information to 're-establish' care if necessary (including for a Transition Coordinator if one exists)?

On completion of this tutorial, you should understand the importance of these questions and why you need to get started early with your planning and preparation.

In the following pages, you will find information on:

Realities of current Transition support processes

The Transition challenge for your family

1. The difference between transfer and transition and related considerations
2. Why carefully planned, 'guided' transition is essential.
3. Common impediments to successful transition:
    a. Providing the required knowledge
    b. Developmental stages
    c. Multiple stakeholders in the process
    d. Differences between the pediatric and adult health care system
    e. Systemic 'disconnects'
    f. Presence of both diabetes and mental health issues

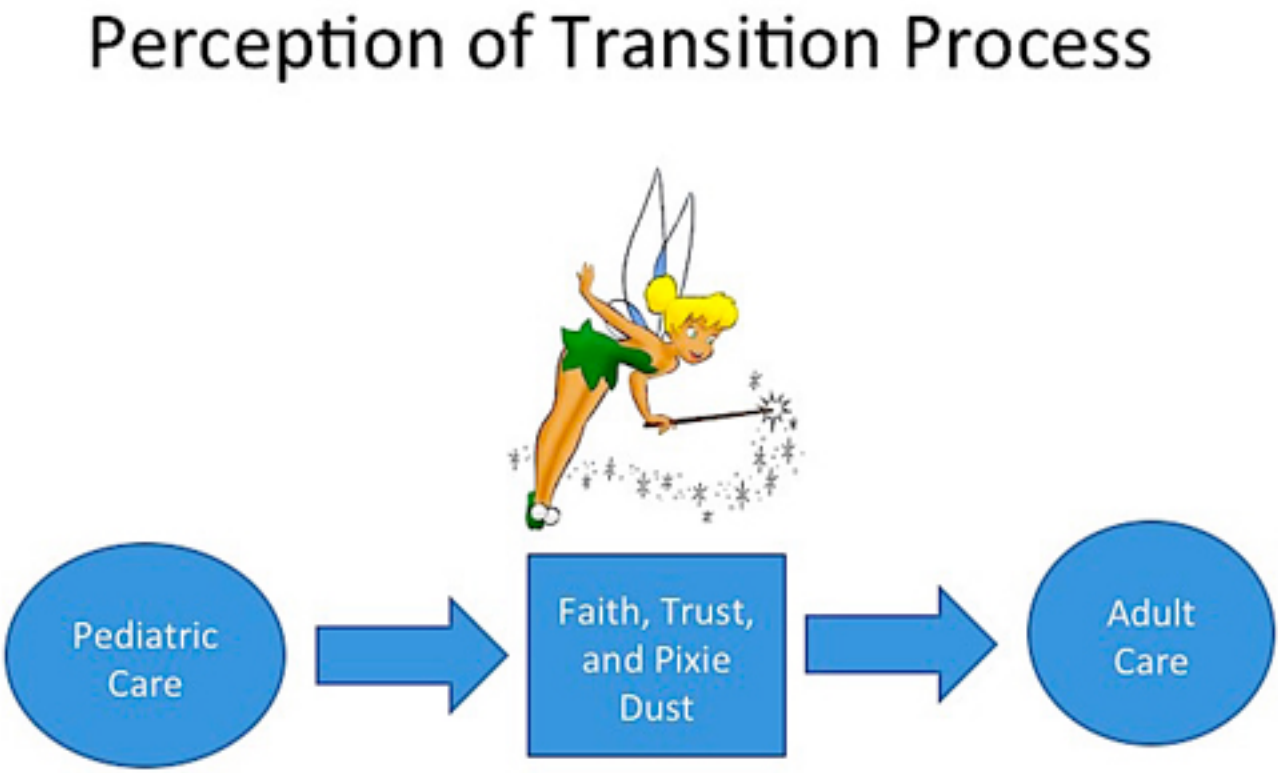
What your family needs to do to 'get ready' for Transition

4. Recognize the required conditions for 'Transition Success'
5. Understand why a person-centred, family approach to transition is essential.

Where to find helpful resources for further study

References cited in this Tutorial

Realities of current Transition support processes



[Graphic courtesy of Dr. W. Carl Cooley, MD, Senior Medical Advisor, Crotched Mountain Foundation, NH]

The Transition requirement for families
In many countries, youth are required to move from the pediatric to adult health care system around age eighteen but it could be before or after. Many jurisdictions are now acknowledging that such a 'fixed' milestone is not appropriate. The timing can differ depending on local or regional policies, guidelines, resources available, the nature and severity of any existing chronic condition and the state of readiness of the youth.

The state of existing support
Health care professionals have been concerned about the transition issue for decades. Despite that, the support available for youth in transition continues to range from excellent to pragmatically non-existent.

This is the case for diabetes and for mental disorders separately. The combination presents an even greater transition support need. The whole is greater than the sum of the parts.

An international scan conducted in 2015 by researchers from The Hospital for Sick Children, Toronto, the Department of Pediatrics, University of Toronto and the Institute for Clinical Evaluative

Sciences, Toronto surveyed nine wealthy Organization for Economic Co-operation and Development (OECD) countries; Australia, Canada, Denmark, Finland, Ireland, New Zealand, Norway, Sweden and the UK. [1]

The conclusions of the scan included, *"Despite the well-documented risks and costs associated with a poor transition from paediatric to adult care, little policy attention has been paid to this issue."*

"From the pond into the sea: Children's transition to adult health services", is a report published by the Care Quality Commission in the UK [2]. This non-disease specific report includes a wealth of case study examples that highlight the systemic shortfalls experienced by youth and their families. It also identifies outcomes required for improvement and associated measures of achievement.

New demands

Historically, the focus of most studies seeking to improve the transition support processes for youth living with diabetes has been on Type 1.

Youth living with Type 1 diabetes are most likely to receive some degree of transition help because of the severity of their condition. Generally, they are 'known' to the system and have likely been under reasonably continuous monitoring. Even so, their transition will not be without challenges.

The support required for Type 2 is 'different' than for Type 1 if all the aspects associated with daily insulin injections are not present. But, there is still a need to learn how to monitor blood glucose levels and use other medication for effective glycemic control. The potential risks arising from lapses in compliance may be less severe but the need for appropriate help is no less essential. Very little research exists on the nature of required transition processes for youth living with Type 2 and much needs to be done.

Recent evidence indicates that some youth with Type 2 diabetes are not responsive to oral medication alone and require insulin at the outset. To the extent that situation exists, there is very little difference in the required preparation for Transition.

The onset of diabetes can create, or amplify existing, mental health issues and thereby bring further complexity to the health care support needs including the challenges for continuity of care.

In general, formalized transition processes, where they exist at all, are more likely to be available for helping youth living with diabetes than for a youth living with a mental disorder despite the fact that continuity of care is imperative for both conditions.

Some major children's hospitals around the world do have multi-discipline 'transition' units that are focused on helping youth with any chronic disease. The Hospital for Sick Children, Toronto, Canada, The BC Children's Hospital, Vancouver, The Royal Children's Hospital, Melbourne Australia, The Sydney Children's Hospitals Network, Australia and the University Hospital, Southampton, England, [3] are examples.

Other major hospitals or institutions may have transition support units that are more focused on one or other chronic condition. For example, the Kovler Diabetes Centre at the University of Chicago provides transition support for youth living with diabetes and comorbid conditions arising from diabetes-related complications or from other conditions such as mental disorders.

Often, these services are available only for those youth who are registered patients with the particular organization. The services may not be available on a 'walk-in' basis nor even on a referral from external sources.

Multi-discipline health care teams are required not only to treat these combinations but to ensure a successful transition. That can be a very difficult requirement for rural locations to meet.

Community-based agencies and individual practitioners who provide care for youth and emerging adults living with diabetes and/or mental disorders also may not have access to such diverse organizational support.

The Transition challenge for your family

1. What is 'transition'?

Transition vs Transfer

Transition needs to be distinguished from 'transfer'. The latter is a one-time event. Transition must be a purposeful, planned and phased process if a successful outcome is to be achieved. The length of that preparation process will be different for each individual depending on the age of diagnosis, their learning capability, presence of other conditions such as mental health difficulties, support resources and processes available. [4[[5] [6]

Transition is not a generic, 'one size fits all' process and must vary depending on the patient's clinical, social, or emotional 'readiness' and must accommodate both disease-specific and individual-driven needs (e.g., transition plans should vary by condition, be culturally sensitive and attuned to rural vs urban concerns) [1]

'Types' of Transition

There are many types of transitions faced by youth and emerging adults with or without the presence of a chronic disease; for example, from primary to secondary school and ultimately to an institution of higher education or into the workforce. Along the way, a transition from living at home to independent or shared living with peers and an accompanying transition to a new geographic location, possibly remote from home, can occur.

While this Tutorial is focused on the transition from the pediatric to adult health care system, other types of transitions such as above can be in play in the background. They are an essential part of the context knowledge required to prepare and execute an effective transition plan for youth as they leave pediatric care and enter the adult health care system.

That 'shift' can be problematic for youth and their families. The intensity of the challenge depends on their health condition, where they are located, the family support, the health care resources available and related ease of access, the acquired skill in self-management of their condition, and the extent to which they have been assisted with prior planning and guidance to 'be ready'.

For youth living with a chronic condition such as diabetes, with or without the presence of other conditions, the planning and preparation requirements for transition are very significant.

2. Why is carefully planned, 'guided' transition essential?

The teenage years bring on many natural diversions and new pressures that can affect the propensity for youth to pay continuing attention to managing their personal health.

A review of the diabetes literature published in 2008 demonstrated that a decrease in diabetes care visits follows the transfer event. Adolescents are at risk of dropping out of medical follow-up, an action that may interfere with their future physical and psychological well-being. [7]

Youth and adolescents living with diabetes are at significant risk of developing multiple complications if they are not diligent in adhering to the essential protocols for managing their condition safely and effectively.

Similar risks apply for youth living with a mental disorder [8]

It is estimated that 70% or higher of mental disorders arise in childhood or adolescence. The lack

of adequate treatment and continuity can have lifelong consequences because children and youth who experience a mental disorder are at much higher risk of experiencing further mental disorders as adults.[9]

The onset of diabetes can create, or amplify existing, mental health issues and thereby bring further complexity to the health care support needs.

These factors, whether arising from diabetes or mental disorders alone or in combination, can lead to the onset of other illnesses, increased emergency hospital visits, and generally poorer health outcomes and quality of life. [4]

3. Common impediments to successful transition.

a. Providing the Required Knowledge

The onset of diabetes in children and youth imposes an immediate learning challenge for both the youth and their family members; for example, checking blood glucose levels, treating high and low blood sugars including how and where to inject insulin or take other medication. Executing and coordinating these tasks with dietary intake and physical activity are all part of daily life with diabetes. Mastering the required skills takes time, involves a degree of trial and error and can be very demanding.

Mental health disorders may already be present and the onset of diabetes can amplify the significance. For example, if the youth is over-weight or obese or weight gain results from diabetic treatment, there may be resulting mental health disorders, mild or severe. The list can include eating disorders such as anorexia nervosa (a common comorbidity with Type 1 diabetes) arising from concerns about 'body image'; or stress arising from the adaptations required for participation and functioning in daily life (e.g., requirement for medical appointments and daily treatment expectations); or potential 'isolating' factors such as fear of being identified as different by peers.

Comorbidities (combinations of conditions) can affect motivation and possibly hinder learning capability. They definitely add to the challenge for educators faced with helping to overcome the knowledge gap and they can impact significantly on health including mental health outcomes.

Parents or other custodial adults must be involved in the process from the outset but, hopefully, with decreasing intensity as the process evolves. Achieving that outcome can be daunting for the family member, the young person and the health practitioner/educator.

b. Developmental Stages

The journey from childhood to emerging adult is a time of rapid physical and mental development accompanied by excitement, discovery, challenge, disappointment, trial and error, risk taking, a search for identity and an inherent quest for independence.

The human brain is a work in progress and, at this stage in life, is engaged in an especially busy and complex process. It is a process influenced not only by biology but by family, friends and culture and also by environmental, social, economic and peer-related factors.

As in all situations, directed learning has to be achieved through age appropriate processes. For those living with a chronic condition or more than one, the added complexity has to be taken into account.

An approach to preparing a youth for transition needs to be planned and executed in stages appropriate to age and capability and with recognition the latter may not conform to otherwise expected norms especially if mental health disorders are also present.[10] [11]

c. Multiple stakeholders in the process

The transition process affects and must involve many players. In addition to adolescents and the parents, health care providers from both the pediatric and adult systems need to be direct participants at key stages to ensure success.

Each of these four stakeholder groups brings widely varying perspectives, experience, expectations and motivations to the process. In turn, the process can trigger degrees of impatience, frustration and disappointment in each group.

Every transition situation is unique but there are some well understood common challenges that can and do arise with varying degrees of intensity. [4]

* The adolescent, on being faced with the fact that a transition is required, may appear indifferent or saddened but is highly likely to feel some degree of apprehension about such a change.
* Parents may feel abandoned and worry that the adult system will not care properly or be sufficiently empathetic for their child. Hence, they may exhibit reluctance about, possibly even active resistance to, the idea of having to transition from the pediatric system.
* Letting go can be equally disturbing for the pediatric health care providers where a genuine sense of attachment may have developed. They may worry that the youth, long under their care, will drop out of the system. The level of worry can be amplified if they feel the youth is not properly prepared or does not have the necessary skills to cope effectively in the adult system.
* Those providing adult health care may feel that adolescents and emerging adults lack responsibility, do not easily take direction, are not well prepared, may be too time consuming and may bring unwelcome interventions from parents.

d. Differences between the pediatric and adult health care system

Fundamental differences in the nature of the pediatric and adult healthcare systems are real and represent potentially unsettling circumstances for the teen.

The pediatric system is typically family-centred with facilities physically appropriate for children and involving readily available multi-disciplinary teams.

By contrast, the adult system focuses on individuals and may have limited team-based resources and all in a physical context that could be intimidating or at the very least, novel for a teen.

e. Systemic 'disconnects'

Systemic 'disconnects' between the pediatric and adult health care systems and between the care providers in each can add to the challenge of achieving a successful Transition.

Processes for timely and effective cross-discipline communication among pediatric and adult health care providers may be excellent or virtually non-existent.

Family physicians 'inherit' youth living with diabetes after their pediatric years and many are not 'ready' for that outcome. Limited consultation time and ineffective communication between involved healthcare professionals add to the challenge. A 2017 paper reporting research outcomes in British Columbia, Canada noted: [12]

"*The greatest burden of youth-onset type 2 diabetes is in older youth aged 15 to 19 years who likely access primary, rather than paediatric care. Therefore, increasing awareness of youth onset type 2 diabetes among primary care practitioners is critical to ensure early identification and initiation of management so as to prevent serious diabetes-related complications and early mortality."*

f. Presence of both diabetes and mental health issues

In general, the discontinuity between the pediatric and adult health care systems can be more acute for those living with a mental disorder. There are many reasons for this. For example, a 'mild' occurrence of a mental disorder treated within the mandate of the pediatric system may not qualify for attention in the adult system. In addition, the nature of adult treatment may be more focused on the individual rather than a family-centred approach.

For mental disorders, research indicates that many youth and emerging adults do not receive even basic attention due in large part to the difficulty of accessing suitable care or not knowing where and how to do so. Under those circumstances, guided transition into adult care is almost an unattainable goal. [8]

While an effective process may exist for Transition of a youth living with diabetes, it does not follow that the process is equally effective for a youth living with both diabetes and a mental health issue.

What your family needs to do to 'get ready' for Transition

4. Recognize the required conditions for 'Transition Success'

Transition success means that youth are able to:

1. Advocate for their health care needs through themselves or through others
2. Maintain health-promoting behaviours
3. Utilize adult health care services appropriately and successfully [13]

5. Understand why a person-centred, family approach to transition is essential.

Transition is a phased process and the nature and pace are dependent on many factors not the least being the time available between age of diagnosis and the transition milestone age. Diagnosis at a younger age obviously allows for a longer learning and preparation period.

Every transition plan has to be tailored to the individual and must be the result of continuous collaboration among the teen, parents and the healthcare providers to ensure success.

Given the variations and uncertainties, the onus is on the family to ensure certain basic requirements are met. Some requirements are dictated by the type of disease or condition and the prescribed treatment but others are somewhat 'independent' and those are factors that families can and should influence.

Such general transition topics include an early introduction of the idea that transition will occur, gathering information about differences between the specific pediatric and adult health systems available to the family, explaining what the young adult can expect at a first visit to an adult health care provider and assessing family financial realities and health insurance plan coverage.

Parents can also take positive and proactive steps to help their teen move gradually to a new level of independence and confidence by delegating tasks such as making medical appointments, refilling prescriptions, asking questions of healthcare providers, and maintaining their records of blood sugar results. Requiring your teen to help with preparation of grocery shopping lists and to participate in the shopping itself are practical steps to help create a broader understanding of the requirements for everyday healthy living.

Are you ready for 'transition'?

Successful transition means not just that the teen has acquired the essential knowledge, skills and confidence but also that specific post-transfer links, follow-up and evaluation processes have been established and shared with all involved.

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Where to find helpful resources and references for further study

There are many tools available online to help teens and families assess and document their answers to the above questions. Such tools can be found on many hospital and associated websites, for example:

* The British Columbia Children's Hospital, Vancouver Canada
* The Children's Hospital of Eastern Ontario, Ottawa, Canada
* The Diabetes Care Program of Nova Scotia, Canada
* The Hospital for Sick Children, Toronto, Canada
* The Kovler Diabetes Center, University of Chicago, Chicago, USA
* The Royal Children's Hospital, Melbourne, Australia
* The Southhampton Children's Hospital, Southhampton, England

and from government sources such as:

* Got Transition, Washington, DC, USA
* The National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, USA

Please download the *SFBLF - Transition Resources for Families* document for further reference. This document provides links to many of the above along with a brief description of the tools and their purpose.

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