

Cystic Fibrosis

Care Guidelines for Adolescent Transition
from Pediatric to Adult Healthcare Services

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This document is based on a consensus of evidence and/or clinical expert opinion.

It is intended that this Care Pathway be reviewed and revised as needed by April 2020.

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General Age Range Guide

Infant	Preschool	Child	Adolescent	Adult
0 to 2 years	2 to 6 years	6 to 12 years	12 to 18 years	≥ 18 years

Abbreviation Guide

BCCH . . . BC's Children's Hospital

CAPHC . . . Canadian Association of Paediatric Health Centres

CF Cystic Fibrosis

Introduction

With continued advancements in medical diagnosis and treatment of cystic fibrosis (CF), the majority of people are living into adulthood. One outcome of this increase in life expectancy is the need for coordinated programs for transitioning adolescents with CF, from the pediatric system to adult healthcare services.

The transition to adult care for young people with chronic disease can be a challenging time: “the timing of transfer to adult CF care often coincides with a dynamic period in adolescence and young adulthood when lung function may be declining and treatment burden and complications of multisystem disease are increasing” (Tuchman, Schwartz, Sawicki, & Britto, 2010, p 568). Therefore, establishing a transition process is of paramount importance and should be considered a standard of care for cystic fibrosis patients.

Overview of Adolescent Transition

Transition is defined as “a purposeful, planned movement of adolescents with chronic medical conditions from child-centered to adult-oriented health care that is supported by individualized planning in the paediatric and community settings, a coordinated transfer of care, and secure attachment to adult services” (National Transition Community of Practice, 2016, p 6).

This definition suggests three distinct phases of transition:

1. Phase I begins at/by age 12 years at the pediatric centre
2. Phase II encompasses the time of actual transfer
 - at around age 18 years depending on patient needs/ institutional policies
 - involves both pediatric and adult clinics
3. Phase III proceeds at the adult clinic from the time of transfer until around age 25 years.

All three phases of transition are important in promoting successful transition outcomes.

a. Current Strengths within BC

- Several commonly cited barriers to transition have already been addressed (within the CF clinic model of care in Canada and current clinical practices).
 - These include a lack of adult specialists or inadequate access to these specialists, and the failure to transfer pediatric patients in a timely manner resulting in adult patients inappropriately being cared for at a pediatric centre.¹
- The experience and expertise of the pediatric CF clinic at BC's Children's Hospital (BCCH) is considered a national leader in CF transition.
 - At BCCH, a CF transition protocol was initiated in 2000 and has evolved into a multi-faceted transition program. The program was developed using BC's *ON TRAC (Transitioning Responsibility to Adult Care)* transition model and framework, and over time, transition tools have been modified and evaluated in a series of quality improvement initiatives.²
 - There has also been a 10-year retrospective evaluation of the transfer period for CF patients who transferred from BCCH to the adult CF clinic in Vancouver or Victoria. Results demonstrated good patient attendance at their 'transition' or 'graduation' clinic; excellent completion rate of medical transfer summaries; and insight into areas which need addressing such as decreasing the time gap between the last pediatric and first adult clinic appointments.³
- There is a close working relationship between the adult and companion pediatric CF clinics.

- In 2016, transition progress was made when the four BC CF clinics collaborated to adapt the new *ON TRAC* transition clinical pathway (a tool to guide and document a patient’s transition progress) to be CF-specific, with the intent to begin implementation in early 2017. At least one CF clinic staff from each BC CF clinic participated in *ON TRAC*’s workshop which provided education about the transition pathway and tips to support its utilization in daily practice. This endeavour would mark the first time that all CF clinics in a province utilized a common CF transition tool.

b. Current Challenges within BC

- Three CF clinics have not yet begun to implement the *ON TRAC* tool.
- This is not entirely surprising, as there are numerous competing and compelling needs of CF patients.
- Implementation of transition protocols is complex and requires a systematic process which takes dedicated time and expertise to address.
- While BC CF clinics are looking to integrate *ON TRAC*’s transition clinical pathway, CF Canada recently decided to take on transition as a national advocacy initiative, and is currently leading a project to adapt a CF transition program from the U.S.A. called *CF R.I.S.E.* (*Responsibility/ Independence/ Self-Care/ Education*) (www.cfrise.com).
- *CF R.I.S.E.* is an online toolset to help people with CF gain the knowledge and skills to more independently manage their CF.

	Using <i>CF R.I.S.E.</i>	Using <i>ON TRAC</i>
Pros	<p>More comprehensive for</p> <ul style="list-style-type: none"> ■ addressing CF-specific education ■ measuring transition readiness within specific age ranges and with a greater age span 	<ul style="list-style-type: none"> ■ Universally recommended for use across BC for all youth with chronic conditions and/or disabilities ■ Clinical pathway is more comprehensive than the tools offered by <i>CF R.I.S.E.</i>
Cons	<ul style="list-style-type: none"> ■ Not yet been adapted for Canadian content ■ Not approved for online use in Canada ■ Lacking in transition implementation methods 	<ul style="list-style-type: none"> ■ Use limited to only BC, possible impact to those patients moving between provinces ■ Not entirely CF-specific (some parts are not relevant for CF)

Transition Recommendations

General Recommendations for CF Clinics

- Use the CF-specific *ON TRAC* clinical pathway for transition care, and supplement with the use of *CF R.I.S.E.*
- Adhere to the Canadian Association of Paediatric Health Centres (CAPHC) transition guideline recommendations (summarized in **APPENDIX**).
- Designate a 'transition champion' in each clinic team who can support and educate fellow team members, as well as initiate and keep transition initiatives active.
- Evaluate the performance of the transition process annually.

Rationale

Although adolescent transition has been studied for many years, there remain significant gaps. In order to address these gaps, the CAPHC established a national Community of Practice in 'Transition from Paediatric to Adult Health Care'. Their detailed guidelines⁴ are the culmination of a comprehensive literature search and input from a wide array of healthcare professionals from across the country with expertise on this topic. They were written to enhance and guide the care of youth with chronic conditions through adolescence into adulthood. This document was used to guide our next steps in addressing the transition needs of individuals with CF in BC.

Transition Framework

1. Transition Phase I: Within the pediatric centre

- Introduce all youth and their caregivers to the concept of transition by or at the age of 12 years.
- Initiate the CF *ON TRAC* Transition Pathway for all patients at the age of 12 years.
- Assess the achievement of transition goals or readiness at regular intervals using *ON TRAC* and/or *CF R.I.S.E.*
 - a. *ON TRAC* (between 15 to 18 years of age)
 - Youth Quiz – Administer once a year.
 - CF Readiness to Graduate questionnaire – Administer once a year.
 - b. *CF R.I.S.E.* (between 12 to 18 years of age)
 - Patient Knowledge Assessments – Administer 4 times a year.
 - Patient Responsibility Checklists – Administer once a year.

2. Transition Phase II: Coordinated Transfer of Care

- Meet with CF Clinic staff from both pediatric and adult clinics as part of a 'Graduation Clinic' appointment.
- Give the date of the first adult clinic appointment at their Graduation Clinic appointment.
- Provide adult clinic with a Medical Transfer summary (including the Transition Pathway to date and completed readiness assessment measures).

3. Transition Phase III: Secure attachment to adult services

- Send copies of the first 3 adult clinic appointment letters to the pediatric CF clinic.
- Continue to use the CF *ON TRAC* Transition Pathway until 24 years of age.
- Continue to administer the *CF R.I.S.E.* knowledge assessments and responsibility checklists until 25 years of age.
- Consider 'transition tips' for young adults from the Transition Care Management Plans Youth Transition Project of BC (youthtransitioncare.ca/page/Transition%20Tips).

Evaluation Framework

- Use a modified evaluation based on the Triple Aim framework to evaluate the success of the patient's transition, looking at:
 - The patient's experience (via a questionnaire)
 - Population health indicators
 - adherence to medication pick-up
 - disease specific outcomes such as FEV1 measurements in the 2 years before and after the transfer to adult care
 - self-care skills such as achievement of Transition Pathways goals and readiness indicators
 - measures of attachment to an adult CF clinic (example: frequency of adult clinic appointments in the first 2 years after the transfer)

Rationale

The number of outcome studies in transition is sparse. The CAPHC guidelines maintain that currently, evaluation is recognized as a key factor to advance transition practice but it is also an emerging science both in terms of determining efficacy (at a population health and cost benefit level) and impact (at the individual patient level). There is general agreement that due to its complex nature, determining

successful transition outcomes requires multifaceted measurement. While the CAPHC guidelines describe three possible frameworks for evaluation, we recommend using the Triple Aim approach to evaluate transitioning in BC. It must be noted that proceeding with an evaluation is outside the scope of the current SSC project, however it should be undertaken as a future endeavour.

Triple Aim framework:⁵ This framework was developed by the Institute for Health Care Improvement and consists of three evaluation measures: patient experience of care; population health; and cost.

APPENDIX: Summary of CAPHC Recommendations Transitioning from Pediatric to Adult Care (2016)⁴

Person Centred Recommendations

1. Transition planning is youth-focused and family-centred, inclusive of personal choice, and is adaptable to the abilities and complexities of the youth's needs.
2. Transition of youth and their families address the youth's physical, developmental, psycho-social, mental health, educational, lifestyle, cultural and financial needs.

Clinical Recommendations

3. Transition for youth is supported by individualized planning in the pediatric and community settings, a coordinated transfer of care and secure attachment to adult services.
4. Healthcare providers engage, educate, and build capacity of youth and their families regarding transition.
5. Collaborative respectful communication between stakeholders (youth, families, their natural networks, community, paediatric, primary and adult care provider(s)) supports the flow of information and ensures safe, caring, and effective transition.
6. All youth have a primary care provider to support care coordination.
7. A developmentally appropriate individualized transition plan is prepared and documented in collaboration with the youth and family.
8. Paediatric and primary providers assess the youth's readiness for adult care, identifying gaps in skill and knowledge requiring intervention.
9. Healthcare providers and family members support youth at their appropriate developmental level to understand their chronic condition, treatment plan, and level of self-management.
10. Care providers educate the youth and family about transfer of care, at least one year prior to transfer, encouraging them to share in the responsibility of accessing community and adult services, and if needed, provide additional navigational support.

11. Priority for care coordination is given to youth with complex needs and their families.
12. Each transferring program is responsible to provide a comprehensive health summary at the time of referral, to the adult health care provider(s), youth, and family.
13. Transfer of care to adult services includes monitoring of youth's attachment to adult services, attendance at adult appointments in an expected time frame, ongoing communication between paediatric, primary and adult providers, and shared responsibility for management of youth with lapses in care.

System Level Recommendations

14. All services have a written policy or the provision of transition.
15. Develop efficient and accredited health information systems to support transfer of information and collaborative communication among sectors.
16. Organizations designate transition champions within their paediatric and adult settings to facilitate and evaluate transition.
17. Organizations provide ongoing transition education, training, and knowledge translation for all stakeholders.
18. Researchers and clinicians develop a method for consistent data collection at an individual and systems level, including qualitative narratives of lived experiences and quantitative data, to be used by clinical teams, decision makers and researchers for quality improvement and evidence based practices.
19. Involve youth, young adults and families, policy and decision makers, administrators, researchers, and government agencies, to jointly identify system barriers, system enablers, and future development opportunities for the responsible transitioning of youth.

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Endnotes

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