



**CYSTIC FIBROSIS
Adolescent Transition Care Clinical Pathway**

Date started on clinical pathway: _____

Pathway introduced to patient and: _____

Age started: _____

Instructions:

1. Clinical pathway to be kept in CF clinic chart.
2. All areas are to be completed by applicable health care team members.
3. Tick boxes and date completed items, as indicated.
4. Page on back is to be used for narrative charting when there is an issue of concern.
5. Information that is documented will be based on discussions between youth, family (parents/guardians) and health care team.
6. Copy of completed pathway will be given to adult CF clinic on graduation.

EARLY TRANSITION (10 - 12 YEARS)

(Focus on Youth and Family)

	INDICATORS	F/U Needed	Completed (Date)	SUGGESTED TOOLS & MATERIALS
Self Advocacy	<ul style="list-style-type: none"> -Learn about transition process -Describes Cystic Fibrosis (basic) -Acknowledges importance of recording health information -Begins to ask health-related questions -Begins to describe how to access health care system when unwell -Able to self report changes in respiratory status 	↑ ↑ ↑ ↑ ↑ ↑	_____ _____ _____ _____ _____ _____	<ul style="list-style-type: none"> -Introductory transition letter to youth and family -WB p.1 "What I need to know about my health condition?"
Independent Behaviours	<ul style="list-style-type: none"> -Basic identification of medications & schedule -Takes own enzymes -Begins to learn about common CF tests and reasons for them (eg. PFT's, sputum C&S) -Basic understanding of CF lung disease & airway clearance techniques -Schedules independent airway clearance techniques, with supervision 	↑ ↑ ↑ ↑ ↑	_____ _____ _____ _____ _____	<ul style="list-style-type: none"> -YP red Medication List -YP red Keeping Trac/Immunizations/Allergies/Tests
Sexual Health	<ul style="list-style-type: none"> -Describes what is being taught in school -Learns about possible delay of puberty in CF -Discuss body image; changes in appearance due to puberty -Learns about impact of puberty on health condition 	↑ ↑ ↑ ↑	_____ _____ _____ _____	<ul style="list-style-type: none"> -YP green "Puberty and my Condition" -"What they Don't Tell You", pgs 4-7
Social Supports	<ul style="list-style-type: none"> -Describe family/people at home -Discuss family role in transition planning/ feelings about youth growing older -Discuss friendships, and telling friends about CF and treatments -Discuss importance of identifying and expressing feelings -Ability to perform treatments in presence of peer group 	↑ ↑ ↑ ↑ ↑	_____ _____ _____ _____ _____	
Educ/Vocation/ Financial Plan	<ul style="list-style-type: none"> -Discuss school – attendance, strengths, goals and concerns -Identify responsibilities at home 	↑ ↑	_____ _____	
Health & Lifestyle	<ul style="list-style-type: none"> -Discuss exercise – gym, teams, activities -Aware of any limitations/restrictions -Discuss knowledge of peer use of tobacco/marijuana – review risks of smoking -Begins to learn how body uses food -Describes & records a healthy CF diet -Aware of ↑ salt & fluid needs in hot weather/strenuous exercise 	↑ ↑ ↑ ↑ ↑ ↑	_____ _____ _____ _____ _____ _____	<ul style="list-style-type: none"> -YP red My exercise – activity log

MIDDLE TRANSITION (13 - 15 YEARS)

(Focus on Youth, with assistance from Family)

	INDICATORS	F/U Needed	Completed (Date)	SUGGESTED TOOLS & MATERIALS
Self Advocacy	<ul style="list-style-type: none"> -Describes CF in own words, incl. possible complications -Names GP and/or pediatrician -Lists allergies & describes reactions -Helps parent to fill out clinic questionnaire -Names & describes the role of those on CF team -Learns about rights & responsibilities to information (privacy, participating in decision-making, consent, hospital chart) -Learns importance of knowing family health history -Learns how to be a part of health care decision making 	↑ ↑ ↑ ↑ ↑ ↑ ↑ ↑	_____ _____ _____ _____ _____ _____ _____ _____	
Independent Behaviours	<ul style="list-style-type: none"> -Reviews treatment plan -Names medications (correct name); basic dosage; reason for taking -Basic understanding of common CF tests & results -Basic understanding of CF respiratory baseline & changes that may occur -Performs independent airway clearance techniques -Describes a basic plan to access CF care if unwell 	↑ ↑ ↑ ↑ ↑ ↑	_____ _____ _____ _____ _____ _____	<ul style="list-style-type: none"> -YP red/ "Me & my tests" WP p.5 -YP red/ "Take a medication quiz" WB p.15
Sexual Health	<ul style="list-style-type: none"> -Basic understanding of CF fertility issues -Learns about stress incontinence, yeast infections in CF -Names persons/places for reliable, accurate information about sexual health questions -Identifies sexual health concerns/questions -Discuss contraception in CF, as ready 	↑ ↑ ↑ ↑ ↑	_____ _____ _____ _____ _____	<ul style="list-style-type: none"> -"Who to question about sex" WB p.47 -"Healthy relationships puzzle" QB p.51 -"Sexuality & CF: Information for Adolescents" pamphlet -"What they don't tell you" booklet
Social Supports	<ul style="list-style-type: none"> -Aware of resources that offer family support and ideas for youth living with CF/a chronic condition -Discuss ways to benefit from peer support around CF and youth issues -Discuss friendships, and impact of CF -Describes who to talk to during difficult times -Understands ways to connect safely through internet, if wishes to 	↑ ↑ ↑ ↑ ↑	_____ _____ _____ _____ _____	<ul style="list-style-type: none"> -"Easy for you to say" WB p.32 -YP green/ "Looking for peer support group" WB p.60 -Parent support groups (including internet) & information -"Who can I talk to?" WB p.63
Education/Vocation/ Financial Planning	<ul style="list-style-type: none"> -Discuss possible restrictions to educational or work opportunities -Discuss volunteering opportunities in the school and/or neighborhood -Identify school issues, strengths, concerns -Aware of resources (eg school counselor) to discuss options -Identifies emerging education/career plans 	↑ ↑ ↑ ↑ ↑	_____ _____ _____ _____ _____	
Health & Lifestyle	<ul style="list-style-type: none"> -Describes ways of coping with stress and anxiety -Lists ways to relax and feel good about self -Learns about the use of drugs, alcohol and smoking in CF, and when mixed with medications -Aware of posture and relationship to respiratory status; exercises to promote good posture -Basic understanding of relationship btwn. Nutrition and lung health -Begin reporting on what influences appetite (eg reflux, lung infection, side effect of medications) 	↑ ↑ ↑ ↑ ↑ ↑	_____ _____ _____ _____ _____ _____	<ul style="list-style-type: none"> -YP/"Booklists – must reads" WB p.104 -"Medications do not mix" WB p.103 -"Cocktails: Facts for youth about Mixing Medicine, Booze and Street Drugs" -"Posture Exercises" pamphlet

LATE TRANSITION (16 – 18 YEARS)

(Focus on Youth independently; Family included in process)

	INDICATORS	F/U Needed	Completed (Date)	SUGGESTED TOOLS & MATERIALS
Self Advocacy	<ul style="list-style-type: none"> -Able to give more complex definition of CF -Understands the importance of preparing for environment/expectations of adult care -Understands who will need to be involved in providing adult health care -Reviews “pre-graduation CF package” (16 yrs.) -Able to fill out own clinic questionnaire -Practices communicating with CF health care team -Can identify basic family and personal health history -Continue learning about rights & responsibilities to information 	<ul style="list-style-type: none"> ↑ ↑ ↑ ↑ ↑ ↑ ↑ ↑ 	<ul style="list-style-type: none"> _____ _____ _____ _____ _____ _____ _____ _____ 	<ul style="list-style-type: none"> -“Adult CF Clinic” handout -“The CF Graduation Clinic” handout -“Adult care is different” WB p.110 -“Changes” WB p.109
Independent Behaviours	<ul style="list-style-type: none"> -Sees health care team on own at clinic -Demonstrates knowledge of medications, actual dosages, schedule, & possible side effects -Self administers oral and inhaled medications -Begins to learn about refilling prescriptions and booking appointments -Understands common CF tests & results, and implications for their health -Able to determine appropriate airway clearance technique for respiratory status -Begins to take steps to access own care (calls CF clinic if unwell) 	<ul style="list-style-type: none"> ↑ ↑ ↑ ↑ ↑ ↑ ↑ 	<ul style="list-style-type: none"> _____ _____ _____ _____ _____ _____ _____ 	<ul style="list-style-type: none"> -“Getting ready for adult care” WB p.111 -YP red/ “Take a medication quiz” WB p.15
Sexual Health	<ul style="list-style-type: none"> -Basic understanding of ability to have children -Knowledge of appropriate contraception in CF -Can identify health care providers/family to discuss sexual health, contraception and family planning -Learns about the reasons and process for genetic counseling/ carrier testing of future partner -Understands risks of sexual behaviours (STD’s/ pregnancy) on health condition -Understands potential for yeast infection/ stress incontinence, and how to address problem 	<ul style="list-style-type: none"> ↑ ↑ ↑ ↑ ↑ ↑ 	<ul style="list-style-type: none"> _____ _____ _____ _____ _____ _____ 	<ul style="list-style-type: none"> -“Questions to be answered” WB p.53 -Breast & Testicular self-examination pamphlet/ “What are STD’s” WB p.50 - “What they don’t tell you” -“Sexuality & CF: Information for Adolescents” -“Sexuality, Fertility and CF: Information for Adults”
Social Supports	<ul style="list-style-type: none"> -Aware of condition-specific associations, organizations for support and information -Discuss concerns around gaining independence – changing roles in family -Identifies sources of support & a person he/she could contact if feeling lonely, sad or depressed -Discuss friendships and impact of CF; makes healthy friendship choices 	<ul style="list-style-type: none"> ↑ ↑ ↑ ↑ 	<ul style="list-style-type: none"> _____ _____ _____ _____ 	<ul style="list-style-type: none"> -“You are not alone” WB p.61 -“Who can I talk to?” WB p.63 -CCFF ‘Circle of Friends’ newsletter, and Adult CF Committee
Education/Vocation/ Financial Planning	<ul style="list-style-type: none"> -Describe strengths in school; set career or college goals -Aware of opportunities to job shadow/ volunteer/work experiences (and impact due to CF) -Discuss importance of giving information about condition to potential employers or college programs -Discusses resources available for education career assistance, counseling and job placement -Learns about CF travel/medication grants -Review plans for future medical insurance benefits (youth and/or parent) -Discuss future plans for living 	<ul style="list-style-type: none"> ↑ ↑ ↑ ↑ ↑ ↑ ↑ 	<ul style="list-style-type: none"> _____ _____ _____ _____ _____ _____ _____ 	<ul style="list-style-type: none"> -“Every experience counts” WB p.79 -YP green/“Keep a work journal” WB p.82 -“What I need to tell my employer or college” WBp.83 -YP/ “Career planning suggestions” QB p.84 -clinic info. on CF medication, travel & accommodation grants YP red/“Am I and will I be covered?” WB p.86 “Future plans for living” WB p. 85
Health & Lifestyle	<ul style="list-style-type: none"> -Describes exercise/activity routine -Increased understanding of complex relationship btwn nutrition, lung health, complications of CF (CFRD, G-E reflux, etc) -Able to plan a healthy ‘CF meal’ -Self monitors for increased salt intake as necessary -Review coping skills -Makes healthy choices re smoking, drugs and/ or alcohol -Discuss importance of planning ahead for trips/being away from home -Can identify their most common CF respiratory pathogens and how this might impact their health, and interactions with other CF individuals 	<ul style="list-style-type: none"> ↑ ↑ ↑ ↑ ↑ ↑ ↑ ↑ 	<ul style="list-style-type: none"> _____ _____ _____ _____ _____ _____ _____ _____ 	<ul style="list-style-type: none"> -YP green/ Personal travel plans” WB p.99 -CCFF: “Travel Tips for Individuals with CF”

Summary Page:

Would like a tour of adult CF centre: _____

Attended CF pre-graduation clinic: _____

Attended CF graduation clinic: _____

(If "NO", Last CF clinic appt.): _____

Overall, patient is ready for transfer to adult CF healthcare:

YES / NO (patient's perspective)

YES / NO (parent's perspective)

YES / NO (CF team's perspective)

Date: _____

