

Appendix 1 - Transition Integrated Care Pathway

TRANSITION OF CARE FROM THE PAEDIATRIC SERVICE TO THE ADULT SERVICE

Name:

Referring consultant:

CRN or referring hospital:

Please attach a referral letter if outside the Royal Brompton Hospital.

Transition: Is the planned process of changing from paediatric family centred care to a more independent adult service. This process usually starts during the latter stages of paediatric care and ends in the early years of attendance in the adult service. It is a process that fully involves the young adult, their parents, and both the paediatric and adult Cystic Fibrosis (CF) teams.

INTEGRATED CARE PATHWAY

The aim of this document is to improve the process of transition from paediatric to adult care

Date ICP started:

Date ICP ended:

This ICP will start in the paediatric CF service and end after transition to the adult CF service. It must be kept at the front of the medical notes throughout this time. Please initial and date the YES/NO boxes.

This ICP is for adolescents with CF who are 14-17 years old and planning their move to adult care. Transition from the paediatric to adult clinic may take place over a period of up to three years.

- Patients will be contacted by the paediatric nurse specialist with an appointment for both the Pre-transition and Transition clinics.
- Both paediatric and adult CF teams are informed of the dates.
- Information will be provided and arrangements made for patients and families in advance of the clinic.

a. 14th Birthday Letter sent: Yes No

b. Pre-Transition 1 Clinic Date/...../..... Attended: Yes No
i. If NO, action taken:

c. Pre-Transition 2 Clinic Date/...../..... Attended: Yes No
i. If NO, action taken:

d. Transition Clinic Date/...../..... Attended: Yes No
i. If NO, action taken:

Please ensure that the Family & Social Information Form is attached before sending to the adult team.

	PLANNING TRANSITION	YES	NO	VARIANCE AND/OR ACTION TAKEN
1	<p>Has transition been discussed with the patient?</p> <p>Has transition been discussed with parents / caregiver?</p> <p>Are there any concerns?</p>			<p>If NO reasons why:</p> <p>If NO reasons why:</p>
2	Has the patient been given a Family & Social Information form to complete?			If NO reasons why:
3	Has the form been returned			If NO reasons why:
4	Has the pre-transition ICP data been fully completed?			If NO reasons why:
5	Is the transition ICP available for the adult team to review?			If NO reasons why:
CLINICAL DATA				
6	<p>Age at diagnosis:</p> <p>Presentation at diagnosis:</p>			<p>Genotype:</p> <p>1:</p> <p>2:</p>
7	<p>CURRENT CLINICAL STATUS</p> <p>Date of measurements:</p> <p>Height: cm Weight: kg BMI:</p> <p>Lung function: FEV₁: (%) FVC: (%) MEF 25-75: (%)</p> <p>SaO₂: %</p>			
8	<p>INTRAVENOUS ACCESS</p> <p>What type of access is usually used?</p> <p>Are there any problems associated with this (seen psychology)?</p> <p>Portacath: Date inserted: Type:</p> <p>Any problems?</p>			

	ORGANISMS	Ever grown (YES/NO)?	Where grown (RBH, local?)	Date of first growth	Current
	Please include eradication attempts - successful or not				
16	Staphylococcus aureus Haemophilus influenzae Pseudomonas aeruginosa Stenotrophomonas maltophilia Achromobacter xylosoxidans Burkholderia cepacia complex, type: MRSA Non-tuberculous mycobacteria, type: Other bacteria Aspergillus fumigatus Other fungus				
17	HOSPITALISATION How many times in the last 12 months? Reasons for admission: No. of courses IV antibiotics: At home: In hospital:				
18	Medication list (please include whether patient has tried DNase or HTS previously but stopped, with reasons why)	Dose	Frequency	Route	

19	Any allergies?			If YES describe the reaction:
20	COMPLICATIONS Oxygen therapy Haemoptysis Pneumothorax ABPA DIOS Liver disease Oesophageal varices CF Related Diabetes Arthropathy Severe small airways disease Other associated conditions	Details		
21	Does the patient receive any form of outreach support?			If YES please provide further details:
22	Has the patient had involvement/support from social services?			If YES please provide further details:
23	Has there been a psychological assessment and handover?			If NO reasons why:
24	Is the patient taking part in any research trials?			If YES, which ones? Can the patient transition while taking part? Have alternative plans been made?

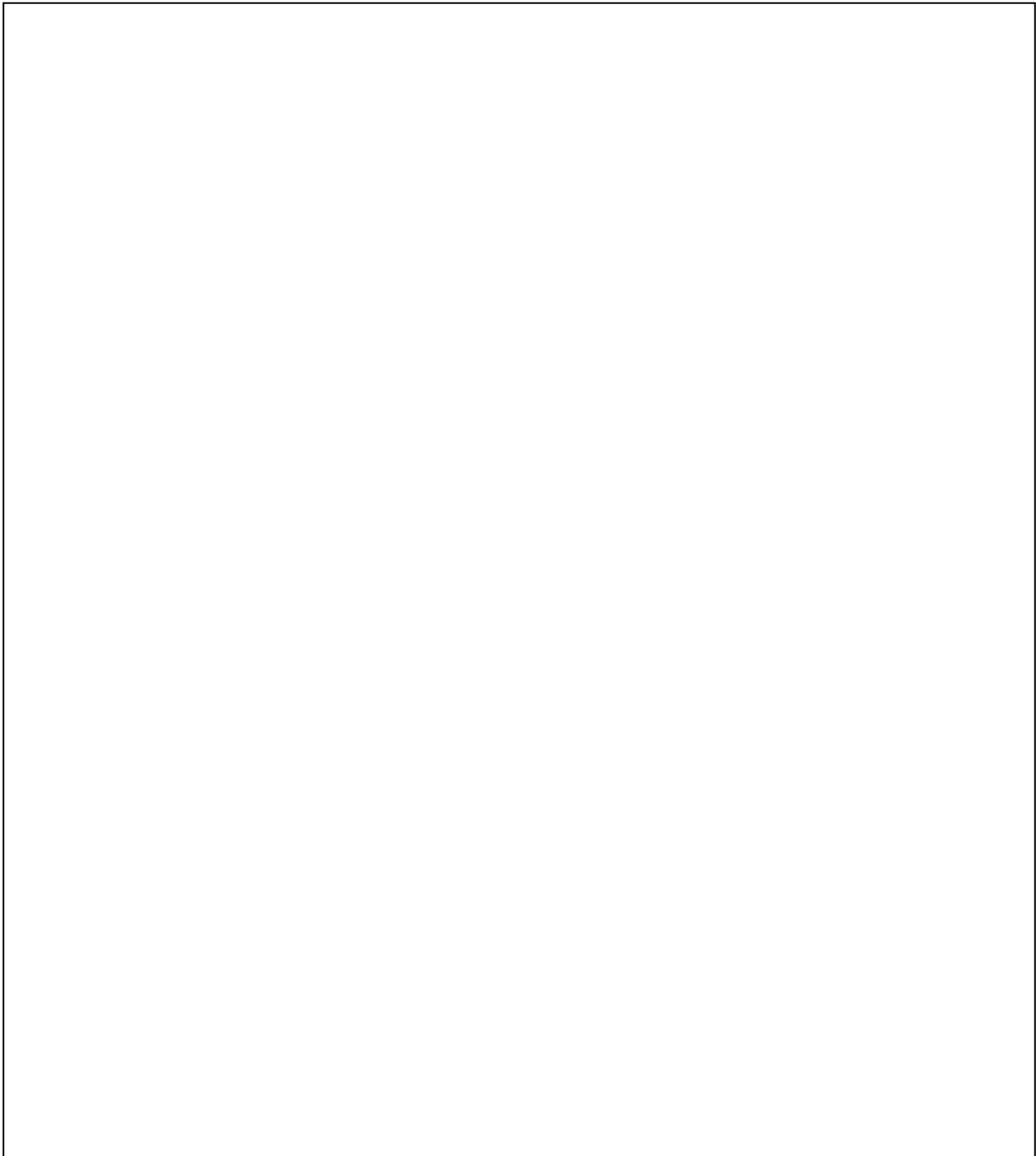
FAMILY & SOCIAL INFORMATION

We would be grateful if you could please complete this form as it helps the Adult CF Team get to know you before transition. Thank you.

YOUR FAMILY BACKGROUND Parents names: Siblings names and ages: CF-Siblings names and ages: Who do you live with? CF in extended family –relationship names and ages: Ethnic origin:
SOCIAL SUPPORT Disability Living Allowance: yes <input type="checkbox"/> no <input type="checkbox"/> Rate: Mobility: yes <input type="checkbox"/> no <input type="checkbox"/> PIP: yes <input type="checkbox"/> no <input type="checkbox"/>
SOCIAL CARE INVOLVEMENT Named social worker: Contact details: Last contact date: Attach any additional information/report yes <input type="checkbox"/> no <input type="checkbox"/>
EDUCATION Sixth Form (GCSEs, A Levels, GVNO) College/University: Career interest: Special educational needs:
EMPLOYMENT (Saturday /part-time/ weekend/full-time)
OTHER COMMENTS
CONTACT DETAILS Your mobile phone number: Your email address: Your next of kin's mobile phone number: Your next of kin's email address:

This is for you to complete and will be sent to the adult CF team

ALL ABOUT ME – please introduce yourself to the adult team

A large, empty rectangular box with a thin black border, intended for the user to write their introduction to the adult team.

Paediatric Clinic - Form completed by:

Date:

	Transition clinic	YES	NO	Variance and action taken
1	At the transition clinic, has the patient been given transition information?			If NO reasons why:
2	Have the patient and family met all the members of the adult team today?			If NO, who do they need to meet? Has this been arranged?
3	Have both teams met to discuss any problems and issues prior to clinic?			If NO reasons why:
4	Were treatment plans discussed?			Please give details.
5	Has the patient been asked if they would like to attend a second transition clinic?			If NO reasons why:
6	If they wish to, has a date been given?			Date:
7	Have family & patient visited Foulis ward?			If NO reasons why:
8	Have they received an appointment for an adult CF clinic?			Date of clinic: A, B or C clinic?

Follow up at adult clinic		YES	NO	Variance and action taken
1	Has the PortCF co-ordinator been informed of the move?			Date:
2	Was the patient seen in the appropriate A, B, or C clinic?			If NO reasons why:
3	Were current medical notes available for the consultation?			If NO reasons why:
4	Has the Annual Review co-ordinator been informed?			Date:

Adult Clinic - Form completed by:

Date

Daniel Office – Clinical Nurse Specialists

(d.office@rbht.nhs.uk)

Dr Nicholas Simmonds – Consultant Physician

(n.simmonds@rbht.nhs.uk)

Dr Andrew Jones - Consultant Physician

(a.jones2@rbht.nhs.uk)

Please send a copy attaching a referral letter if the patient is outside the Royal Brompton Hospital:

Department of Adult Cystic Fibrosis
 Royal Brompton Hospital
 Sydney Street
 London
 SW3 6NP