

STANDARD OPERATING PROCEDURE (SOP) W &C Division

Directorate	Paediatric directorate
Ward/Service	Cystic fibrosis service
Title of SOP	Transition of paediatric cystic fibrosis patients to the adult clinic
Number	14
Author	Pauline Singleton
Date	August 2014
Review Date	August 2016

OBJECTIVES											
OBJECTIVES	To ensure transition to adult services is a smooth process										
SCOPE											
SCOPE	This SOP applies to patients with cystic fibrosis that needs transition to adult services										
TARGET GROUP											
TARGET GROUP	Cystic Fibrosis patients over the age of 11years attending the Teesside CF Service										
EVIDENCE TO SUPPORT PROCEDURE											
EVIDENCE TO SUPPORT PROCEDURE	CF trust Standards of care 2011										
CONTENTS											
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Responsibilities	1										
Procedure	2										
Early Transition (11 – 13 years)	2										
Middle Transition (14 – 16 years)	2										
Late Transition (16 + years)	3										

Responsibilities

The following persons have responsibilities within the SOP:

Paediatric Consultant with responsibility for Children with CF
 Specialist Nurse for Cystic Fibrosis
 Clinical Specialist Physiotherapist
 Senior Clinical Specialist Dietician
 Specialist Pharmacist

NO	PROCEDURE	RATIONALE / ADDITIONAL INFORMATION
1	The expectation that the child will transition to adult services between the ages of 16 and 18 will be discussed around the time of diagnosis	This will set the set scene of what parents can expect as their child gets older
2	Multidisciplinary transition planning checklist and evidence record will be placed in notes	
EARLY TRANSITION (11 -13 YEARS)		
3	Before 12 th birthday a discussion will take place with the young person and their family about transition	Allows child parents to discuss any concerns
4	Home visit by the CF nurses to discuss transition process at or around the young persons 12 th birthday	Depends on individual needs of the child and family Allows family to discuss any issues regarding transition in a safe environment
5	Transition handbook and documentation will be given to support verbal information	Patients / parents have additional information
6	An appointment will be given for evening clinic (timed according to infection risk)	Adolescent clinic – patients are expected to take more responsibility for own care
7	At consultations questions will be aimed at the young person and there is an expectation that the young person will eventually spend part of this time without parents present	To encourage the young person to engage in self-care behaviour. To encourage parents to allow the young person to become independent
8	Education questionnaire will be given to young person to identify individual needs and a plan of care will be formulated to address issues	To identify individual needs of the young person
9	Plan to address CF educational needs will be documented in notes and handbook. This will be addressed at each annual review or more frequently if required	To keep a record of changing needs
MIDDLE TRANSITION (14 – 16 YEARS)		
10	Negotiation will take place regarding the young person being seen alone in the adolescent clinic. Parent/carer	To encourage independent behaviour and maintain confidentiality Parents continue to be involved allowing them

	will be seen with the young person at the end of the consultation	to support the young person
11	Home visit by CF nurse to update handbook, give DVD to watch regarding compliance and highlight and explore any emerging issues	Adolescence is often a time of poor compliance
12	Discussions will take place regarding employment opportunities, selecting education choices for GCSEs and college/apprenticeship options on completing formal education	To help the young person make the right choices, considering how CF affects them and could affects their career
13	Sexual health and fertility issues will be addressed (or revisited) - booklet will be given	
14	Education and transition checklist in notes will be checked and updated	To maintain accurate records
15	Choice of local and national adult service will be discussed	To allow the young person and their family to consider all the options when discussion long term future
LATE TRANSITION (16 + years)		
16	The young person will be expected to attend clinic appointments alone or take the lead in the consultation if accompanied	Changing roles and developing relationships may mean friends or partners may attend with the young person
17	Young person and their family will be given the opportunity to meet the adult CF team at least once, in a transition clinic, before their care is transferred	Standards of care
18	Education and transition checklist will be completed before transfer. If not completed then the adult team will be made aware in order to continue education	
19	Date for transfer to adult services will be negotiated with the patient and their family	
20	The patient will be given the opportunity to visit the adult service facilities before transfer. The CF	

	nurse will accompany the young adult if required	
21	The patient will be given names and contact numbers of the adult team	
22	Patients will be expected to take full responsibility for their own self care	

Developed By:	AUTHOR TITLE (NAME)	JOB TITLE
	Pauline Singleton	Specialist Nurse
	APPROVAL GROUP NAME	DATE
Approved By:	Teesside CF Team	August 2014