

# The QEHB Model of Care

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# Introduction

## QEHB Model of Care

### Transition

- Key Personnel
- Pathway

### Cystinosis Model

- Background to the development of the Cystinosis model
- Cystinosis 'one stop' clinic
- Management pathway
- Ongoing support.

# Transition Key Personnel

## Adult Services

### Consultants

- Dr G. Lipkin
- Dr T. Pankhurst

### Clinical Nurse Specialist

- Katharine Hannon

### Youth Worker

- Mark Thompson

### Renal Psychologist

- Lindsay Chapman

## Child Services

### Consultants

- Larissa Kerecuk

### Clinical Nurse Specialist

- Clare Edwards

### Youth Worker

- Rachel Weston

## MDT

- Specialist Nurses
- Dietician
- Social Worker
- Haemodialysis Nurses
- Peritoneal Dialysis Nurses
- Transplant Coordinator
- Pharmacist

# Transition Model

## 13 Years Old

- Attend an open evening at The Children's Hospital to meet staff from Queen Elizabeth Hospital and discuss transition
- Commence transition plan

## 13-15 Years Old

- Invited to attend the Queen Elizabeth Hospital tour
- Complete mid way adolescent plan

## 15 Years Old

- Formally referred to Youth Worker at Queen Elizabeth Hospital. Introduction pack with contact details will be sent

## 16 Years Old

- Commence final adolescent plan
- Attend first appointment at the Queen Elizabeth combined transition clinic with both The Children's and Queen Elizabeth staff

# Transition Model

## 16-18 Years Old

- At a mutually agreed time formally transfer care to Queen Elizabeth

## 18-20 Years Old

- Attend Queen Elizabeth Young Person Clinic
- Begin to alternate between Young Person Clinic and Adult Cystinosis Clinic

## 20-24 Years Old

- Transfer to Adult Cystinosis Clinic

# Transition Model

## Additional Support

- Transition Filofax to assist with transition. Details medicine information, vocational info, checklists etc.
- Workshops
  - Independence
  - Medication management
  - Sexual health
  - How to cope with transition
- Activity Days
- Weekend getaways
- Ongoing youth worker support

## Limitations

- Requires a considerable amount of time commitment from the patient.
- It doesn't appeal to everybody, and difficult to accommodate all cultures.
- Dependant on resources.

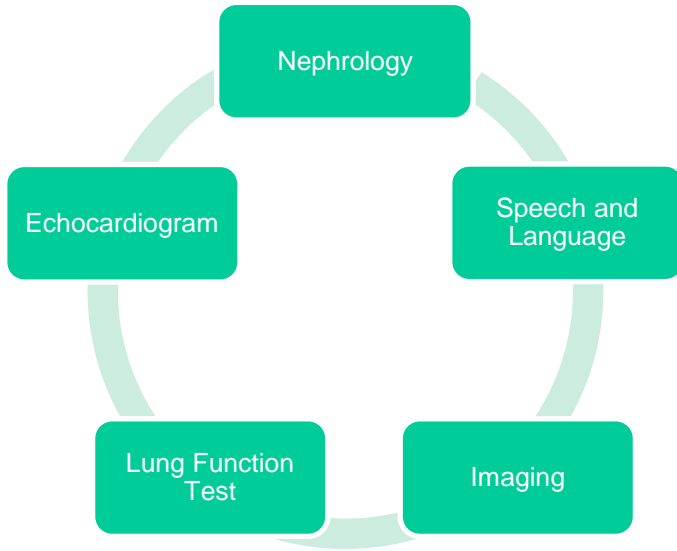
# Cystinosis Model Background

- **Traditional View of Rare Disease Care Coordination:**  
“Care for patients with rare diseases is not always patient centred and does not fully take into account a patients individual needs...Care is often poorly coordinated and fragmented...” – Rare Disease UK
- Multisystemic conditions, such as cystinosis can generate a significant amount of hospital appointments. This can impact upon a patients education, career, social activities and can potentially accrue a sizeable financial burden.
- The response from the consultation on the UK plan for rare diseases showed overwhelming support for better coordinated care.  
Q: Do you agree that commissioners of care for people with rare conditions should assess options for improved care coordination?  
A: 85% Yes, 2% No, and 13% didn't directly answer the question.
- One key way of addressing this is believed to be developing and supporting 'one stop' clinics.
- **One Stop Models at the QE:**  
Based our model around one stop clinics that already existed. The LMBBS and Fabry clinics have proved to be very popular amongst patients and relatives.
- In our experience we've found that patients are willing to travel considerable distance to receive coordinated care.

## References

1. Department of Health (2012). *Consultation on the United Kingdom Plan for Rare Diseases – Summary of Consultation Responses*. DH.
2. Rare Disease UK (2011). *Improving Lives, Optimising Resources: A Vision for the UK Rare Disease Strategy*. RDUK.

# Cystinosis Model (current)



## Annual One-Stop Review Clinic

- Patients attend once a year. We run four clinics per year.
- 5 slots per clinic.
- All appointments are booked for the morning. Visits usually take between 2-3 hours.
- Patients receive letter detailing the outcome of the appointments or can view it on MyHealth@QEHB.

## How is it coordinated?

- Reserve slots /agree dates with departments involved. Requires 8 weeks notice minimum.
- Complete appropriate referral documents ensuring to request specific time slots for each patient.
- Patient receives a summary letter in the post inc. maps, department locations etc.
- *Cross your fingers on clinic day!*

	Patient 1	Patient 2	Patient 3	Patient 4	Patient 5
09:00	Spiro	SALT	Echo		
09:15					
09:30	Lipkin	Spiro	SALT	Echo	USS
09:45					
10:00	USS	Lipkin	Spiro	SALT	Echo
10:15					
10:30	Echo	USS	Lipkin	Spiro	SALT
10:45					
11:00	SALT	Echo	USS	Lipkin	Spiro
11:15					
11:30				USS	Lipkin
11:45					
12:00					



# Cystinosis Model

<u>3 Monthly</u>	<u>Annual</u>	<u>2 yearly</u>	<u>Clinically Indicated</u>
Biochemistry: renal profile, bone profile, liver function tests, HbA1c, thyroid function tests, magnesium, and white cell cystine [monitor immunosuppression if transplanted]	Ultrasound Scan (Abdo)	Neurology Review	Cardiology review
Blood pressure	Spirometry	Echocardiogram	Gastrointestinal review
Nephrology review	Speech and language assessment		DEXA scan
	Ophthalmology review		Dietetic review
	Endocrinology/diabetic review		

# Cystinosis Model

- **What are the advantages to this model?**

- Reduces the amount of hospital visits. Less time of work/school/social activities etc.
- Previously patients may have missed or DNA there appointments for diagnostics. 'One stop' eliminates the confusion and excessive time commitment.
- Reduced stress on the patients behalf. No need to ring multiple departments to change appointments.
- It's allowed us to see patients from all over the UK.
- Patients have reported greater peace of mind in knowing that the rest of their organs are being monitored.

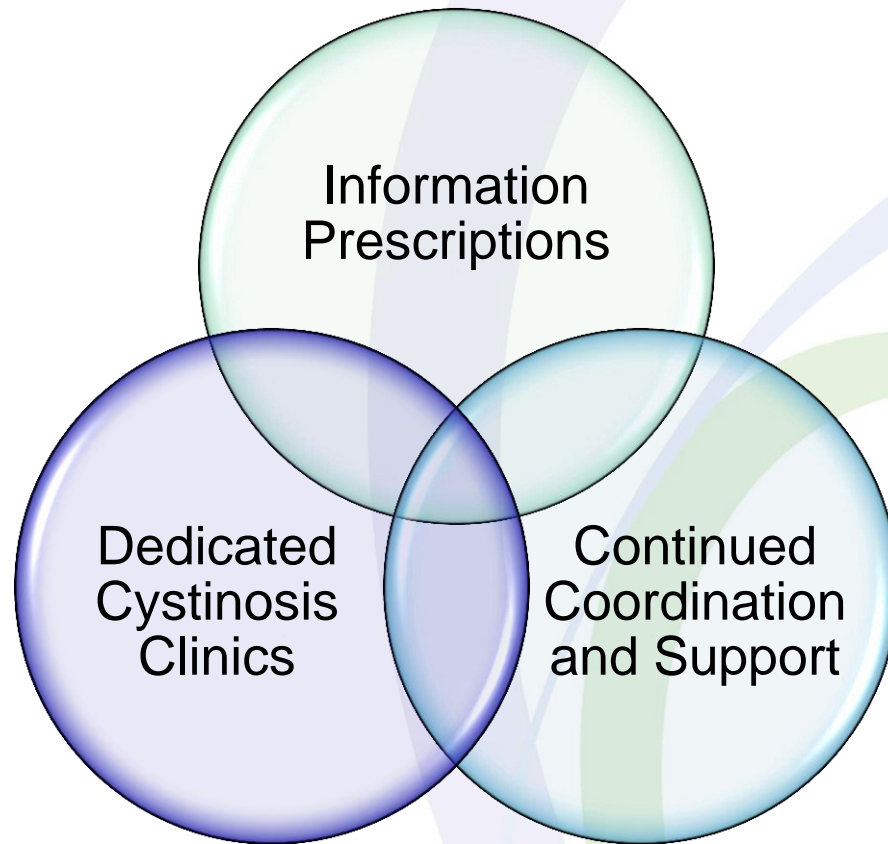
- **Limitations to the model**

- Not all of the organs involved with cystinosis are being addressed
- Highly dependant on available resources
- All or nothing!
- Is it a transferable model?

- **Future Development**

- As a model we think it works for us, however we would like to add in the other annual appointments.

# Ongoing Support



# Conclusion/ Questions