

ADULT HAEMOGLOBINOPATHY ANNUAL REVIEW

PATIENT DETAILS (label)

Date of current Annual Review * _____

Date of last Annual Review * _____

Diagnosis * _____

(* Denotes mandatory questions)

Did patient attend Annual Review?

No Yes

ABOUT THE PATIENT

Height(cm)	Weight(kg)	Spleen Size(cm)	BP	Oxygen Saturation
Urine dip				

Centre Changed in this review period *

No Yes

Patient Status *

Active No longer Seen Patient died Transferred to other center

Your center is this patient's *

Secondary Care Center (LHT) Specialist Haemoglobinopathy Team (SHTC)

Number of Emergency (A&E or Urgent day care) attendances

Does the patient have an emergency care plan

No Yes

Did the patient have a child in this review period
(To be answered by both male and female)

No Yes

Outcome of pregnancy (select one item)

C Section	Preterm baby <36 wks	Spontaneous Miscarriage
Live Birth	ND	Therapeutic termination

Has the patient had any Red Cell Antibodies

No Yes Unknown

COMPLICATIONS *

No

Yes

Complication details				Date	Comments
Acute Chest Syndrome	<input type="radio"/>				
Avascular Necrosis	<input type="radio"/>				
Bone Problem	<input type="radio"/>				
Hepatitis B	<input type="radio"/>				
Chronic Hepatitis C	<input type="radio"/>				
Gallstones	<input type="radio"/>				
Headaches	<input type="radio"/>				
HIV	Positive <input type="radio"/>	Negative <input type="radio"/>	Unknown <input type="radio"/>		
Leg Ulcers	<input type="radio"/>				
Multi Organ Failure	<input type="radio"/>				
Osteomyelitis	<input type="radio"/>				
Parvovirus	<input type="radio"/>				
Pneumococcal Infection	<input type="radio"/>				
Priapism	<input type="radio"/>				
Pulmonary Hypertension	Echo-cardiogram <input type="radio"/>	Other <input type="radio"/>	Proven by Cardiac Catheter <input type="radio"/>		
Renal Failure	<input type="radio"/>				
Severe Septicemia	<input type="radio"/>				
Sickle Retinopathy	<input type="radio"/>				
Splenic Sequestration	<input type="radio"/>				
Stroke	<input type="radio"/>				
TIA	<input type="radio"/>				
Other Bacteraemia	<input type="radio"/>				
Visual Symptoms	<input type="radio"/>				
Oher _____	<input type="radio"/>				

TRANSFUSIONS

Regular Transfusions in this review period *

No

Yes

Tranfusion Details

Transfusion at St Georges?	No <input type="radio"/>	Yes <input type="radio"/>	
Type	Auto Exchange <input type="radio"/>	Manual Exchange <input type="radio"/>	Top Up <input type="radio"/>
Frequency of Transfusions (in weeks)	_____ (value between 1-8)		
Average units per Transfusion episode	_____ (value between 0-15)		
Usual Venous Access	Peripheral Access <input type="radio"/>	Temporary Central Line <input type="radio"/>	Long Term Indwelling Line <input type="radio"/>
Year Transfusion Started	_____		
Have regular transfusion stopped in this period?	No <input type="radio"/>	Yes <input type="radio"/>	

Adhoc Transfusions in this review period
(Transfusions not part of a transfusion regime)

No Yes

How many Episodes of Adhoc Transfusions

VACCINATIONS

Vaccinations in this review period

- Childhood schedule
- Haemophilus
- Hepatitis B booster
- Influenza
- Meningitis + Hib (menitorix)
- Meningitis Group C conjugate
- Pneumovax
- Prevenar
- Other

Date of Vaccination	Expiry of Vaccination	Comments

INVESTIGATIONS

No Yes

Investigations in this review period

- Audiometry
- Bone Profile
- Brain MRI/MRA
- DEXA
- Echocardiogram
- Ferritin
- Fructosamine
- FSH/LH
- Glucose Tolerance Test
- Liver Function
- Mean Haemoglobin Untransfused
- Microalbuminuria
- Oestrogen(for females)
- Ophthalmology review
- PTH
- Sleep Studies
- Steady State Untransfused
- Testosterone (for males)
- Urine/Protein Creatinine ratio
- Thyroid
- Viral Serology
 - Hep Bs Ab
 - Hep C
 - HCV Ab
 - HIV
- Vitamin D
- Other

Date	Result	Comments

SPECIALIST IMAGING

Ferriscan result

MRI Cardiac result T2* (ms)

MRI Liver result T2* (ms)

Ferriscan date

MRI Cardiac T2* date

MRI Liver T2* date

Serious adverse event reported

No

Yes

Number of serious adverse events _____

Serious Adverse Event	Date of event

Medications in this review period

- Ace Inhibitors
- Biphosphonates
- Folic Acid
- Hydroxycarbamide
- Penicillin V
- Vitamin D

Other _____

Continued

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-
-
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-
-

Dose	Start date	End date	Comments

Iron Chelation in this review period

- Desferoxamine
- Deferiprone
- Deferasirox
- Desferoxamine +
Deferiprone

Continued

-
-
-
-

Start date	End date	Comments

Operations in this review period

- Adenotonsilectomy
- Hip replacement
- Laparoscopic
- Othorpaedic
- Retinal Surgery
- Splenectomy
- Cholecystectomy
- Other _____

-
-
-
-
-
-
-
-

Operation date	Comments

Additional Comments

Name _____

Signature _____

Date _____

DISCUSSION CHECKLIST *(tick all that apply and document)*

Acute care plan:

Emergency department:

Home pain plan:

Chronic pain review: Opiate use

Referral to pain management:

Adherence to medications:

Discussion of infection prevention and need for early treatment:

Review of visual symptoms:

Referral to other specialist services:

Fertility/contraception. Pre-pregnancy counselling:

Priapism:

Discussion of therapeutic options currently available and new information including ongoing trials. Is the patient eligible for a clinical trial?

Emotional and psychosocial well-being; is psychology referral needed?

Holistic assessment – lifestyle, education, work or welfare issues. Consideration of referral to community services.

Offer additional information: Include key contact details, NHR information, local patient support groups, relevant patient information.

Offer patient satisfaction survey (optional)

Any other comments:

Referral for MDT (local or network) discussion if needed.

Management Plan: (Insert acute pain plan action points from consultation)

Date:

