

COMPLEX MOVEMENT DISORDER DBS CLINICAL PATHWAY BOOKLET

Hospital Number:	Next of kin/Guardian:
Name:	Relationship:
Address:	CP Register:
Sex: DOB:	Social Worker:
Telephone/Mobile:	School:
Email:	
Consultant:	
GP:	GP Telephone/e-mail:
Family Tree:	
ASSESSMENTS:	
Referral Date:	Initial CMD Clinic Date:
Baseline PT Assessment:	Pre-op:
Goal setting & MDT:	Enhanced MRI:
CPChild: Pre-op <input type="checkbox"/> 3/12 <input type="checkbox"/> 6/12 <input type="checkbox"/> 1year <input type="checkbox"/> 2Year <input type="checkbox"/>	
TRANSITION TO ADULT SERVICES:	
Year of planned Transition:	Centre:
Initial discussion with family: Date:	By:
Referral Date:	
Named Consultant:	NHS Trust:
Paperwork completed: <input type="checkbox"/> Date:	By:
Paperwork sent: <input type="checkbox"/> Date:	By:
DBS IMPLANT DETAILS:	
Implant Date	
Implant Centre	
Implant make	
Implant activation date	
WRITTEN INFORMATION GIVEN :	

PROFESSIONALS INVOLVED:

Community Paediatrician:

Name:	Address:
Tel No.:	
Email:	

Paediatrician:

Name:	Address:
Tel No.:	
Email:	

Neurologist:

Name:	Address:
Tel No.:	
Email:	

Orthopaedic Surgeon:

Name:	Address:
Tel No.:	
Email:	

Physiotherapist:

Name:	Address:
Tel No.:	
Email:	

OT:

Name:	Address:
Tel No.:	
Email:	

Other:

Name:	Address:
Tel No.:	
Email:	

INITIAL OUTPATIENT APPOINTMENT

Clinic date:	Referrer:
Consultant:	Speciality:
CCG Area:	GMFCS level:

PC

HPC

PMH

Investigations:

Medications:

Previous interventions / Surgery

SH:

O/E:

Impression:

Plan:

Signed: Designation
GMC/NMC N°: Date:

PHYSIOTHERAPY ASSESSMENT

Date:

Mobility/Transferring	
Positioning/ Seating Tolerance	
Equipment	Standing frame: Y N Specialist seating: Y N Orthotics: Other:
Care giving	CPChild
Sleeping	Sleep system: Y N
Pain	

Name: Hospital N°:

UL function	
Continence	
Communication	
Drooling/eating/drinking	

Signed: Designation

GMC/NMC N°: Date:

OBJECTIVE ASSESSEMENT

Position:

Current Medication

SPASTICITY					MUSCLE STRENGTH (oxford scale)		
	Spasticity		Dystonia				
HIP	R	L	R	L	HIP	R	L
EXTENSORS					EXTENSION		
FLEXORS					FLEXION		
ABDUCTORS					ABDUCTORS EXT		
ADDUCTORS					ADDUCTION		
KNEE							
EXTENSORS					KNEE		
DUNCAN ELY					EXTENSION		
FLEXORS					FLEXION		
ANKLE					ANKLE		
PLANTERFLEXORS					PLANTERFLEXION		
DORSIFLEXORS					DORSIFLEXION		
TIB. POST.							
TARDIEU							

SPASM SCALE

1	2	3	4
---	---	---	---

B.A.D – Dystonia Scale:

Eyes	Mouth	Neck	Trunk	R UL	L UL	R LL	L LL

PASSIVE RANGE OF MOVEMENT:

Date & Time						
	Right	Left	Right	Left	Right	Left
Hip Flexion						
Hip Extension						
Hip Abduction						
Hip Adduction						
Knee Flexion						
Knee Extension						
Ankle Dorsiflexion						
Ankle Plantarflexion						
Shoulder Flexion						
Shoulder Extension						
Shoulder Abduction						
Shoulder Adduction						
Elbow Flexion						
Elbow Extension						
Elbow pronation/supination						
Wrist Flexion						
Wrist Extension						
Finger Flexion						
Finger Extension						

OBJECTIVE:

Outcome measure	Completed (date)	By
Dyskinesia Impairment Scale		
Burke-Fahn-Marsden Dystonia scale		
BAD		
TUG		
6MWT		
GMFM		

GOAL SETTING:

Name: Hospital N°:

Date				
Occupational Performance Problem	P	S	P	S

P – performance

S – satisfaction

MDT SUMMARY

Clinicians Present:

Comment:

Signed: Designation

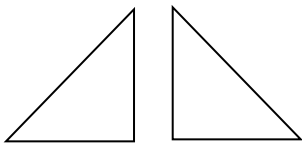
Drug H_x:

FH_x:

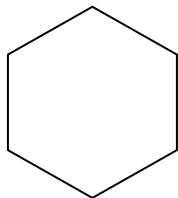
SH_x:

O/E:
CVS:

Resp:



Abdo:



Date:

Name:

Designation:

Signature:

Specialist Opinion (Anaesthetist/Cardiologist)

Reason for referral (& to whom):	
Date & Time:	Signature:
Outcome with instructions:	
Date & Time:	Signature:

Investigation	Date:	Indication:	Signature:	Results:
MRSA				
Bloods				

Abnormal results? Action taken/Comments:

Date & Time: _____ Signature: _____

Date & Time:	Additional Notes:	Name & Signature:

Signed: **Designation**

GMC/NMC N^o: **Date:**

IMPLANTATION PHASE

PHYSIOTHERAPY & NURSING DISCHARGE PLANNING

PHYSIOTHERAPY ADDITIONAL D/C INFORMATION

PHYSIOTHERAPY CHECKLIST – PRIOR TO DISCHARGE			YES	NO	Initials
Report to local physiotherapist			YES	NO	
DBS leaflet(s) given and explained			YES	NO	
Discussion of physiotherapy role in ongoing assessments			YES	NO	
COMMENTS:					
DISCHARGE DATE & TIME			SIGNATURE OF DISCHARGE NURSE		

NURSING CHECKLIST – PRIOR TO DISCHARGE			YES	NO	Initials
Vital signs stable?			YES	NO	
Fully conscious?			YES	NO	
Has taken diet and fluids post operatively?			YES	NO	
Has passed urine?			YES	NO	
Has adequate analgesia on board?			YES	NO	
Parent/carer aware of post-operative instructions?			YES	NO	
Date may wash hair					
Wound check? If not why not?			YES	NO	
Dressing clean & dry?			YES	NO	
Cannula removed?			YES	NO	
Parent/carer aware of who to contact with concerns?			YES	NO	
Health Visitor/School Nurse Contacted?			YES	NO	
GP Contacted?			YES	NO	
Follow up information given to parent/carer? (If NO, why not?)			YES	NO	
COMMENTS:					
DISCHARGE DATE & TIME			SIGNATURE OF DISCHARGE NURSE		

APPENDIX

Spasm Scale: Please circle appropriate score.

- 0 No spasm
- 1 No spontaneous spasm, vigorous sensory and motor stimulation results in spasms.
- 2 Occasional spontaneous spasms and easily induced spasms.
- 3 More than 1 but less than 10 spontaneous spasms per hour.
- 4 More than 10 spontaneous spasms per hour.

Modified Ashworth Score of Spasticity:

- 0 No increase in muscle tone.
- 1 Slight increase in muscle tone manifested by a catch and release or by minimal resistance at the end of range of motion.
- 1⁺ Slight increase in muscle tone manifested by a catch followed by minimal resistance throughout the remainder (less than half) of the ROM.
- 2 More marked increase in muscle tone through most of the ROM, but the affected part is easily moved.
- 3 Considerable increase in muscle tone, passive movement is difficult.
- 4 Affected part is rigid in flexion or extension, abduction or adduction.

Barry-Albright Dystonia Scale

Eyes: signs of dystonia of the eyes include: prolonged eyelid spasms and/or forced eye deviations

- 0- Absent
- 1- Slight: dystonia less than 10% of the time and does not interfere with tracking
- 2- Mild: frequent blinking without prolonged spasms of eyelid closure, and/or eye movements less than 50% of the time
- 3- Moderate: prolonged spasms of eyelid closure, but eyes open most of the time, and/or eye movements more than 50% of the time that interfere with tracking, but able to resume tracking
- 4- Severe: Prolonged spasms of eyelid closure, with eyelids closed at least 30% of the time, and/or eye movements more than 50% of the time that prevent tracking
- 5- Unable to assess eye movements

Mouth: signs of dystonia of the mouth include grimacing, clenched or deviated jaw, forced open mouth, and/or forceful tongue thrusting

- 0- Absent
- 1- Slight: dystonia less than 10% of the time and does not interfere with speech and/or feeding
- 2- Mild: dystonia less than 50% of the time and does not interfere with speech and/or feeding
- 3- Moderate: dystonia more than 50% of the time and/or dystonia that interferes with speech and/or feeding
- 4- Severe: dystonia more than 50% of the time and/or dystonia that prevents speech and/or feeding
- 5- Unable to assess mouth movements

Neck: signs of dystonia of the neck include pulling of the neck into any plane of motion: extension, flexion, lateral flexion or rotation

- 0- Absent
- 1- Slight: pulling less than 10% of the time and does not interfere with lying, sitting, standing and/or walking
- 2- Mild: pulling less than 50% of the time and does not interfere with lying, sitting, standing and/or walking
- 3- Moderate: pulling more than 50% of the time and/or dystonia that interferes with lying, sitting, standing and/or walking
- 4- Severe: pulling more than 50% of the time and dystonia that prevents sitting in a standard wheelchair (e.g. requires special head rest), standing and/or walking
- 5- Unable to assess neck movements

Trunk: signs of dystonia of the trunk include pulling of the trunk into any plane of motion: extension, flexion, lateral flexion or rotation

- 0- Absent
- 1- Slight: pulling less than 10% of the time and does not interfere with lying, sitting, standing and/or walking
- 2- Mild: pulling less than 50% of the time and does not interfere with lying, sitting, standing and/or walking
- 3- Moderate: pulling more than 50% of the time and/or dystonia that interferes with lying, sitting, standing and/or walking
- 4- Severe: pulling more than 50% of the time and dystonia that prevents sitting in a standard wheelchair (e.g. requires adapted seating system), standing and/or walking
- 5- Unable to assess trunk movements

Upper extremities: signs of dystonia of the upper extremities include sustained muscle contractions causing abnormal postures, score each limb separately

- 0- Absent
- 1- Slight: dystonia less than 10% of the time and does not interfere with normal positioning and/or functional activities
- 2- Mild: dystonia less than 50% of the time and does not interfere with normal positioning and/or functional activities
- 3- Moderate: dystonia more than 50% of the time and/or dystonia that interferes with normal positioning and/or upper extremity function
- 4- Severe: dystonia more than 50% of the time and/or dystonia that prevents normal positioning and/or upper extremity function (e.g. arms restrained to prevent injury)
- 5- Unable to assess upper extremity movements

Lower extremities: signs of dystonia of the lower extremities include sustained muscle contractions causing abnormal postures, Score each limb separately

- 0- Absent
- 1- Slight: dystonia less than 10% of the time and does not interfere with normal positioning and/or functional activities
- 2- Mild: dystonia less than 50% of the time and does not interfere with normal positioning and/or functional activities
- 3- Moderate: dystonia more than 50% of the time and/or dystonia that interferes with normal positioning and/or lower extremity weight bearing and/or function
- 4- Severe: dystonia more than 50% of the time and/or dystonia that prevents normal positioning and/or lower extremity weight bearing and/or function
- 5- Unable to assess lower extremity movements

Name..... Hospital No..... Date.....

Completed by..... Designation..... Prof Reg N^o.....

FAHN-BURKE MARS DEN DYSTONIA SCALE

REGION	ACTION			REST		
	Single activity	Duration factor 0-1-2-3-4	Amplitude factor 0-1-2-3-4	Single position	Duration factor 0-1-2-3-4	Amplitude factor 0-1-2-3-4
Eye dystonia	Eye tracking			Sitting position		
	Eye blinking					
Eye choreoathetosis	Eye tracking			Sitting position		
	Eye blinking					
Mouth dystonia	Mouth open/closed			Sitting position		
	Speech					
Mouth choreoathetosis	Mouth open/closed			Sitting position		
	Speech					
Neck dystonia	Lateral flexion R/L			Sitting position		
	Rotation R/L					

Name..... Hospital No..... Date.....

Completed by..... Designation..... Prof Reg N°.....

Neck choreoathetosis	Lateral flexion R/L	Sitting position
	Rotation R/L	

Trunk dystonia	Forward flexion	Sitting position
-----------------------	-----------------	------------------

Trunk choreoathetosis	Forward flexion	Sitting position
------------------------------	-----------------	------------------

Right arm proximal dystonia	Arm abduction	Sitting position
------------------------------------	---------------	------------------

Right arm proximal choreoathetosis	Arm abduction	Sitting position
---	---------------	------------------

Left arm distal dystonia	Grasp and move a cup	Lying position
	Grasp and move a pen	

Left arm distal choreoathetosis	Grasp and move a cup	Lying position
	Grasp and move a pen	

Name..... Hospital No..... Date.....

Completed by..... Designation..... Prof Reg N°.....

Right leg proximal dystonia Rolling Lying position

Standing

Right leg proximal choreoathetosis Standing Lying position

Rolling

Left leg proximal dystonia Standing Lying position

Rolling

Right leg proximal choreoathetosis Standing Lying position

Rolling

Left leg distal dystonia Rolling Lying position

Heel/toe raising

Right leg distal choreoathetosis Rolling Lying position

Heel/toe raising

Name..... Hospital No..... Date.....

Completed by..... Designation..... Prof Reg N°.....

left leg distal dystonia

Rolling

Lying position

Heel/toe raising

**Right leg distal
choreoathetosis**

Rolling

Lying position

Heel/toe raising