

Freedom of Information Request: Our Reference CTHB_291_18

You asked:

- 1. What is the total number of children and young people diagnosed with Cerebral Palsy by your Health Board in the last five years? (N.B.: this should be recorded as a total figure rather than figures for each year individually.)**

Paediatric Occupational Therapy have 21 children under the age of 5 with a confirmed diagnosis of Cerebral Palsy (CP) known to them as of 18/07/2018.

Paediatric Physiotherapy have 36 children under the age of 5 with a confirmed diagnosis of Cerebral Palsy known to them as of 13/07/2018.

- 2. What is the care pathway for children and young people with cerebral palsy in your Health Board? Please provide a copy of this if possible.**

Paediatric Occupational Therapy do not currently have a care pathways for Cerebral Palsy. There is however, an Upper Limb Paediatric Occupational Therapy Splinting Protocol which we use to address this specific area. This has been attached for you (Attachment 1).

Paediatric Physiotherapy have a checklist identifying key items for review with the child with Cerebral Palsy (CP) (Attachment 2). We also use the Cerebral Palsy Integrated Pathway (CPIP) from Scotland for monitoring and reviewing children with CP (Attachments 3 and 4). We currently have 1 CPIP train the trainer and all registered staff are accredited assessors with an accreditation number.

Speech and Language therapists are not involved in diagnosis of cerebral palsy. A Health Visitor will refer to the GP any presenting concerns with regard to any infants and children with developmental concerns /delay; the GP will in turn refer to a paediatrician. Infants born with any emerging developmental issues are referred to paediatrician at the earliest point.

- 3. Is there a specific timescale set out in your care pathway for referral to a child development service for diagnosis of cerebral palsy from the point when symptoms are initially identified? If so, please provide this data.**

No, there is no specific timescale.

4. What is the total number of:

- **Health visitors employed by your Health Board?**
- **Specialist health visitors for children with special needs employed by your Health Board?**

There are 99.5 whole time equivalent (WTE) Health Visitors currently employed. There are 2 WTE specialist Health Visitors for children with special needs employed by the Health Board.

5. What training is given to healthcare professionals, including health visitors and GPs, to recognise the risk factors and possible symptoms for Cerebral Palsy?

Health Visitors receive regular updates on child development and updates of conditions including cerebral palsy. Any developmental deviation is monitored and referred to GP/paediatrician for further assessment as appropriate. Paediatric physiotherapy provide training sessions each year to the paediatrician training program of which at least one session is on identifying children with abnormalities of muscle tone and motor patterns.

Paediatric Occupational Therapy do not offer any formalised training however work jointly as required with Healthcare professionals which shares knowledge and skills across the professional groups. Paediatric Occupational Therapy are more involved in training to mainstream and special schools for Cerebral Palsy.

6. What is the total number of specialist staff employed by your Health Board, who are trained to work with children and young people with Cerebral Palsy, from the following disciplines:

- **Paediatric speech and language therapy**
- **Paediatric physiotherapy**
- **Paediatric occupational therapy**

We have 9 qualified Occupational Therapy registered staff (6.09 WTE) who are trained to work with Children and young people with Cerebral Palsy. One of the staff members will be designated as a Clinical Specialist for Paediatric Neurodisability.

Within physiotherapy there are 10 registered staff (8.27 WTE) who are trained to work with Children and young people with Cerebral Palsy, one of whom is the Clinical Specialist for Paediatric Neurodisability.

Children and young people requiring specialist assessment for augmentative and alternative communication (AAC) are referred to the Wales Electronic Assistive Technology (EAT) Centre and supported locally. Children with feeding difficulties are seen by specialist speech

and language therapists in dysphagia of which 1.8 WTE are dysphagia trained. There are 4.4 WTE Specialist Health Visitor for Children with Special Needs & Community Nursery Nurses.

7. How many children and young people with Cerebral Palsy are currently on a waiting list to access any of the above services within your Health Board?

There are no children are currently awaiting SLT therapy across the service. Paediatric Physiotherapy have no children with Cerebral Palsy on the waiting list as of 13/07/2018.

Paediatric Occupational Therapy have less than five children currently waiting on the waiting list as routine and will be seen within 14 weeks of their referral date.



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Upper Limb Paediatric Occupational Therapy Splinting Protocol

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DATE APPROVED: September 2017

VERSION: 2

OPERATIONAL DATE: January 2015

DATE FOR REVIEW: 3 years from date of approval or if any
legislative or operational changes require

DISTRIBUTION:

FREEDOM OF INFORMATION STATUS: Open

Definition of Protocol

These are detailed descriptions of the steps taken to deliver care or treatment to a patient and are sometimes called the “integrated care pathway”. They are designed at local level to implement the national standards and determine care provision by using the best evidence if national standards are not available

Minor Amendments

If a minor change is required to the document, which does not require a full review please identify the change below and update the version number.

Type of change	Why change made	Page number	Date of change	Version 1 to 1.1	Name of responsible person

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1. Introduction

This protocol provides a detailed description of the provision of upper limb splints from the Paediatric Occupational Therapy Service for Children and Young people.

2. Definition

This protocol outlines a description of the upper limb service provided by Cwm Taf Paediatric Occupational Therapy. It outlines the following:

- Types of conditions regularly requiring splinting
- Responsibilities of the named therapist to assess tone, range of movement and functional abilities
- Purpose of upper limb splinting and outcomes to be achieved
- Description of the Upper Limb Splinting Clinic including process for referral to it, care pathway, written documentation relating to the clinic and procedures regarding children and young people who are unable to attend (UTA) or do not attend (DNA) their appointments.

3. Background

The Upper Limb Splinting Clinic was set up in the Paediatric OT Service in order to provide a specialist resource for children and young people in line with the National Institute for Health and Clinical Excellence guidelines on "Spasticity in children and young people with non-progressive brain disorders" (July 2012).

Two named OT clinicians were identified to take the lead for upper limb splinting so that knowledge and skills could be utilised, as well as training opportunities steered to these individuals. The clinic was also set up due to capacity/demand issues and to allow equity across both sites of the Paediatric OT Service.

4. Referral

The child/young person's named OT can make a referral to the splinting clinic, if following initial assessment they feel specialist input is required; (see Appendix

A - Referral to Upper Limb Splinting Clinic and Pathway and Appendix B - Referral Form).

Factors for referral include: -

- Tone
- Range of Movement
- Functional abilities
- Splinting for positioning – to promote function and stabilisation of the joint
- Prolonged stretch
- Sensory feedback
- To aim to prevent deformity and contractures
- Serial splinting following surgery or Botulinum toxin upper limb injections (further work is required to create a separate pathway for this area)

Upon receipt, referrals are discussed jointly by the Splinting Clinic OT's and given an appointment slot based on need and availability (see Appendix C – Clinic Appointment Forms).

5. Splinting Clinic

The OT Upper Limb Splinting Clinic is held on a monthly basis (rotating between Ysbyty Cwm Cynon, Mountain Ash and Carnegie Clinic, Trealaw) to assess and issue specifically identified children with thermoplastic, neoprene and/or off the shelf upper limb splints. The splinting clinic is a full day in duration with 2-4 children being seen per day depending on complexity. This may be a mixture of new and follow-up (reviews) cases.

Children attending the clinic will have been identified by their named OT as requiring specialist upper limb splinting. This could be due to their tone, range of movement and/or functional abilities. During the clinic the child's/young person's hand function, tone and range of movement will be assessed. This is completed through discussion with the child/young person and their carer, hands on examination of the upper limb and optional completion of the Hand Function Assessment form (Appendix D).

Conditions regularly requiring splinting:

Cerebral palsy
Aircardi syndrome
Juvenile Idiopathic Arthritis
Developmental Co-ordination Disorder (for stabilisation)
Hypermobility
Undiagnosed children with upper limb difficulties

If appropriate a suitable splint/splint's are identified and issued. The splint will provide positioning; promote function and stabilisation of the joint. It will assist with providing a prolonged stretch, provide sensory feedback, and attempt to prevent deformity and contractures. A Splint Instruction and Information Sheet is discussed with the carer and child/young person. This is signed by the parent/legal guardian and a copy kept in the OT notes. (Appendix E)

A Feedback Form is completed by one of the splinting clinic OT's and provided back to the named therapist, with any follow up work that needs to be completed. It is the responsibility of the named OT to pass information on to school regarding stretches of the upper limb, use of the splint, donning and doffing of splint and any other relevant information. (Appendix F).

6. UTA/DNA

If a child is unable to attend (UTA) they will be offered another splinting clinic appointment when there is an available slot. A did not attend (DNA) the child will be discharged from the splinting clinic and it will be the responsibility of the named therapist to look into the situation and appropriate course of action alongside existing UTA/DNA Health Board policies. (See Appendix G for full procedure)

7. Review

Splinting clinic OT's will determine the frequency of the splint review based on the age of the child and the complexity of the splint. If the child has been issued with off the shelf splints responsibility for review may be passed to the named OT.

8. References

National Institute for Health and Clinical Excellence "Spasticity in children and young people with non-progressive brain disorders"
July 2012 Nice clinical guideline 145

Appendix A -

REFERRAL TO SPLINTING CLINIC

Children's Occupational Therapy YCC and Carnegie clinic

Prior to referring to the splinting clinic the named OT needs to have carried out the following:

1. Named OT identifies upper limb difficulty affecting function.
 - a) Consider muscle tone, power, range of movement, skin integrity and the impact on function.
 - b) Consider the goals for splinting:
 - Promote function
 - Prevent deformity / contractures
 - Provide prolonged stretch
 - Stabilise joints
 - Provide sensory feedback
 - Hygiene
2. Named OT identifies and provides appropriate "off the shelf" Splint (if appropriate):
 - Wrist brace (with metal bar in the centre of the wrist) – ottobock or eveswell.
 - Wrist brace with thumb support (with metal bar in the centre of the wrist) – ottobock or eveswell.
 - Ulna deviation support (with metal bar in the centre of the wrist and 2nd metal bar ulna side)
 - Thumb spica (with metal bar)
 - Thumb spica (with thermoplastic mould)
 - Musgrove thumb
 - Weighted splint
3. Named OT to provide advice/sessions for joint protection, hand strength and range of movement exercises as appropriate in conjunction with hand splint and as part of named OT role.
4. Named OT reviews off the shelf splint as and when required.
5. Named OT to place child's name on splinting list with completed

Referral form if they feel:

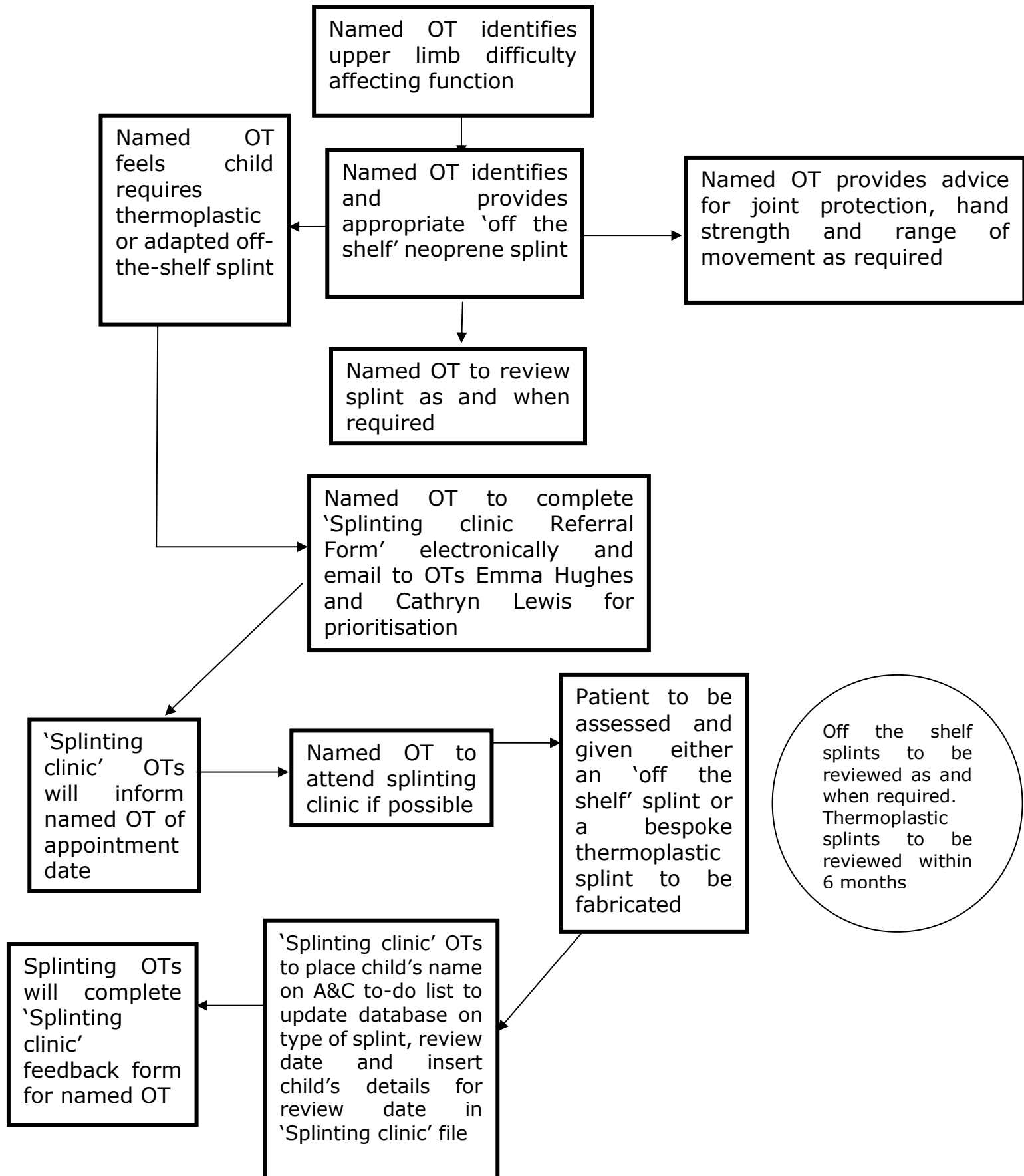
- a) a more complex splint is required e.g. Thermoplastic splint night/day,
- b) more specialist OT support is required.

6. Child will be prioritised and allocated an assessment slot by EH. Named OT to attend if possible.

7. Following the clinic the named OT will receive a feedback sheet of therapy input and also follow up needs to be completed by the named OT e.g. to attend school to ensure teaching staff are aware of fitting, wear and monitoring of the splint/s, to give programmes of specific advice for the upper limb.

8. The child will be placed on review by EH and feedback will continue as required to the named OT.

Referral Process to Splinting Clinic
Paediatric Occupational Therapy Service



Appendix B -**CWM TAF UHB**

**SPLINTING CLINIC REFERRAL FORM
PAEDIATRIC OCCUPATIONAL THERAPY SERVICE
YCC AND CARNEGIE CLINIC.**

Child's Name:**D.O.B:**.....
M Number:
School:
Named Occupational Therapist:
Month of preferred clinic:

Presenting diagnosis	
Splinting history – what has been tried previously. When were they last seen by named OT	
Area to be splinted (L or R, wrist, fingers...)	
Clinical reasoning for referral to splinting clinic	
When to wear splint, day or night, home/school and frequency	
Contra-indications/risks: sensory/ skin conditions, manual handling	

EH September 2017

Appendix C -**CWM TAF UHB****CHILDREN'S OCCUPATIONAL THERAPY SPLINTING CLINIC
YCC AND CARNEGIE CLINIC MONTHLY ALLOCATION SHEET**

MONTH:

APT TIME	NAME	D.O.B	M NUMBER	TYPE OF SPLINT & TIME ALLOCATED	OT	REVIEW DATE	SCHOOL

Appendix D -

Hand Function / Assessment Form

Hand dominance / use

Sensory issues

Night time position (i.e. tight / flexed / relaxed etc)

Are there any changes in tone or position noted during the day?

ROM of upper limb comparing one limb to the other

What has already been tried?

What effect was seen on function?

What are you hoping to achieve from splint clinic?

Any other information

Signed Date

Appendix E -

SPLINT INSTRUCTION & CONSENT FORM

Child’s Name:

NHS No: D.O.B:

Therapist:

The splint you have been given to wear is called a
.....

This is to help with
.....

You need to wear your splint:

- Full time and remove for exercises only ☐
- To wear your splint during the day only
and remove during the night ☐
- To wear your splint at night and
intermittently during the day ☐
- To wear your splint at night only
and remove during the day ☐
- To wear whilst performing a specific functional activity ☐

.....
.....

You should follow any instruction to you by your therapist. If you have any questions about your splint, please ask your therapist

If you have any problems with your splint, **DO NOT** try to alter the fit or the straps, contact the number above if you are unhappy with the fit.

I have consented to the fitting of the above splint/appliance and understand the instructions given:

Signed: (Parent/Carer/Child)

Date:

a. SPLINT CARE

i. SKIN CARE

If you experience any of the following problems when wearing your splint **STOP WEARING IT** and contact the number below.

1. Pain/discomfort/tingling
2. If the splint rubs anywhere
3. Redness of skin caused by pressure that doesn't disappear with 20 minutes of removing the splint.
4. Blisters

NB. If your splint makes you hot and you suffer from sweat rash, wash and dry your skin regularly and wear tubi-grip or a stockinette if advised by your therapist.

NB. Use some cream if your skin becomes dry.

ii. CARE OF YOUR SPLINT

Keep your splint away from very hot water, radiators or direct sunlight such on a windowsill or on the seat of a car.

Do not place the splint in the washing machine. Hand wash, it only.

To wash your splint, use warm but not **HOT** soapy water then leave it to dry naturally.

NB. Ensure your splint is dry before wearing it again.

iii. COMFORT

If your splint, are secured by straps, ensure they are all fastened firmly but not tightly. A loose splint may cause rubbing.

NB. If your fingers or toes become discoloured, loosen straps immediately.

For any questions or adjustments contact your named Occupational Therapist between 9:00am and 5.00pm Monday to Friday.

Appendix F -

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Children's Occupational Therapy
Splinting Clinic Feedback Form.

Child's Name:

Named OT:

Date of Splinting Clinic:

Observations:	
Splint issued:	
Follow up needs (to be completed by named OT):	

Review month:	

Splinting Clinic OTs:

Signed:

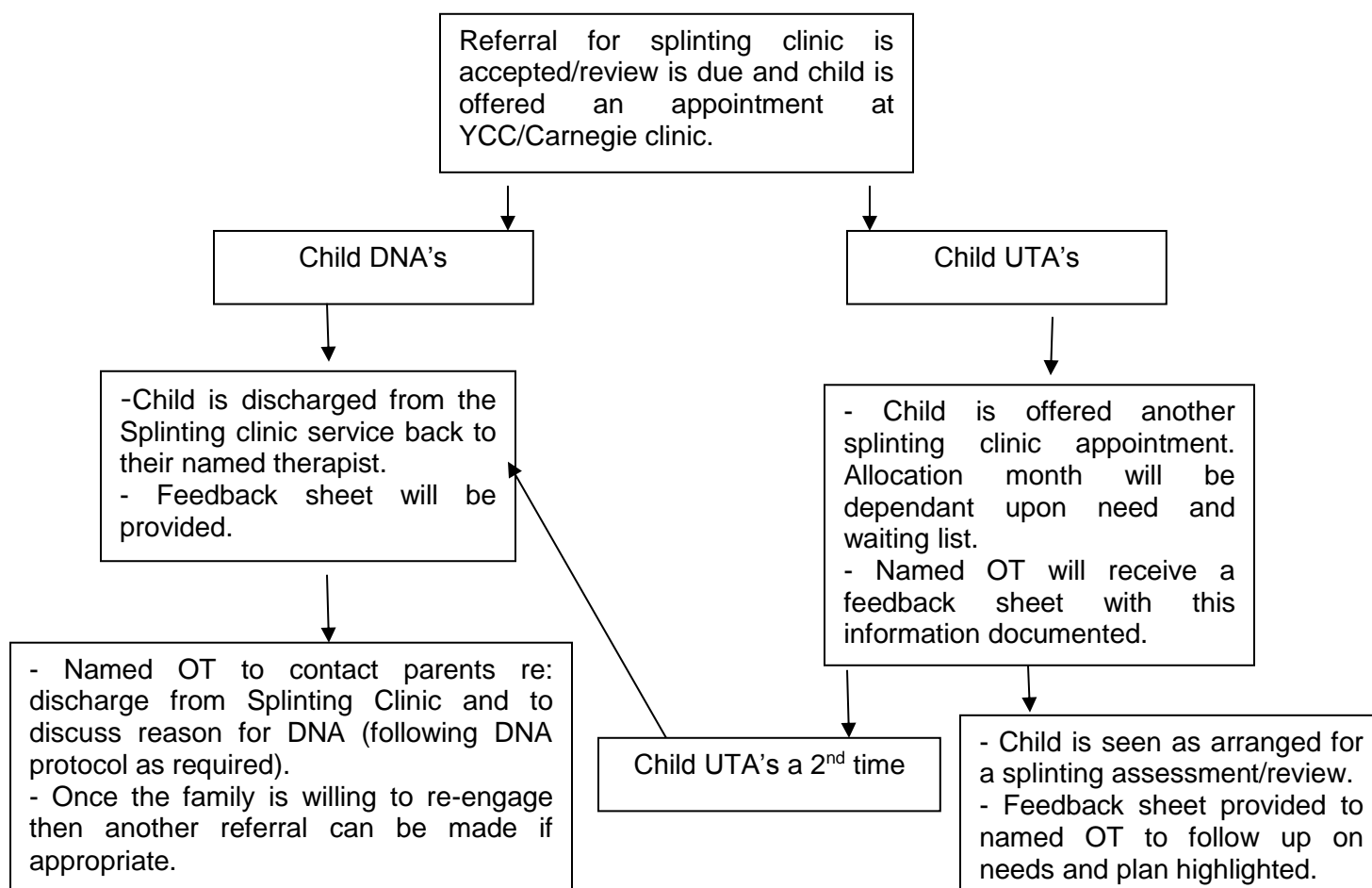
Date

Appendix G -

UTA/DNA Procedure

CHILDREN'S SPLINTING CLINIC **YCC AND CARNEGIE CLINIC**

MANAGEMENT OF DNA'S/UTA'S.





Child's named OT to review splinting needs and feedback to EH & CL on splinting needs and if Splinting Clinic appointment is required.



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Paediatric Physiotherapy service

Physiotherapy Review For The Child With Cerebral Palsy

Name: _____ **D.O.B:** _____.

Address: _____ **Hospital No:** _____.

_____ **Post Code:** _____.

Test	Date	Date	Date	Date	Date
GMFCS Level					
GMFM Score A					
Score B					
Score C					
Score D					
Score E					
Total Score					
Orthopaedic LL- Yes					
LL - No					
UL- Yes					
UL- No					
Timed Walk – 25 m					
- 100m					
PCI & Speed					
Tardieu – Range TA					
Hams					
Rec Fem					
Biceps					
Modified Ashworth					
Muscle- Score					
Score					
Score					
Score					
Score					
Chailey Levels-Supine					
-Prone					
-Sitting(Floor)					
-Sitting(Box)					
-Standing					
Gait-Roslyn Boyd/ Describe					
Muscle power- Yes/No					



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Paediatric Physiotherapy service

Physiotherapy Review For The Child With Cerebral Palsy

Selective movement Yes/No					
Other- Orthotics					
Pain scale- score					
Respiratory/swallowing problems Y/N					
Wheelchair/Buggy/Seating- review Y/N					
Standing frame-review Y/N					
Walker review Y/N					
Bobath Prioritisation- score					
Goals set Y/N					
GAS – Y/N					

Comments	Date:
GMFCS	Level
GMFM -	
Chailey Levels	
Orthopaedic LL/UL	



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Paediatric Physiotherapy service

Physiotherapy Review For The Child With Cerebral Palsy

Timed walk/ PCI	
Tone/ selective movement	
Chailey	
Gait	
Muscle Power	
Orthotics	
Pain(where/frequency)	
Respiratory/Feeding problems	
Wheelchair/ Seating	



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Cwm Taf UHB
Paediatric Physiotherapy service
Physiotherapy Review For The Child With Cerebral Palsy

Standing frame	
Walker	
Bobath Prioratisation	
Goals(SMART)	1. 2. 3. 4. 5.
GAS	1. 2.
Cross referrals required	1. 2. 3.

Action Plan :



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Paediatric Physiotherapy service
Physiotherapy Review For The Child With Cerebral Palsy

Need	Action	Timescale
<u>1.</u>		
<u>2.</u>		
<u>3.</u>		
<u>4.</u>		

Date of Plan:_____.

Duration of Plan:_____.

Assessment and Plan By:_____.

Signed:_____.

Position:_____.

Date:_____.

CC.

Parents

Consultant

Physiotherapy File

Other

CPIPS- Assessment for Hip Surveillance GMFCS 1-3				
Name:		DOB:		CHI:
Date:				
Therapist :				
GMFCS:				
	Right	Left	Right	Left
HIP - supine				
Thomas Test/ Hip flexion deformity GMFCS IV-V < -10° -10°- 0° > 0°				
Abduction – bilateral knees flexed over corner of plinth Slow passive movement (R2) GMFCS I-III <30° 30°- 40° >40°				
Abduction hip neutral knee extended Fast (R1)				
Abduction –opp hip and knee flexed on plinth (unilateral) Slow passive movement (R2) GMFCS I-III <30° 30°- 40° >40°				
Popliteal angle Slow passive movement (R2) GMFCS I-III >50° 40°- 50° <40°				
Popliteal angle Fast (R1)				
Pain on Hip ROM yes/no				
KNEE- supine				
Extension (Fixed Flexion) GMFCS I-III <0° 180°/0°				
Knee hyperextension				
ANKLE/FOOT-supine				
Dorsiflexion-knee flexed GMFCS I-III <10° 10°- 20° > 20°				
Dorsiflexion-knee extended Slow passive movement (R2) GMFCS I-III < 0° 0°- 1 0° >10°				
Dorsiflexion knee extended Fast (R1)				
Leg Length mm				

Name:		DOB:		CHI:	
Date :					
Therapist :					
	Right	Left	Right	Left	
HIP - prone					
Duncan Ely Slow Passive movement (R2) GMFCS I-III <100° 100°- 120° >120°					
Duncan Ely Fast (R1)					
Hip Extension GMFCS I-III < 10° >10° GMFCS IV-V < -10° -10°- 0° > 0°					
Internal rotation hip extended <30° 30°- 40° >40°					
External rotation hip extended <30° 30°- 40° >40°					
HINDFOOT - weight bearing Valgus/norm/varus					
MIDFOOT BREAK - weight bearing Yes/No					
SPINE- Scoliosis sitting Scoliosis standing Lumbar lordosis excessive Thoracic kyphosis excessive	Yes or No				
Functional Mobility Scale FMS	5m		5m		
	50m		50m		
	500m		500m		

Red: value requires referral to orthopaedic department for further assessment

Amber: value should prompt a review of the child's management strategy

Green: indicates what we should regard as normal or almost normal value
(Traffic light values apply to slow PM only)

Signed:

Designation:

CPIP

Cerebral Palsy Integrated Pathway

Information for parents

What is 'CPIP'?

CPIP is a follow-up programme for children with **cerebral palsy or suspected cerebral palsy**, allowing early detection of changes in muscles and joints with the option of earlier treatment for your child. This may help prevent problems developing in the future.

What is Cerebral Palsy?

Cerebral Palsy (CP) is the term used for the physical disorder caused by brain injury or dysfunction occurring before the age of two. There are many different causes of cerebral palsy and the degree of functional impairment varies in each child from nearly normal function, to pronounced functional impairment.

Children with cerebral palsy often have increased tone (spasticity) in certain muscles while other muscles may be weakened. This can interfere with children's ability to move and to learn to walk. Spasticity can also cause pain, and, over time, shortening of muscles and tendons. When joints do not move normally they become permanently stiff because the soft tissues tighten around them (known as a contracture).

In some children, the imbalance in the hip joint can lead to pulling of the head of the thigh bone out of its position in the hip joint leading to hip dislocation. Imbalance in the back, can lead to a curved spine or scoliosis. There are many different treatment methods to decrease spasticity and to prevent contractures and hip dislocation. These may include exercise or stretching and positioning programmes from your physiotherapist, the use of splints during the day or at night or drug treatments to reduce the tightness in muscles. This does not describe all the treatments available. It is very important that the right treatments are available at an early stage to help prevent problems developing in order to achieve the best possible outcome.

What is the purpose of CPIP?

The purpose of CPIP is to ensure that children with risk of developing contractures or hip dislocation are detected early enabling timely intervention.

The goal is that no child should be affected by severe contractures or hip dislocation and that every child should achieve the best function possible.

Research has shown that x-rays of the hip taken at the right time can help us to spot this problem earlier – and take steps to reduce the chance of it getting worse.

The follow-up within CPIP involves the child's physiotherapist who will make an assessment of the child's muscle tone, joint motion, ability and function twice a year until the child is aged six. After that, an annual assessment is made until the child reaches adulthood. These assessments help the physiotherapist decide how often your child needs to be seen for treatment and what treatment options are best for your child. Regular assessment and early treatment combine to improve outcomes.

X-rays

Children with CP should have an x-ray at 2 years of age. If your child is mildly affected you can expect one further x-ray aged 6 years. For those more severely affected there will be annual x-rays until age 8 years and then every other year. This is because there is a greater risk of dislocation in more severe cases. All children will be invited for a final x-ray at age 16.

How successful is CPIP?

Children treated under a similar programme in Sweden experienced significantly fewer hip dislocations. Significantly fewer children from this group developed contractures and scoliosis through participation in the programme. There was also a decrease in the number of major orthopaedic operations performed for hip dislocation and the co-operation between the different specialists involved in the care of children with cerebral palsy improved.

Participation

All the information from the CPIP assessments is stored in a secure NHS database. We can learn from experiences across Scotland to improve care in the future.

The child's community paediatric team and doctor are able to get a CPIPS report, showing the child's development over time and give warning signals showing when there is a need for intervention. This is fundamental in order to initiate the right treatment at the right time for each individual child.

Only anonymised information (that cannot be traced to you or your family) will be used in research. This means that a single child will never be identified when experiences from this follow-up programme are compiled into general reports. By carrying out research on the information available in the CPIPS database, we can improve our knowledge regarding changes over time in different types of cerebral palsy. The different treatments can be compared as to how they affect final outcome.

Further information

For more information regarding CPIPS, please contact your own physiotherapist or orthopaedic surgeon.