



# Paediatric Pain Profile

**This profile belongs to**

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# Background to Paediatric Pain Profile

The Paediatric Pain Profile is a tool that has been developed specially to help in assessing and monitoring pain in children with severe neurological impairments, especially those with impairments which lead them to be unable to communicate pain through speech. Such impairments mean that the children are dependant on their carers for interpretation of their signs of pain. These signs may include changes in the child's movement and posture, in vocalization and in facial expression. The Paediatric Pain Profile is designed to pick up those behaviours which have been shown in a series of studies to be the most important indicators of pain.

The goals of the Paediatric Pain Profile are to:

- make it easier to describe and record pain behaviours
- make it easier to monitor pain and the effectiveness of treatments
- make it easier to communicate any concerns about your child's pain to professionals.

The Paediatric Pain Profile is a 20-item behaviour rating scale. Each item is rated on a four point scale as occurring "not at all" to "a great deal" in any given time period. After the score on each item is added together the total score will range from 0 to 60. This score is sometimes called the PPP score. In a recent study PPP scores of 14 or more were generally associated by observers with moderate or severe pain. Although this was the pattern across a lot of children, the picture can be different in individual children and with different types of pain. Each child will have his or her own range of behaviours in response to pain.

The Paediatric Pain Profile is designed to assist in describing, assessing and monitoring a child's pain behaviour. The task of assessing pain in

children is complex. Parents are advised that they should seek medical advice before introducing new medications or altering the dosage of any medications on account of their child's Pain Profile score. Healthcare practitioners are advised that Pain Profile scores should always be used in context and only as additional information to inform clinical judgements. Neither the Royal College of Nursing Institute or University College London, Institute of Child Health can accept responsibility for any consequences which might result from decisions made on account of using the Paediatric Pain Profile.

The Paediatric Pain Profile was developed in association with researchers at the Royal College of Nursing Institute, Oxford and the Institute of Child Health, London. Studies to develop and test the tool were funded by Action Research (with full funding from the National Lottery Charities Board) and PPP Foundation.

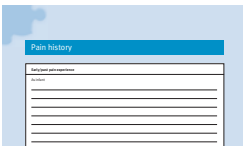
The developers give their permission for pages to be photocopied and used in the care of children with severe neurological and learning impairments.

We hope you will find the tool useful. Further copies can be obtained through

[www.ppprofile.org.uk](http://www.ppprofile.org.uk)

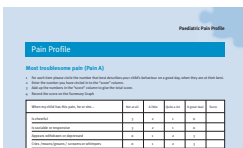
If you have any questions or comments about the tool do feel free to contact: **Dr Anne Hunt**, Research Fellow, RCN Institute, Radcliffe Infirmary, Oxford OX2 6HE. Tel: 01865 224392. Email: [anne.hunt@rcn.org.uk](mailto:anne.hunt@rcn.org.uk)

# Instructions and guidance for use



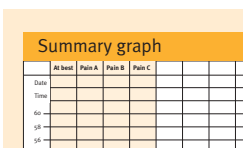
## The pain history

This part of the profile asks about your child's history of pain. It provides space to write about your child's experience with pain as an infant, during surgery or from injuries, or pains that have occurred due to your child's illness or disability. Knowing how your child has coped with pain and injury in the past can help to guide how pain is managed in the present.



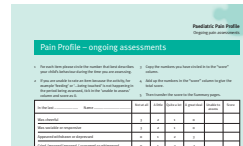
## Baseline assessments

In this section we ask you to describe on the pain profile your child's behaviour when they are 1) at their best or 'on a good day' and 2) if your child has any current or recurring pains. Using the pain profiles you just circle the number that best describes how much your child is like the item in the left hand column. There are sheets to describe your child's most troublesome pain (Pain A) and up to two other pains (Pains B and C). Then transfer the numbers you have circled to the right hand column of each profile and add up the totals. The total scores can then be plotted by placing a cross in the shaded area on the Summary Graph.



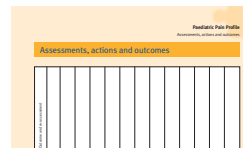
## Summary Graph

The baseline assessments provide a comparison for any further assessments you need to make in the future.



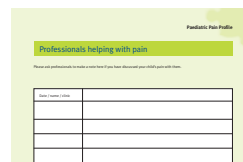
## Ongoing pain assessments

You can use the Pain Profile – ongoing pain assessments sheets to make assessments at any time that suits you, for instance if you need to record your child's behaviour or if you are monitoring your child's response to a treatment. The scores can be transferred to the Summary Graph and/or the Assessments, actions and outcomes page.



## Assessments, actions and outcomes

Using this sheet you can describe the actions that have been taken to relieve your child's pain and your child's response. It is often a good idea to use the profile again after the intervention to see and record if the action has been effective in relieving the pain.



## Talking to professionals about your child's pain

Some pains can be quite troublesome and difficult to relieve. You might like to talk to your doctor or another health professional about your child's pain. It might be helpful to show them your child's Profile. Ask them if they would like to write something on the professional's page about your child's pain problem.

# Paediatric Pain Profile

Pain history

## Pain history

Early/past pain experience
<p>As infant</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
<p>Surgery</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>
<p>Illness and injury</p> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>

Completed by \_\_\_\_\_

Date \_\_\_\_\_

## On a good day

- 1 For each item please circle the number that best describes your child's behaviour on a good day, when they are at their best.
- 2 Enter the number you have circled in to the "score" column.
- 3 Add up the numbers in the "score" column to give the total score.
- 4 Record the score on the Summary Graph

On a good day my child...	Not at all	A little	Quite a lot	A great deal	Score
Is cheerful	3	2	1	0	
Is sociable or responsive	3	2	1	0	
Appears withdrawn or depressed	0	1	2	3	
Cries /moans/groans / screams or whimpers	0	1	2	3	
Is hard to console or comfort	0	1	2	3	
Self-harms e.g. biting self or banging head	0	1	2	3	
Is reluctant to eat / difficult to feed	0	1	2	3	
Has disturbed sleep	0	1	2	3	
Grimaces / screws up face / screws up eyes	0	1	2	3	
Frowns / has furrowed brow / looks worried	0	1	2	3	
Looks frightened (with eyes wide open)	0	1	2	3	
Grinds teeth or makes mouthing movements	0	1	2	3	
Is restless / agitated or distressed	0	1	2	3	
Tenses / stiffens or spasms	0	1	2	3	
Flexes inwards or draws legs up towards chest	0	1	2	3	
Tends to touch or rub particular areas	0	1	2	3	
Resists being moved	0	1	2	3	
Pulls away or flinches when touched	0	1	2	3	
Twists and turns / tosses head / writhes or arches back	0	1	2	3	
Has involuntary or stereotypical movements / is jumpy / startles or has seizures	0	1	2	3	
TOTAL					

Is your child like this? *(Tick applicable box)*  All the time  Most of the time  Some of the time  Hardly ever

Do you think your child has pain even on a good day like this? *(Tick applicable box)*

No pain  Mild pain  Moderate pain  Severe pain  Very severe pain

Completed by \_\_\_\_\_

Date \_\_\_\_\_

## Current pain problems

### Most troublesome pain (Pain A)

What is your child's most troublesome pain?

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How long has your child had this pain?

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When does this pain usually occur?

---

Approximately how often does this pain occur, e.g. all the time, every day, weekly etc

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What usually helps?

*Please can you now score this pain using the Pain Profile on the opposite page (page 7)*

Completed by

Date

# Pain Profile

## Most troublesome pain (Pain A)

- 1 For each item please circle the number that best describes your child's behaviour when they have this pain.
- 2 Enter the number you have circled in to the "score" column.
- 3 Add up the numbers in the "score" column to give the total score.
- 4 Record the score on the Summary Graph

When my child has this pain, he or she...	Not at all	A little	Quite a lot	A great deal	Score
Is cheerful	3	2	1	0	
Is sociable or responsive	3	2	1	0	
Appears withdrawn or depressed	0	1	2	3	
Cries /moans/groans / screams or whimpers	0	1	2	3	
Is hard to console or comfort	0	1	2	3	
Self-harms e.g. biting self or banging head	0	1	2	3	
Is reluctant to eat / difficult to feed	0	1	2	3	
Has disturbed sleep	0	1	2	3	
Grimaces / screws up face / screws up eyes	0	1	2	3	
Frowns / has furrowed brow / looks worried	0	1	2	3	
Looks frightened (with eyes wide open)	0	1	2	3	
Grinds teeth or makes mouthing movements	0	1	2	3	
Is restless / agitated or distressed	0	1	2	3	
Tenses / stiffens or spasms	0	1	2	3	
Flexes inwards or draws legs up towards chest	0	1	2	3	
Tends to touch or rub particular areas	0	1	2	3	
Resists being moved	0	1	2	3	
Pulls away or flinches when touched	0	1	2	3	
Twists and turns / tosses head / writhes or arches back	0	1	2	3	
Has involuntary or stereotypical movements / is jumpy / startles or has seizures	0	1	2	3	
TOTAL					

Please **tick the box** next to the word that best describes the severity of this pain

None
  Mild
  Moderate
  Severe
  Very severe

## Current pain problems

### Second most troublesome pain (Pain B)

If your child has a second pain, what sort of pain is it?

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How long has your child had this pain?

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When does this pain usually occur?

---

Approximately how often does this pain occur, e.g. all the time, every day, weekly etc

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What usually helps?

*Please can you now score this pain using the Pain Profile on the opposite page (page 9)*

Completed by

Date

# Pain Profile

## Second most troublesome pain (Pain B)

- 1 For each item please circle the number that best describes your child's behaviour when they have this pain.
- 2 Enter the number you have circled in to the "score" column.
- 3 Add up the numbers in the "score" column to give the total score.
- 4 Record the score on the Summary Graph

When my child has this pain, he or she...	Not at all	A little	Quite a lot	A great deal	Score
Is cheerful	3	2	1	0	
Is sociable or responsive	3	2	1	0	
Appears withdrawn or depressed	0	1	2	3	
Cries /moans/groans / screams or whimpers	0	1	2	3	
Is hard to console or comfort	0	1	2	3	
Self-harms e.g. biting self or banging head	0	1	2	3	
Is reluctant to eat / difficult to feed	0	1	2	3	
Has disturbed sleep	0	1	2	3	
Grimaces / screws up face / screws up eyes	0	1	2	3	
Frowns / has furrowed brow / looks worried	0	1	2	3	
Looks frightened (with eyes wide open)	0	1	2	3	
Grinds teeth or makes mouthing movements	0	1	2	3	
Is restless / agitated or distressed	0	1	2	3	
Tenses / stiffens or spasms	0	1	2	3	
Flexes inwards or draws legs up towards chest	0	1	2	3	
Tends to touch or rub particular areas	0	1	2	3	
Resists being moved	0	1	2	3	
Pulls away or flinches when touched	0	1	2	3	
Twists and turns / tosses head / writhes or arches back	0	1	2	3	
Has involuntary or stereotypical movements / is jumpy / startles or has seizures	0	1	2	3	
TOTAL					

Please **tick the box** next to the word that best describes the severity of this pain

None
  Mild
  Moderate
  Severe
  Very severe

## Current pain problems

### Third most troublesome pain (Pain C)

If your child has a third pain, what sort of pain is it?

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How long has your child had this pain?

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When does this pain usually occur?

---

Approximately how often does this pain occur, e.g. all the time, every day, weekly etc

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What usually helps?

*Please can you now score this pain using the Pain Profile on the opposite page (page 11)*

Completed by

Date

# Pain Profile

## Third most troublesome pain (Pain C)

- 1 For each item please circle the number that best describes your child's behaviour when they have this pain.
- 2 Enter the number you have circled in to the "score" column.
- 3 Add up the numbers in the "score" column to give the total score.
- 4 Record the score on the Summary Graph

When my child has this pain, he or she...	Not at all	A little	Quite a lot	A great deal	Score
Is cheerful	3	2	1	0	
Is sociable or responsive	3	2	1	0	
Appears withdrawn or depressed	0	1	2	3	
Cries /moans/groans / screams or whimpers	0	1	2	3	
Is hard to console or comfort	0	1	2	3	
Self-harms e.g. biting self or banging head	0	1	2	3	
Is reluctant to eat / difficult to feed	0	1	2	3	
Has disturbed sleep	0	1	2	3	
Grimaces / screws up face / screws up eyes	0	1	2	3	
Frowns / has furrowed brow / looks worried	0	1	2	3	
Looks frightened (with eyes wide open)	0	1	2	3	
Grinds teeth or makes mouthing movements	0	1	2	3	
Is restless / agitated or distressed	0	1	2	3	
Tenses / stiffens or spasms	0	1	2	3	
Flexes inwards or draws legs up towards chest	0	1	2	3	
Tends to touch or rub particular areas	0	1	2	3	
Resists being moved	0	1	2	3	
Pulls away or flinches when touched	0	1	2	3	
Twists and turns / tosses head / writhes or arches back	0	1	2	3	
Has involuntary or stereotypical movements / is jumpy / startles or has seizures	0	1	2	3	
TOTAL					

Please **tick the box** next to the word that best describes the severity of this pain

None
  Mild
  Moderate
  Severe
  Very severe



These first 12 pages form the baseline for your child's pain profile. You will also find pages for recording your assessment scores and a pad of additional ongoing assessment pages.

If you require any further information about the tool or more copies of individual pages these can be found on the web at:

[www.ppprofile.org.uk](http://www.ppprofile.org.uk)

or please contact

Dr Anne Hunt  
RCN Institute  
Radcliffe Infirmary  
Oxford  
OX2 6HE

Email: [anne.hunt@rcn.org.uk](mailto:anne.hunt@rcn.org.uk)

Telephone: 01865 224392



Great Ormond Street Hospital  
for Children NHS Trust and  
Institute of Child Health