



Paediatric Pain Profile

This profile belongs to

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.

© 2003. University College, London/Institute of Child Health and Royal College of Nursing Institute. Studies to develop and test the tool were funded by Action Research (with full support from the National Lottery Charities Board) and The Health Foundation.

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



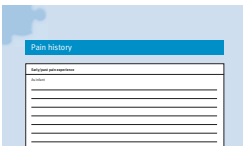
Great Ormond Street Hospital
for Children NHS Trust and
Institute of Child Health

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

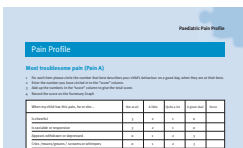


Instructions and guidance for use



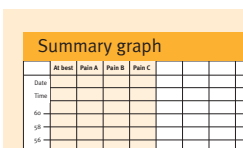
The pain history

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.



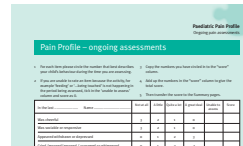
Baseline assessments

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.



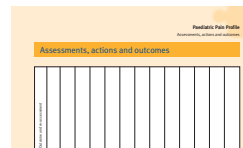
Summary Graph

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



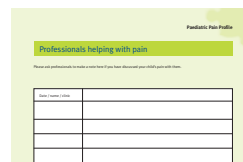
Ongoing pain assessments

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?

How long has your child had this pain?

When does this pain usually occur?

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

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?

How long has your child had this pain?

When does this pain usually occur?

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

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?

How long has your child had this pain?

When does this pain usually occur?

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

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

or please contact

Dr Anne Hunt
RCN Institute
Radcliffe Infirmary
Oxford
OX2 6HE

Email: anne.hunt@rcn.org.uk

Telephone: 01865 224392

Summary graph

Date	At best	Pain A	Pain B	Pain C															
Time																			
60																			
58																			
56																			
54																			
53																			
50																			
48																			
46																			
44																			
42																			
40																			
38																			
36																			
34																			
32																			
30																			
28																			
26																			
24																			
22																			
20																			
18																			
16																			
14																			
12																			
10																			
8																			
6																			
4																			
2																			
0																			

PPP score

Pain Profile – ongoing assessments

- For each item please circle the number that best describes your child’s behaviour during the time you are assessing.
- If you are unable to rate an item because the activity, for example ‘feeding’ or ‘...being touched’ is not happening in the period being assessed, tick in the ‘unable to assess’ column and score as 0.
- Copy the numbers you have circled in to the “score” column.
- Add up the numbers in the “score” column to give the total score.
- Then transfer the score to the Summary pages.

In the last Name	Not at all	A little	Quite a lot	A great deal	Unable to assess	Score
Was cheerful	3	2	1	0		
Was sociable or responsive	3	2	1	0		
Appeared withdrawn or depressed	0	1	2	3		
Cried /moaned/groaned / screamed or whimpered	0	1	2	3		
Was hard to console or comfort	0	1	2	3		
Self-harmed e.g. bit self or banged head	0	1	2	3		
Was reluctant to eat / difficult to feed	0	1	2	3		
Had disturbed sleep	0	1	2	3		
Grimaced / screwed up face / screwed up eyes	0	1	2	3		
Frowned / had furrowed brow / looked worried	0	1	2	3		
Looked frightened (with eyes wide open)	0	1	2	3		
Ground teeth or made mouthing movements	0	1	2	3		
Was restless / agitated or distressed	0	1	2	3		
Tensed / stiffened or spasmed	0	1	2	3		
Flexed inwards or drew legs up towards chest	0	1	2	3		
Tended to touch or rub particular areas	0	1	2	3		
Resisted being moved	0	1	2	3		
Pulled away or flinched when touched	0	1	2	3		
Twisted and turned / tossed head / writhed or arched back	0	1	2	3		
Had involuntary or stereotypical movements / was jumpy / startled or had seizures	0	1	2	3		
TOTAL						

Completed by _____ Date _____ Time _____

Assessments, actions and outcomes

Outcome and re-assessment													
Action taken													
What sort of pain do you think it is?													
PPP score													
Time													
Date													

Professionals helping with pain

Please ask professionals to make a note here if you have discussed your child's pain with them.

Date / name / clinic	