



Wellbeing for Life Pain and Distress



Learning Outcomes

- Understand what pain is and the different types of pain.
- To understand the different ways people communicate pain and distress.
- To use the Person Centred Thinking Tools to understand, record and help manage a person's pain and distress.
- To have ideas to support people to manage their pain and distress.



What is Pain?

Pain can be defined as:

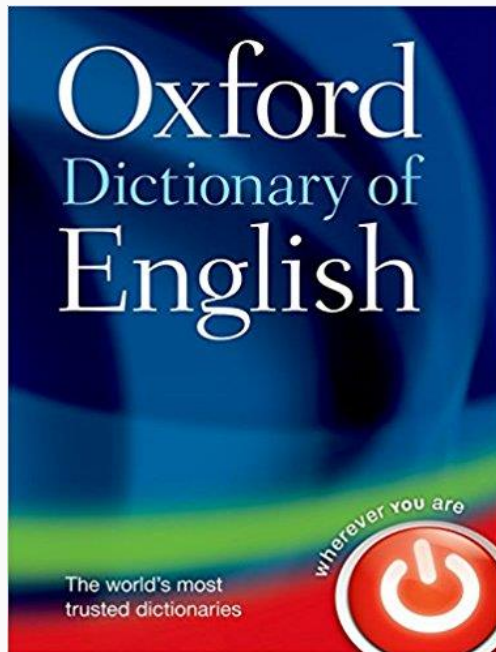
“an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”

- (www.iasp-pain.org). International Association for the Study of Pain

This definition is important as it makes the link between emotions and the sensory experience. This only way of deciding whether someone has pain is by asking them, or watching them.

What is Distress?

Distress can be defined as: “extreme anxiety, sorrow or pain”



- It is not always possible to differentiate between anxiety, sorrow or pain. Therefore, it is often identified as distress rather than pain.
- What is important is to recognise the person's signs and behaviours of distress and what works to help them manage the distress.
- Suggested ways to manage both pain and distress are included throughout this eBook.



Busting the Myths

“People with a learning disability don’t feel pain”

“People with a learning disability have a high pain threshold”

A plea: These statements are not true and you must challenge them every time you hear them.

Some facts:

Everyone experiences pain, but how they communicate their pain is different.

People with a learning disability *may* be unable to:

- recognise their pain
- describe their pain
- tell others about their pain
- say where the pain is

This is very different to saying they do not experience pain or have a high pain threshold.



Looking at Pain in More Detail

- Pain can come from any part of your body: skin, muscle, ligaments, joints, bones (nociceptive pain), injured tissue (inflammatory pain), nerves (neuropathic pain), internal organs (visceral pain) or a combination of these types of pain (mixed pain).
- Pain signals normally travel from the painful part of the body along thousands of specialised nerve fibres, through the spinal cord, to the brain.
- In some cases (for example, pain after a stroke), damage to the brain or to the spinal cord itself can start the pain sensation.
- Pain signals are initially processed in the spinal cord and then in the brain, where they can be associated with anxiety, emotions, sleep, appetite and memory - this creates a very personal experience of pain for each person.
- Only the person in pain can really say how painful something is. Because pain is always personal, no two people experience it in the same way. This makes it very difficult to define and to treat.



Case Study Example – Meet Michael

Michael is 35 years old; he is very active and loves to be busy. He is very agile and likes climbing – climbing walls, climbing frames, climbing trees!

Michael has autism and is described as having a severe learning disability. Michael has a sensory processing disorder that means he has heightened sensitivity to lights, sounds and touch – these are continuous all day, every day.

Recently Michael fell off a climbing wall. He was wearing safety equipment but still landed heavily onto the mat. Even though Michael had numerous bruises on the side of his body where he fell, his staff said they felt he was not in pain and stated that he had a high pain threshold.

Time to talk as a team:

What do you think about this situation? Should Michael be allowed to climb again?

Case Study Example – Meet Michael

A Suggestion Solution: Michael has many sensory experiences in his day to day life which he needs to adapt to. He also has autism and the additional challenges of coping with his anxiety and increased stress levels each and every day. This may be all consuming, meaning he is unable to recognise he is in pain – everything else takes all his attention and energy. He may be unable to differentiate the sensations of pain and those he experiences continuously. He may not know how to show you he is pain and ask for help – maybe in the past he has been told to “stop being silly and go away.”

If staff believe he “has a high pain threshold” they won’t be looking out for any signs of pain or even be offering ways to manage any pain.

- If it is likely that someone is in pain, then offer the right support to help manage pain. Just because you cannot recognise the person’s unique signs of pain, don’t assume they are not in pain. Leaving someone in pain is inhumane – and against their human rights.
- There is a link between undiagnosed pain in people as they age and developing age-related conditions.

Busting the Myths

These are some quotes by staff from a study completed by The Joseph Rowntree Foundation (2006)

- *“She’s very challenging, physically aggressive, verbally aggressive. I’ve been told that if she’s in so much pain she wouldn’t be able to lash out..... it is just seen as challenging behaviour.”*
- *“Their pain threshold is so high that sometimes you can have behavioural problems before you realise that it’s actually pain that they’re suffering from.”*
- *“A great percentage of people with learning disabilities also have extremely high pain thresholds.”*

These are subjective, inaccurate and untrue statements – these are from staff who do not understand pain and distress and people with a learning disability.



The Different Types of Pain:

So what are the different types of pain that a person can be diagnosed with?

- Acute pain (short term): temporary and results from something specific, e.g. sprained ankle, broken leg, constipation, heart burn/indigestion, toothache or ill-fitting dentures, pressure ulcers.
- Persistent pain (chronic, long term): pain that continues for more than 3 months or more e.g. back pain, arthritis, diabetic peripheral neuropathy.
- Recurrent pain: comes and goes, e.g. headache, migraine.

Remember: it is possible to have more than one sort of pain or to have pain in several places.



Pain in People with Dementia and Learning Disability:

- Pain in people diagnosed with dementia and learning disability is often undetected and untreated.
- Pain intensity is no different in people who are cognitively impaired (by dementia or learning disability for example) compared with people who are not.
- Study has shown that as cognitive impairment increases (for example the more severe the learning disability or the more advanced the dementia), people were less likely to receive pain medicines.
- Describing the pain can be difficult when thinking skills are impaired.
- Risks of “diagnostic overshadowing” – behaviour is attributed to dementia and/or learning disability.
- Part of the brain that understands the body is damaged. Therefore they cannot show where they are experiencing the pain.



How do people communicate pain and distress when they are unable to tell you directly?

People communicate pain in different ways, this may be:

- Using sounds, noises and words
- Facial expressions
- Body language
- Emotions and moods
- Gestures



Looking at Pain in more Detail

Sounds, noises and words:

- Calling out
- Vocalising differently to usual
- Shouting out
- Screaming
- Sighing
- Groaning noises
- Grinding teeth
- Speaking louder than usual / being quieter than usual
- Using certain words or vocalisations – “ow” “ouch” or many others



Looking at Pain in more Detail

Facial Expressions:

- Frowning
- “Pained look”
- Grimacing
- Sad
- Frightened look
- Worried
- Wide eyes
- Chewing the inside of their cheek
- More or less eye contact than usual





Looking at Pain in more Detail

Body Language:

- Not moving
- Rigid posture
- Walking about
- Running
- Fidgeting
- Reluctance to move a part of their body
- Holding a part of their body or covering it up
- Hitting out
- Biting self
- Flinching when being touched
- Restless
- Curled up
- Arches back
- “Jumpy” or easily startled
- Moving away from others



Using the MacIntyre Person-Centred Thinking Tools

We can use the MacIntyre's Person Centred Thinking Tools to understand, record and help manage a person's pain and distress.

We use the person-centred thinking tools to make sure people with pain or distress are listened to; have more choice and control; and are given the right support.

The person centred thinking tools allow us to pay attention to what matters to the person, and what good support looks like to help manage their pain and distress.

The person-centred thinking tools allow the signs and behaviours of wellbeing and pain or distress to be recorded; gather information to help manage the pain and distress; and to share important information with others.

Remember: We also have devised the Pain and Distress Assessment Tool – Found on the MacIntyre Health Noticeboard, and on MyMacIntyre. The MacIntyre Pain and Distress Assessment Tool has be adapted from the Disability Distress Assessment Tool (DISDAT).



MacIntyre Communication Charts

Communication Charts

Communication charts are vital sources of information when a person does not use words to communicate; they are also useful for anyone who needs support.

To complete a communication chart you will need to spend time with the person and record your observations, ask colleagues and others to do the same; ask family for their observations and knowledge about the person.

Every person you support should have a communication profile and/or chart. This will include information to understand what the person wants to tell you and how to respond, plus how to give the person information so it makes sense to them.



The MacIntyre Pain and Distress Assessment Tool



Pain and Distress: Assessment Tool



Person's Name: _____

When I am in pain or distress	I do this		We think it means	We should
	Appearance	Movement		
Eyes				
Body Posture				
Body Movements				
Facial expression				
Jaw and tongue movement				
Skin colour				
Vocal sounds				
Habits and mannerisms				
Pulse				
Breathing				
Sleep				
Appetite/Eating Pattern				

Completed by: _____ Date Completed: _____
 Review Date: _____ * To be included in the Risk Assessment Schedule Annual Review

Every person you support should have a Pain and Distress Assessment Tool.

This will identify how the person communicates pain, what it means and what to do about it.



Using 'Important To' and 'Important For'

This tool helps to organise information so that we know what is important to and for the person and are able to support them to get a balance between the two, in their support and life as a whole.

'Important to' describes:

- What makes the person comfortable and happy
- Things to have or avoid
- Their preferred rhythm and pace of life

'Important for' describes:

- What we need to do to support the person well
- What is necessary for their health, wellbeing and safety
- Support needed to be involved
- It is a description of what we need to do to support the person well



Learning Logs

Are a way of capturing information that is important without adding unnecessary detail/words.

Enables us to try out and record things when people do not use words to communicate to establish if they enjoy it or not.

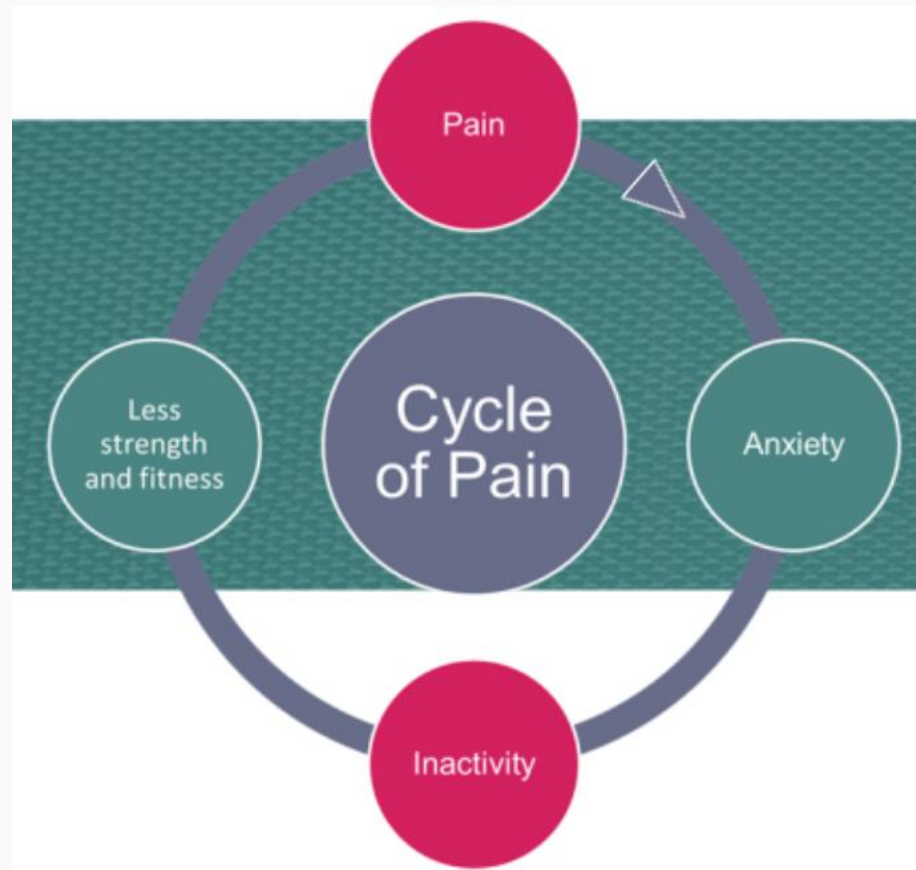
Help us to identify what is important to and for someone.

The Learning Log allows us to find out what helps to:

- Prevent any pain or distress – and maintain wellbeing and contentment.
- Minimise any pain or distress experience.
- How to manage any pain or distress.

The Pain Cycle

This is the pain cycle, it shows the continuous cycle of how pain affects people and shows how easy it is for pain and distress to quickly impact a person's quality of life:





What Can you do to Help Someone Manage their Pain or Distress?

In a person with a learning disability and dementia, undiagnosed pain may make their dementia symptoms more pronounced (i.e. they may be *more* confused).

Exactly what will help depends on the type of pain, how long the pain has been experienced, the person's previous experiences, what else is happening in their life at that time, who is with them.

Here are some tips:

- Complete the communication chart and continually review and update as you learn more about the person.
- Complete a learning log to understand what helps and when it helps.
- Keep good records – information is critical in assessment and treatment of pain or distress.
- Arrange to see the GP for pain management advice.
- Ask for a referral to a specialist pain clinic if the pain is persistent and long term. The GP or Hospital Doctor makes the referral.



What Can you do to Help Someone Manage their Pain or Distress?

Pain medicines:

- There are a variety of pain medicines, each type of pain medicine works differently and works well for some types of pain.
- For example: paracetamol and anti-inflammatory painkillers work well for pain associated with inflammation – back pain, headaches.
- If pain is caused by nerve damage or sensitive nerves a particular pain relief is needed.



What Can you do to Help Someone Manage their Pain or Distress?

Pain medicines:

- The aim of taking pain relief medicine is to improve quality of life. All pain relief medicines have side effects, therefore the advantages and disadvantages need to be weighed up.
- Taking more and more pain relief is often not the best option, other lifestyle and non-medicine treatments can help.
- Always consult a doctor before supporting someone to take pain relief medicines – any interactions with other medicines they are taking need to be considered as well as other health factors.



Supporting the Person

Lifestyle changes and non-medicine options can sometimes be more effective than medicine:

- Try different things - recording the effect on the person's pain and distress on the Learning Log.
- Pace the activity during the day and week – prioritise and plan each day/week.
- Set goals and actions to help with a sense of achievement as well as pace their day.
- Support the person to be physically active – keeping active prevents other health conditions occurring and gives an overall sense of wellbeing. Always seek advice for specific exercise or if pain gets worse.



Supporting the Person

Lifestyle changes and non-medicine options can sometimes be more effective than medicine:

- Work out what helps the person relax and reduce their distress.
- Support the person to keep socialising – this not only gives them something else to think about but will help them feel better.
- Concentrate on what the person enjoys and that they can do.
- Pursue existing, past or new hobbies – this helps psychologically and also gives the person something to talk about, not just their pain.



Produced by the MacIntyre Dementia Project with the support of an Innovation, Excellence and Strategic Development Fund Award from the Department of Health.

A special thank you to Beth Britton, and for all her hard work on the MacIntyre Dementia Project.

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