



The pain communication toolkit will provide parent and carers opportunities to advocate for the person with a learning disability, when working with health professionals. Providing the information needed to allow for appropriate prescribed medication, or, alternative therapies based on the information given by the person with a learning disability. Using the thermometer, body map and pain descriptors within the toolkit

Before using the 'let me tell you about my pain' booklet, it is important to consider whether the person you are supporting is in pain or distress? Use the guide below to identify potential reasons that may cause distress.

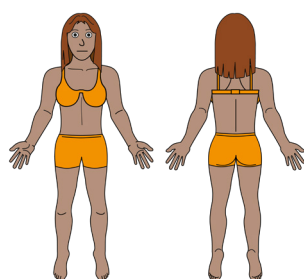
Environmental	Tick	Physical causes of distress	Tick	Life changes	Tick
Distress due to loud noises		Postural care – change of position required		If supported by a staff team, will a change of staff help reduce distress	
Does sitting in a quiet room reduce distress?		Reflux or indigestion – is the person in distress after meals.		Life changes such as moving house, change of daytime occupation.	
Lighting too bright or too dull?		Pain during bowel movements or constipation personal care, does the person need help with toileting/changing?		Has there been a change of staff in the team?	
Room temperature, is the room too cold or hot?		Does the person have PEG feeds, is there trapped wind. Does venting reduce the distress?		Has the person had a bereavement – this may not have been recent. It could have been many years ago, but is still effecting the person.	

Using the 'Let me Tell you About my Pain' Booklet.

The booklets are available free of charge on the website Getcheckedoutleeds.nhs.uk, you can support a person with a learning disability to choose the accessible version which works for them. Page 2 of the 'let me tell you about my pain booklet' has a section where you can record distress or pain which the person experiences. This may for example be distress in crowded rooms or sudden loud noises. Pain could be recorded when a person has a condition which causes regular known pain, such as a dislocated hip which causes pain on transfers, or migraines which the person has regularly.

Please consider the following when supporting a person to use the booklet.

Body Maps –



These are used to support in identifying the location of pain. Choose the body map which the person prefers.

These are currently available in mid skin tone, male, female, naked and partially clothed. We are working to create a wider variety of skin colour and clothing options which should be available on the website soon. Some people may choose a naked image to identify an area of the body, some people need to see the area unclothed to identify where it hurts. For others this may not be an image they would choose. The image with shorts and top is often preferred, but be led by the choice of the person who will be using the body map.

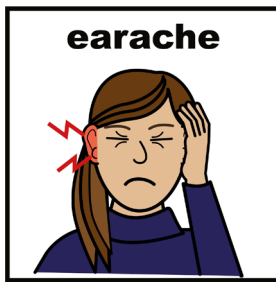
Pain Thermometers/Pain Scale



This will help the person you support to tell a health professional how severe the pain is. Use a set of images that the person understands and can relate to. In reviews by people with learning disabilities the face and hand images were the most preferred, but for some people they may like to use a thermometer which changes in shape and colour as an abstract option. Or for some the more concrete images such as those with the ambulance may be preferred.

As with the body maps, support the person with a learning disability to choose the most appropriate for them. By choosing a pain thermometer that people can use to describe their level of pain, you will be able to gauge whether medication or alternative interventions are working. This can be done by repeating the use of the scale after providing pain relief options. To help with this you can use the 'let me tell you about my pain' recording chart, available in the booklet and website.

Pain Pictures.



The images of types of pain can help a person with a learning disability describe what their pain feels like. This is very important as different pain types may need to be treated using different methods. The images were produced with people with learning disabilities with the intention to make them as user friendly as possible. Images with specific descriptors of ear and toothache are included, as these pain types are often very difficult to identify.

Once a person has been able to say where on the body it hurts and how bad the pain is, you can use these images to support a health professional to understand what type of pain the person is feeling.

For some people with learning disabilities, it can be really hard to understand or verbalise what type of pain they are experiencing. To support identifying pain sensations, sensory tools may help. Here are some examples.

Frozen peas could help someone understand what cold feels like; this may help if an area of the body had a cold sensation. A warmed (NOT hot) wheat bag could be used to support someone to explain that a part of their body feels warm or hot. Other tools might include a prickly hairbrush which could support a person to explain or understand what pins and needles or prickly sensations feel like. Sometimes feeling the sensation on an arm or hand can help a person to understand and explain how they feel.

For People With Complex Learning Disabilities

It is recognised that they may not be able to give information using these tools. In instances where a person is unable to communicate consider using the DisDAT (Disability and Discomfort Assessment Tool). This can be found on the internet from St Oswald's Hospice www.stoswaldsuk.org/how-we-help/we-educate/education/resources/disability-distress-assessment-tool-disdat/how-to-use-disdat/ The DisDAT, once completed can provide you with an opportunity to identify when a person becomes distressed or is experiencing potential discomfort. This can also support you in identifying whether any pain relief provided, has been effective in the management of the person's pain.

This resource has been developed by Michelle Evans, RNLD at the Health Facilitation Team Leeds and York Partnership Foundation Trust (LYPFT), co-produced with the service user team at Your Health Matters Involvement team (LYPFT), support from colleagues Lucy Keane, LYPFT and Jasmine Jones, Leeds Community Healthcare Trust (LCH), Jane Chatterjee, St Gemma's Hospice, Leeds. With all graphics produced by Dean Milner-Bell, Accessible Information Designer at easy on the i, (LYPFT).