

**Known triggers of distress** (write here any actions or situations that usually cause or worsen distress)

# Disability Distress Assessment Tool



Please take some time to think about and observe your client's appearance and behaviours when they are both content and distressed, and describe these cues in the spaces given. We have listed words in each section to help you to describe your client or patient. You can circle the word or words that best describe the signs and behaviours when your client or patient is content and when they are distressed. Document the cues in each category and, if possible, give a fuller description in the spaces given. Your descriptions will provide you with a clearer picture of your client's 'language' of distress.

## COMMUNICATION LEVEL \*

This person is unable to show likes or dislikes	<input type="checkbox"/>	Level 0
This person is able to show that they like or don't like something	<input type="checkbox"/>	Level 1
This person is able to show that they want more, or have had enough of something	<input type="checkbox"/>	Level 2
This person is able to show anticipation for their like or dislike of something	<input type="checkbox"/>	Level 3
This person is able to communicate detail, qualify, specify and/or indicate opinions	<input type="checkbox"/>	Level 4

\* This is adapted from the Kidderminster Curriculum for Children and Adults with Profound Multiple Learning Difficulty (Jones, 1994, National Portage Association).

## FACIAL SIGNS

### Appearance

Information / instructions	Appearance when content	Appearance when distressed
<b>Ring</b> the words that best describe the facial appearance	Passive      Laugh      Smile      Frown Grimace      Startled      Frightened Other:	Passive      Laugh      Smile      Frown Grimace      Startled      Frightened Other:

### Jaw movement

Information / instructions	Movement when content	Movement when distressed
<b>Ring</b> the words that best describe the jaw movement	Relaxed      Drooping      Grinding Biting      Rigid Other:	Relaxed      Drooping      Grinding Biting      Rigid Other:

### Appearance of eyes

Information / instructions	Appearance when content	Appearance when distressed
<b>Ring</b> the words that best describe the appearance	Good eye contact      Little eye contact Avoiding eye contact      Closed eyes Staring      Sleepy eyes 'Smiling'      Winking      Vacant Tears      Dilated pupils Other:	Good eye contact      Little eye contact Avoiding eye contact      Closed eyes Staring      Sleepy eyes 'Smiling'      Winking      Vacant Tears      Dilated pupils Other:

## SKIN APPEARANCE

Information / instructions	Appearance when content	Appearance when distressed
<b>Ring</b> the words that best describe the appearance	Normal      Pale      Flushed Sweaty      Clammy Other:	Normal      Pale      Flushed Sweaty      Clammy Other:



## VOCAL SOUNDS (NB. The sounds that a person makes are not always linked to their feelings)

Information / instructions	Sounds when content	Sounds when distressed
<b>Ring</b> the words that best describe the sounds  <i>Write down</i> commonly used sounds (write it as it sounds; 'tizz', 'eeiow', 'tetetetete'): ..... ..... .....	<b>Volume:</b> high      medium      low <b>Pitch:</b> high      medium      low <b>Duration:</b> short    intermittent    long <b>Description of sound / vocalisation:</b> Cry out      Wail      Scream      laugh Groan / moan      shout      Gurgle Other:	<b>Volume:</b> high      medium      low <b>Pitch:</b> high      medium      low <b>Duration:</b> short      intermittent long <b>Description of sound / vocalisation:</b> Cry out      Wail      Scream      laugh Groan / moan      shout      Gurgle Other:

## SPEECH

Information / instructions	Words when content	Words when distressed
<i>Write down</i> commonly used words and phrases. If no words are spoken, write NONE		
<b>Ring</b> the words which best describe the speech	Clear      Stutters      Slurred      Unclear Muttering      Fast      Slow Loud      Soft      Whisper Other:	Clear      Stutters      Slurred      Unclear Muttering      Fast      Slow Loud      Soft      Whisper Other:

## HABITS & MANNERISMS

Information / instructions	Habits and mannerisms when content	Habits and mannerisms when distressed
<i>Write down</i> the habits or mannerisms, eg. "Rocks when sitting"		
Write down any special comforters, possessions or toys this person prefers.		
Please <b>Ring</b> the statements which best describe how comfortable this person is with other people being physically close by	Close with strangers Close only if known No one allowed close Withdraws if touched	Close with strangers Close only if known No one allowed close Withdraws if touched

## BODY POSTURE

Information / instructions	Posture when content	Posture when distressed
<b>Ring</b> the words that best describe how this person sits and stands.	Normal      Rigid      Floppy Jerky      Slumped      Restless Tense      Still      Able to adjust position Leans to side      Poor head control Way of walking: Normal / Abnormal Other:	Normal      Rigid      Floppy Jerky      Slumped      Restless Tense      Still      Able to adjust position Leans to side      Poor head control Way of walking: Normal / Abnormal Other:

## BODY OBSERVATIONS

Information / instructions	Observations when content	Observations when distressed
<i>Describe</i> the pulse, breathing, sleep, appetite and usual eating pattern, eg. eats very quickly, takes a long time with main course, eats puddings quickly, "picky".	Pulse: Breathing: Sleep: Appetite: Eating pattern:	Pulse: Breathing: Sleep: Appetite: Eating pattern:



## When to use DisDAT

### ***When the team believes the client is NOT distressed***

The use of DisDAT is optional, but it can be used as a

- baseline assessment document
- transfer document for other teams

### ***When the team believes the client IS distressed***

If DisDAT has already been completed it can be used to compare the present signs and behaviours with previous observations documented on DisDAT. It then serves as a baseline to monitor change.

If DisDAT has not been completed:

- a) When the client is well known DisDAT can be used to document previous content signs and behaviours and compare these with the current observations
- b) When the client or the distress is new to the team, DisDAT can be used to document the present signs and behaviours to act as a baseline to monitor change.

## How to use DisDAT

1. **Observe the client** when content and when distressed- document this on the inside pages. *Anyone* who cares for the patient can do this.
2. **Observe the context** in which distress is occurring.
3. **Use the clinical decision distress checklist** on this page to assess the possible cause.
4. **Treat or manage** the likeliest cause of the distress.
5. **The monitoring sheet** is a separate sheet, which may help if you want to see how the distress changes over time.
6. **The goal** is a reduction in the number or severity of distress signs and behaviours.

## Remember

- Most information comes from the whole team in partnership with the family.
- The assessment form need not be completed all at once and may take a period of time.
- Reassessment is essential as the needs of the client or patient may change due to improvement or deterioration.
- Distress can be emotional, physical or psychological. What is a minor issue for one person can be major to another.
- If signs are recognised early then suitable interventions can be put in place to avoid a crisis.

## Clinical decision distress checklist

Use this to help decide the cause of the distress

### Is the new sign or behaviour?

- Repeated rapidly?  
*Consider* pleuritic pain (in time with breathing)  
*Consider* colic (comes and goes every few minutes)  
*Consider*: repetitive movement due to boredom or fear.
- Associated with breathing?  
*Consider*: infection, COPD, pleural effusion, tumour
- Worsened or precipitated by movement?  
*Consider*: movement-related pains
- Related to eating?  
*Consider*: food refusal through illness, fear or depression  
*Consider*: food refusal because of swallowing problems  
*Consider*: upper GI problems (oral hygiene, peptic ulcer, dyspepsia) or abdominal problems.
- Related to a specific situation?  
*Consider*: frightening or painful situations.
- Associated with vomiting?  
*Consider*: causes of nausea and vomiting.
- Associated with elimination (urine or faecal)?  
*Consider*: urinary problems (infection, retention)  
*Consider*: GI problems (diarrhoea, constipation)
- Present in a normally comfortable position or situation?  
*Consider*: anxiety, depression, pains at rest (eg. colic, neuralgia), infection, nausea.

If you require any help or further information regarding DisDAT please contact:

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Northgate & Prudhoe NHS Trust Palliative  
Care Team  
and St. Oswald's Hospice

## Further reading

Regnard C, Matthews D, Gibson L, Clarke C, Watson B. Difficulties in identifying distress and its causes in people with severe communication problems. *International Journal of Palliative Nursing*, 2003, 9(3): 173-6.

**Distress may be hidden,  
but it is never silent**

Document the daily frequency of each distress sign or behaviour with a ✓  
Mark down the usual time each sign or behaviour lasts in minutes

**Patient sign or behaviour of distress:** (EXAMPLE): *grimaces*

[illegible][illegible]

**Patient sign or behaviour of distress:**

[illegible]

**Patient sign or behaviour of distress:**

[illegible]

**Patient sign or behaviour of distress:**

[illegible]

**Patient sign or behaviour of distress:**

[illegible]

**Patient sign or behaviour of distress:**

[illegible]

**Patient sign or behaviour of distress:**

[illegible]

TOTAL

[illegible]



- |     |  |   |
|-----|--|---|
| Q 1 | Is the sign/behaviour of distress present? | If No, score 0; if Yes, go to next question |
| Q 2 | Is it moderately affecting on the day?     | If No, score 1; if Yes, go to next question |
| Q 3 | Is it dominating the day?                  | If No, score 2; if Yes, score 3             |

Score based on PACA. (Ellershaw J)

**Patient sign or behaviour of distress: (EXAMPLE):** *grimaces*

[illegible]

**Patient sign or behaviour of distress:**

[illegible]

**Patient sign or behaviour of distress:**

[illegible]

**Patient sign or behaviour of distress:**

[illegible]

**Patient sign or behaviour of distress:**

[illegible]

**Patient sign or behaviour of distress:**

[illegible]

**Patient sign or behaviour of distress:**

[illegible]

**Patient sign or behaviour of distress:**

[illegible]

**Patient sign or behaviour of distress:**

[illegible]**TOTAL score**[illegible]

## Disability Distress Assessment Tool (Monitoring Tool)



**Edinburgh University (Matt Hayes), Northgate Palliative Care Team and St. Oswald's Hospice**

<b>Client's name:</b>	<b>DoB:</b>	<b>Page No:</b>	<b>Please affix patient addressograph here</b>
<b>Unit/ward:</b>	<b>Gender:</b>	<b>NHS No:</b>	

**Please complete at any times when you are concerned that the patient is distressed**  
**This individual's signs and behaviours of contentment / distress are detailed on the first page of the DisDAT assessment sheet**

[illegible]