



Disability Distress Assessment Tool

Individual's name:

DoB: _____ **Gender:** _____

NHS No: _____

Your name: _____

Date completed: _____

Names of others who helped complete this form: _____

THE DISTRESS PASSPORT

Summary of signs and behaviours when content and when distressed

Appearance when CONTENT

Face _____ Eyes _____

Tongue/jaw _____

Skin _____

Appearance when DISTRESSED

Face _____ Eyes _____

Tongue/jaw _____

Skin _____

Vocal signs when CONTENT

Sounds _____

Speech _____

Vocal signs when DISTRESSED

Sounds _____

Speech _____

Habits and mannerisms when CONTENT

Habits _____

Mannerisms _____

Comfortable distance _____

Habits and mannerisms when DISTRESSED

Habits _____

Mannerisms _____

Comfortable distance _____

Posture & observations when CONTENT

Posture _____

Observations _____

Posture & observations when DISTRESSED

Posture _____

Observations _____

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

Distress Assessment Tool

Please take some time to think about and observe the individual under your care, especially their appearance and behaviours when they are both content and distressed. Use these pages to document these.

We have listed words in each section to help you to describe the signs and behaviours. You can circle the word or words that best describe the signs and behaviours when they are content and when they are distressed.

Your descriptions will provide you with a clearer picture of their 'language' of distress.

COMMUNICATION LEVEL *

This individual is unable to show likes or dislikes	Level 0
This individual is able to show that they like or don't like something	Level 1
This individual is able to show that they want more, or have had enough of something	Level 2
This individual is able to show anticipation for their like or dislike of something	Level 3
This individual is able to communicate detail, qualify, specify and/or indicate opinions	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
<i>Ring</i> 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
<i>Ring</i> 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
<i>Ring</i> 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
<i>Ring</i> 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
<p>(Ring) the words that best describe the sounds</p> <p>Write down commonly used sounds (write it as it sounds; 'tizz', 'eeiow', 'tetetetete'):</p> <p>.....</p> <p>.....</p> <p>.....</p>	<p>Volume: high medium low</p> <p>Pitch: high medium low</p> <p>Duration: short intermittent long</p> <p>Description of sound / vocalisation: Cry out Wail Scream laugh</p> <p>Groan / moan shout Gurgle</p> <p>Other:</p>	<p>Volume: high medium low</p> <p>Pitch: high medium low</p> <p>Duration: short intermittent long</p> <p>Description of sound / vocalisation: Cry out Wail Scream laugh</p> <p>Groan / moan shout Gurgle</p> <p>Other:</p>

SPEECH

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

HABITS & MANNERISMS

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

BODY POSTURE

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

BODY OBSERVATIONS

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

Information and Instructions

DisDAT is

Intended to help identify distress cues in individuals who have severely limited communication.

Designed to describe an individual's usual content cues, thus enabling distress cues to be identified more clearly.

NOT a scoring tool. It documents what many carers have done instinctively for many years thus providing a record against which subtle changes can be compared.

Only the first step. Once distress has been identified the usual clinical decisions have to be made by professionals.

Meant to help you and the individual in your care. It gives you more confidence in the observation skills you already have, which in turn will give you more confidence when meeting other carers.

When to use DisDAT

When the team believes the individual 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 individual 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:

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

How to use DisDAT

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

Remember

- Most information comes from several carers together.
- The assessment form need not be completed all at once and may take a period of time.
- Reassessment is essential as the needs 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:
Lynn Gibson 01670 394 260
Dorothy Matthews 01670 394 808
Dr. Claud Regnard 0191 285 0063 or e-mail on claudregnard@stoswaldsuk.org

For more information see
www.disdat.co.uk

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.

Regnard C, Reynolds J, Watson B, Matthews D, Gibson L, Clarke C. Understanding distress in people with severe communication difficulties: developing and assessing the Disability Distress Assessment Tool (DisDAT). *J Intellect Disability Res.* 2007; **51(4)**: 277-292.

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