v15

Disability Distress Assessment Tool

Client's name:

DoB: **Gender:**

Unit/ward: **NHS No:**

Your name: **Date completed:**

Names of others who helped complete this form:

DisDAT is

Intended to help identify distress cues in people who because of cognitive impairment or physical illness have severely limited communication.

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

NOT a scoring tool. It documents what many staff have done instinctively for many years thus providing a record against which subtle changes can be compared. This information can be transferred with the client or patient to any environment.

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

Meant to help you and your client or patient. It gives you more confidence in the observation skills you already have which in turn will help you improve the care of your client or patient.

INSTRUCTIONS FOR USING DisDAT ARE ON THE BACK PAGE

SUMMARY OF SIGNS AND BEHAVIOURS

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)

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	☐	Level 0
This person is able to show that they like or don't like something	☐	Level 1
This person is able to show that they want more, or have had enough of something	☐	Level 2
This person is able to show anticipation for their like or dislike of something	☐	Level 3
This person 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
(Ring) 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
(Ring) 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
(Ring) 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
(Ring) 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
Ring the words that best describe the sounds *Write down* commonly used sounds (write it as it sounds; 'tizz', 'eeiow', 'tetetetete'): …… …… ……	**Volume**: high medium low **Pitch**: high medium low **Duration:** short intermittent long **Description of sound / vocalisation**: Cry out Wail Scream laugh Groan / moan shout Gurgle Other:	**Volume:** high medium low **Pitch:** high medium low **Duration**: short intermittent long **Description of sound / vocalisation**: Cry out Wail Scream laugh Groan / moan shout Gurgle Other:

SPEECH

Information / instructions	Words when content	Words when distressed
Write down commonly used words and phrases. If no words are spoken, write NONE		
Ring 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
Write down the habits or mannerisms, eg. "Rocks when sitting"		
Write down any special comforters, possessions or toys this person prefers.		
Please Ring 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
Ring 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
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".	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 document the present signs and behaviours to act 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 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:
Lynn Gibson 01670 394 260
Dorothy Matthews 01670 394 808
Dr. Claud Regnard 0191 285 0063 or e-mail on claudregnard@stoswaldsuk.org

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**

[v14a] **DisDAT Monitor** **Patient:**______________________ **Start month:**________ **Year:**_____

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*

DATE	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	30	1	2	3	4	5	6	7
3																										
2																										
1																										
0																										

DATE or TIME																										

Patient sign or behaviour of distress:

3																										
2																										
1																										
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Patient sign or behaviour of distress:

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Patient sign or behaviour of distress:

3																										
2																										
1																										
0																										

TOTAL score

[v14] **DisDAT Monitor** **Patient:**_____ **Start month:**_____ **Year:**_____

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*

DATE	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	1	2	3	4	5	6	7
Frequency	✓																								
	✓	✓																							
	✓	✓		✓																					
	✓	✓	✓	✓		✓																			
	✓	✓	✓	✓	✓	✓	✓	✓		✓		✓													
How long?	10	12	6	8	5	5	2	<1	-	1	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-
DATE																									

Patient sign or behaviour of distress:

Frequency

How long?

Patient sign or behaviour of distress:

Frequency

How long?

Patient sign or behaviour of distress:

Frequency

How long?

Patient sign or behaviour of distress:

Frequency

How long?

Patient sign or behaviour of distress:

Frequency

How long?

Patient sign or behaviour of distress:

Frequency

How long?

TOTAL

Total frequency

Total time

V3

Disability Distress Assessment Tool (Monitoring Tool)

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

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

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

Date	Time	Is Patient Content/ Distressed	Please record observations of severity and duration of distress in these columns		Action Taken	Outcome
			Signs of Distress	Context of Distress		