



The Disability Distress Assessment Tool

Distress may be hidden, but it is never silent!

Background

In the late 1990's a combined learning disability and palliative care team at Northgate Hospital in Northumberland, UK, began to explore the issue of identifying distress in people with severe communication difficulties. They made three observations:

- Lay and professional carers were skilful at identifying distress, but had little confidence in that skill.
- This lack of certainty in what carers were observing made it difficult for them to advocate for the person with the communication difficulty when faced with a challenge to their observation.
- A number of pain score tools existed for people with cognitive impairment despite the absence of any evidence in the literature that pain produced any specific signs or behaviours.

The team gradually realised that what was needed was the development of a process that

- 1) Identified distress, rather than pain
- 2) Documented signs and behaviours when a person was content and when they were distressed
- 3) Helped to put the distress into context by providing a checklist that suggested possible causes of distress
- 4) Summarised the signs and behaviours for easy reference by other carers and teams
- 5) Monitored changes in distress as an intervention was tried.

The team piloted an early version of DisDAT in 2001 and in 2003 completed a validation study under the auspices of Northumbria University which was published in 2006 (see references).

These studies found that:

- distress signs and behaviours are not specific to the cause
- each person has their own 'vocabulary' of distress signs and behaviours
- teams pick up more signs and behaviours than any one individual
- DisDAT documents distress accurately and carers find it easy to use

DisDAT is

- **Intended** to help identify distress cues in people who because of cognitive impairment or physical illness have severely limited communication.
- **Designed** to also document 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.
- **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.
- **Useable by any carer.** Both lay and professional carers find they can use this tool.
- **A means of providing a clearer picture** of a client's 'language' of distress.
- **Only the first step:** see 'How to use DisDAT'

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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 of DisDAT. *Anyone* who cares for the patient can do this.
- 2) **Observe the context** in which distress is occurring.
- 3) **Identify possible causes of distress.** Use the clinical decision distress checklist on the back page of DisDAT to help you.
- 4) **Use the monitoring sheets** if the cause is not obvious. Sometimes the cause of distress only becomes clear by monitoring daily (or even hourly for 24 hours) to show a pattern of distress.
- 5) **Which monitoring sheet?** There are a choice of three! It does not matter which you use as each type is capable of monitoring the signs and behaviours. Just pick whichever one makes most sense to you, and whichever one you feel most comfortable in using.
- 6) **Treat or manage** of the likeliest cause of the distress.
- 7) **Monitor the distress:** if necessary use the monitoring sheets if you want to see how the distress changes over time.
- 8) **What then?** If the distress resolves, the process stops. If not, you start an intervention for the second possible cause of distress
- 9) **The goal** is a reduction the number or severity of distress signs and behaviours.

The clinical decision checklist

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: pains at rest, infection, nausea.

Finally, 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.

Contact

DisDAT is constantly evolving and we welcome comments from users.

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References

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