

# ***Finding the words***

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on behalf of

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**St Oswald's Hospice**

**University of Northumbria**

# Warren (Mencap Report)



## **Warren (Mencap Report)**

- **Difficulty sleeping, seizures, not eating, not swallowing tablets**
- **Worried parents called doctor – told he had a virus – given diazepam + paracetamol**
- **Next day, condition worse**
- **Out of hours doctor called – advised an X-ray**
- **A few hours later, parents phoned to say Warren was worse. Ambulance called**
- **In A&E mum noticed his colour had changed**
- **Arrested and died.**

# Warren (Mencap Report)

- **PM =  
Peritonitis due to  
perforated  
appendix**



## What is it about distress?

- Pheromones, sixth sense, intuition, experience, observation, body language?
- Carers seem to have the skill in picking up distress eg. 'She's not right....'
- Why don't carers have confidence in that skill?

## Existing pain tools

- **Almost all are pain tools (eg. Doloplus2, PAIN-AD)**
- **Some derived from work with pre-verbal children, some from adults with dementia**
- **Assess multiple cues eg. facial expression, autonomic changes, function, tone, interaction**
- **Many use a scoring system**
- **Some are restricted to 'core' cues**

# Is it pain?

## Published signs and behaviours

### Pain

- Facial expression, vocalisation
- Behaviours (aggression, withdrawal)
- Change in posture
- Change in activity
- Autonomic changes

### Distress

- Facial expression, vocalisation
- Behaviours (aggression, withdrawal)
- Change in posture
- Change in activity
- Autonomic changes

**There is no evidence that pain has any specific signs or behaviours**

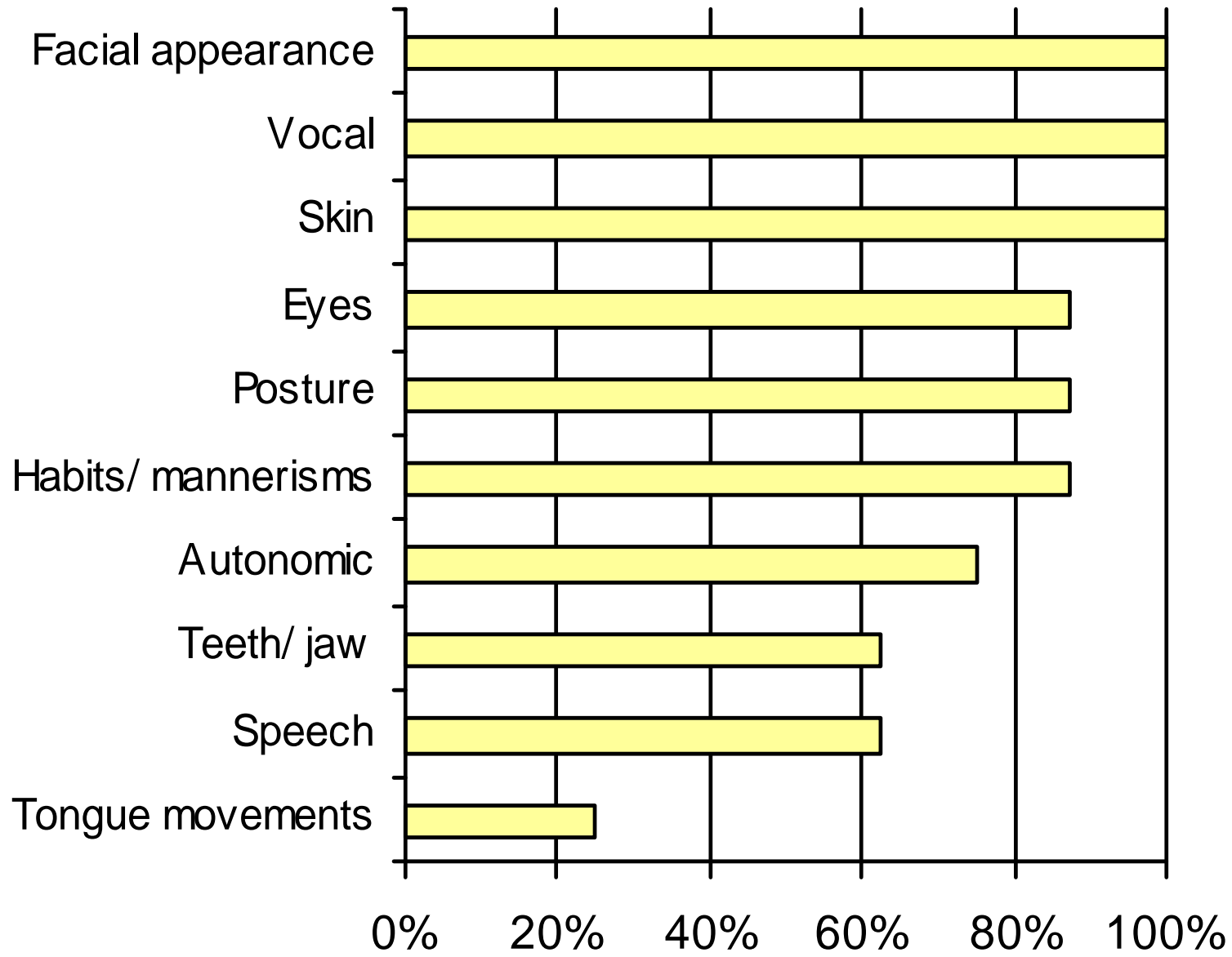
## Is it pain?

- If the response to any distress was 5mg morphine what would be your response?
- Are we not doing the same in using pain tools in this client group?  
ie. any distress sign or behaviour = analgesic
- Pain tools = risk of poor analgesia

## Existing assessment tools

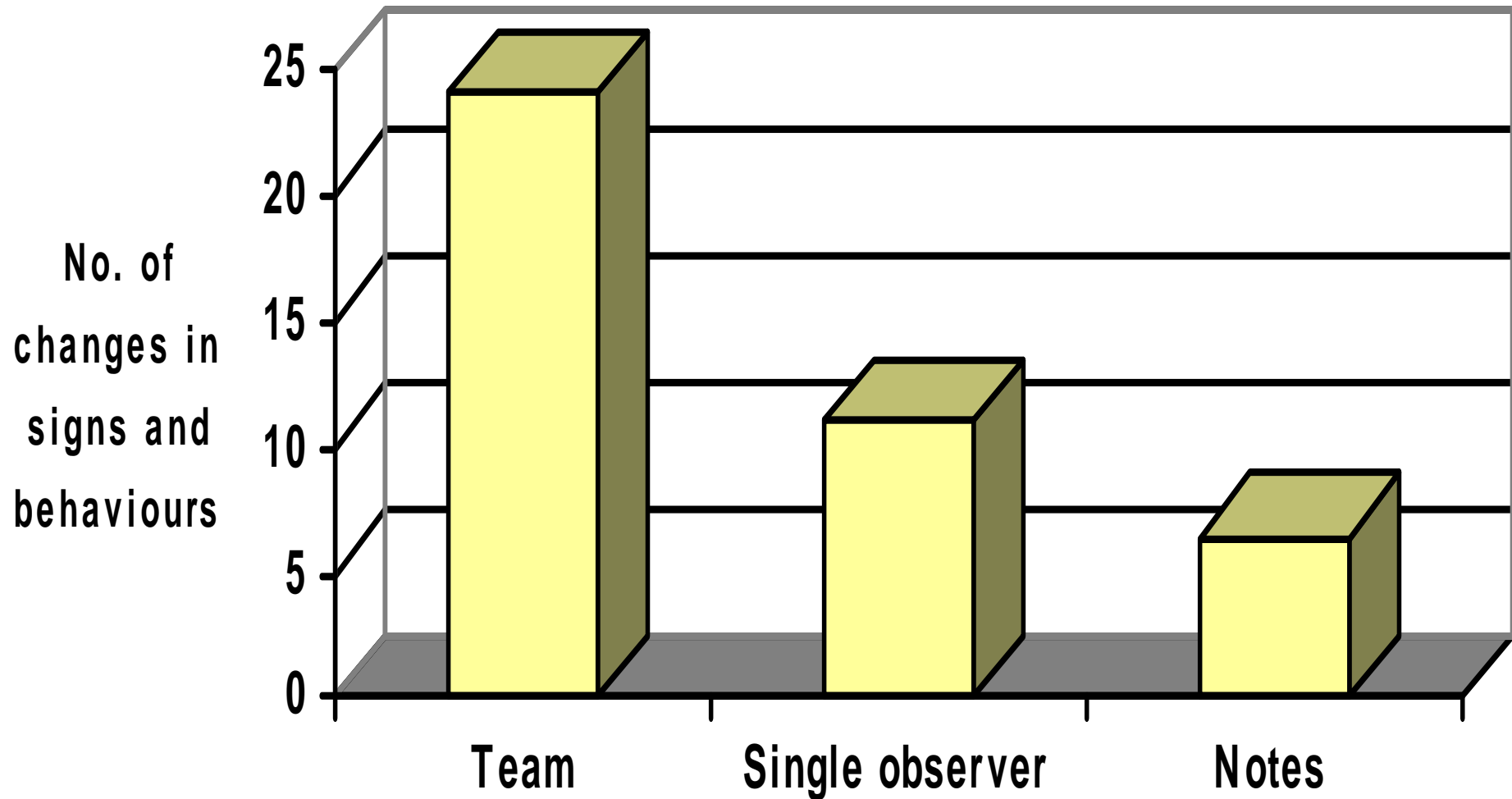
**But... some tools have been validated**  
**Possible explanations:**

- **Pain is common**  
(2/3 patients with advanced disease have pain).  
So any 'pain' tool' will be correct in over 50% of clients
- **They pick up non-pain distress,**  
which is as common as pain
- **Distress is interpreted as pain** so  
analgesia > sedation > less distress
- **Why pain tools in this client group?**  
-missing from the author lists of published pain tools are:  
SALTs, nurses, lay carers, pain / PC specialists



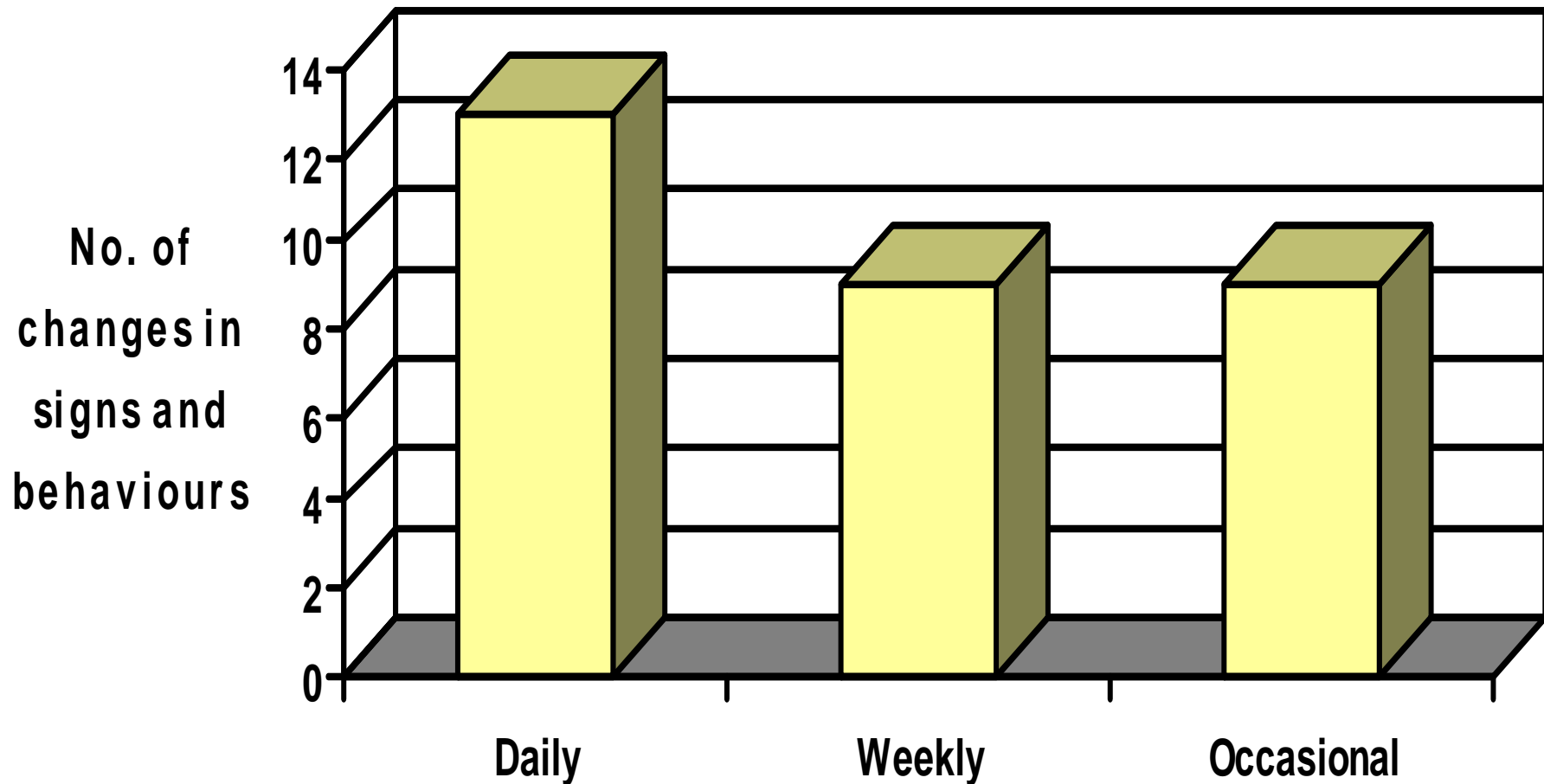
# Finding the words

## Team v single observer v notes

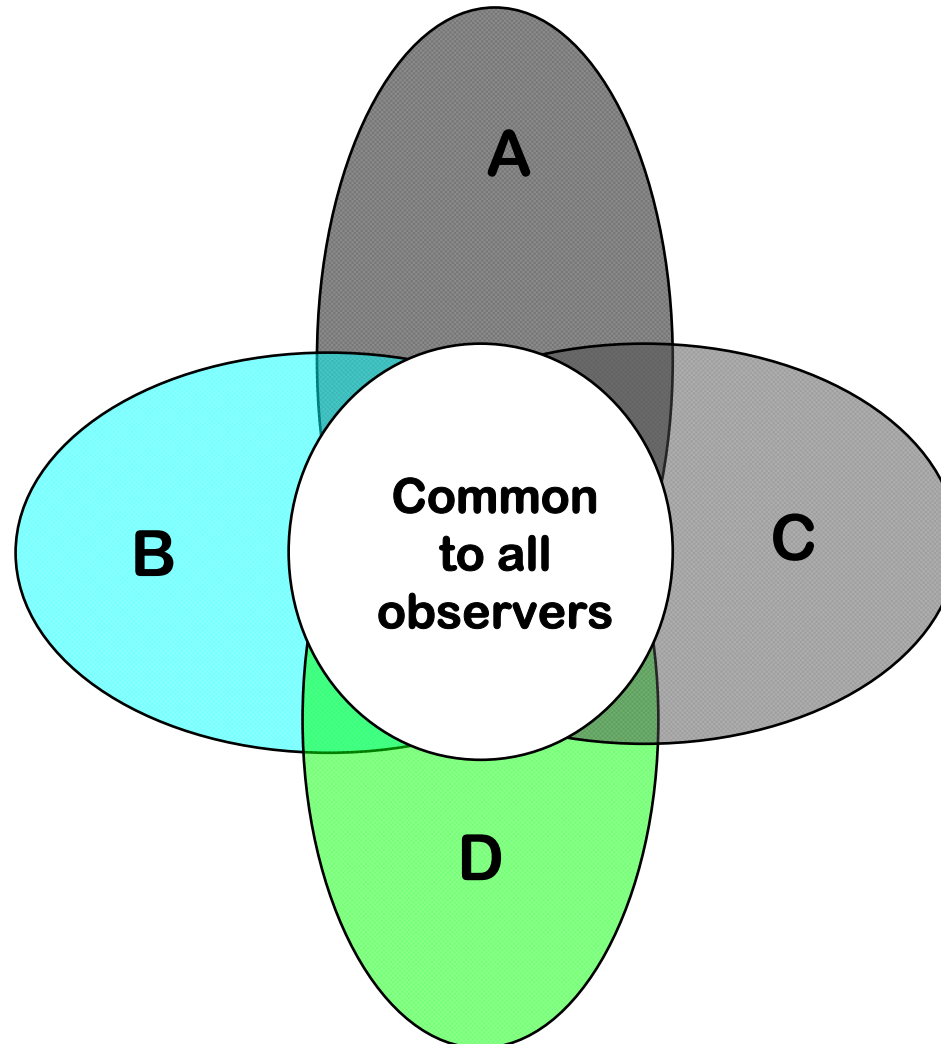


# Finding the words

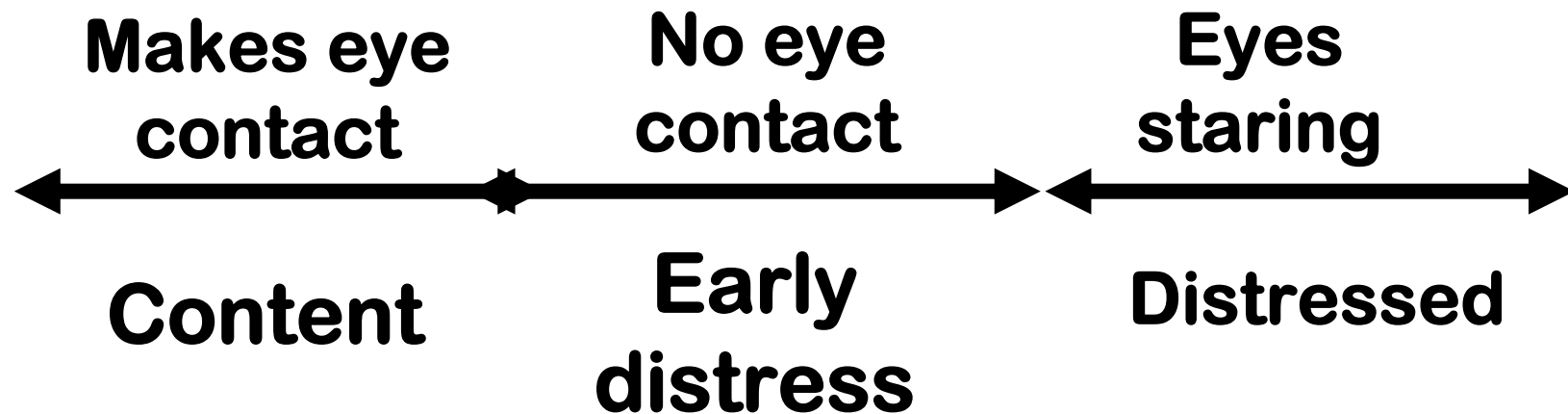
## Effect of frequency of contact



# Inter-observer variation



## Early signs & behaviours of distress



ie. the vocabulary may be even larger than  
suspected

## The vocabulary of distress

- No signs or behaviours specific to one type of distress
- Individuals use the same 'vocabulary' of signs and behaviours for different causes of distress
- Patterns of signs and behaviours seem to be unique for an individual

Regnard C, Matthews D, Gibson L, Clarke C, Watson B.  
*International Journal of Palliative Nursing*, 2003, 9(3): 173-6.

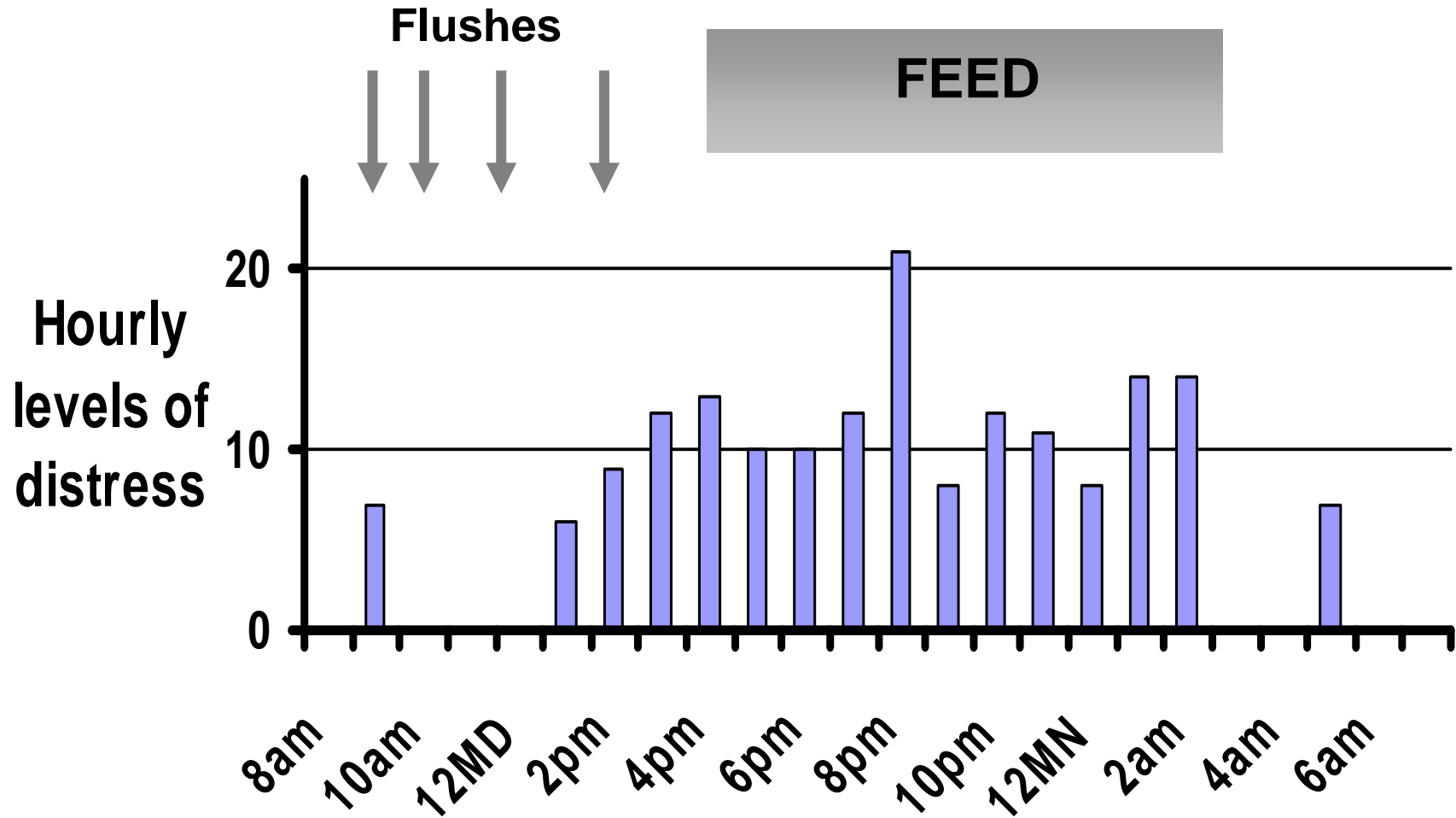
- **PAINAD** – responds to non-pain triggers  
Jordan A, current research.

# Let's look at DisDAT

also available on  
[www.disdat.co.uk](http://www.disdat.co.uk)

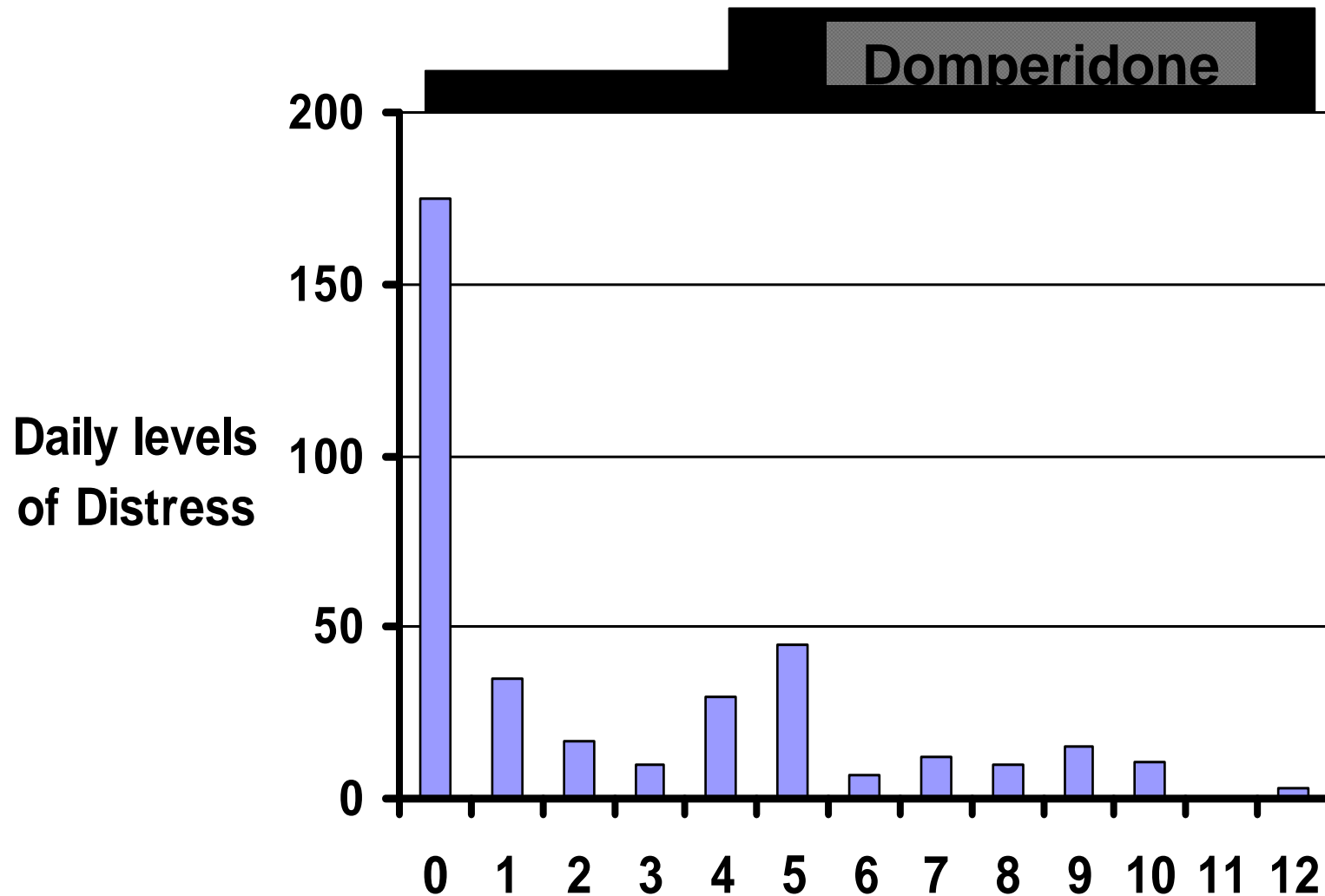
# Freddie

## A case study



# Freddie

## A case study



# Using DisDAT

- **Document signs and behaviours (content/distressed)**
- **Not a scoring tool**
- **Observe the context of distress**
- **Identify possible causes of distress (checklist)**
- **Use the monitoring sheets (optional)**
- **Treat or manage of the likeliest cause**
- **Resolved? Yes – stop**  
**No - start an intervention for the next cause**
- **The goal is a reduction the number or severity of distress signs and behaviours.**

## Summary

- **Distress shouts at us through signs and behaviours**
- **Carers have the skill to identify distress, but little confidence in those skills**
- **Carer confidence in identifying distress can be increased by documenting change**
- **There is a process to identify the cause**
- **As demonstrated today - A work in progress!**

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

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