



# Distress in dementia

## Distress and unmet needs toolkit for carers and families

### Step 1: recognise distress

#### Examples of presentation requiring further assessment



Sad  
Tearful  
Hopeless  
Irritable/Screaming  
Guilty  
Anxious/suicidal



Hallucinations  
Delusions  
Misidentification  
Suspicion



Euphoria  
Pressured  
Speech  
Irritable



Withdrawn  
Lacks interest  
Lack of  
motivation



Pacing  
Repetitive actions  
Dressing/undressing  
Restless/anxious  
Sleep  
disturbance



Physical aggression  
Verbal aggression  
Aggressive  
resistance  
to care

### Step 2: report and act

- Access medical review (via usual GP or 111) who will review the symptoms, possible causes and start investigations or treatments

**T**

**T – Toilet:** assess toileting needs frequently. Consider if there is evidence of constipation or difficulty passing urine.

**I**

**I – Infection:** soft signs of infection could include: increased breathlessness or chestiness; reduced drinking or eating; shivery fever or feeling hot or cold to touch; reduced mobility (“off legs”); increased confusion / agitation / anxiety / pain; changes to alertness / sleeping more or less; changes in urine

**M**

**M – Medication:** new or changed medication

**E**

**E – Electrolytes:** becoming dehydrated or high or low sodium or calcium levels

- If the change is sudden or severe ask for an urgent review

**A**

**A – Anxiety / Depression:** changes in mood can impact on behaviours

**N**

**N – Nutrition / Hydration:** reduced fluids and diet can cause distress

**D**

**D – Disorientation:** Changes in social circumstances or place of care can impact on distress

- If the change is gradual (ie over weeks or months) ask for a routine review

**S**

**S – Sleep:** sleep can impact on symptoms in dementia, try to minimise disturbances

**P**

**P – Pain:** consider if there is any physical or psychological pain e.g. from arthritis or muscle cramps

**A**

**A – Alcohol / Drugs:** withdrawal from these can lead to behaviour change – consider if change in food shopping or deliveries

**C**

**C – Constipation:** try to prevent and where necessary treat constipation

**E**

**E – Environment:** changes can impact on severity – try to reduce moving between settings

- Consider recent changes to circumstances (this could include one of the following from the TIME AND SPACE mnemonic

## Person centred non-drug approaches

- Review and adjust existing care plan using behaviour charts to identify triggers to distress and unmet needs. Meet the unmet need if possible, including pain, constipation, bladder symptoms etc as per the TIME AND SPACE guide.
- Support nutrition and hydration e.g. offer food and drinks little and often, including if appropriate finger foods
- Consider environmental triggers e.g. noise, temperature; ensure access to quiet areas and bedroom; ensure good signage to bedrooms and toilets
- Encourage engagement in personally meaningful activities (hobbies, interests) and social engagement (family contact, group activity, conversation)
- Use of individualised music, animal assisted therapies (e.g. therapy dogs), aromatherapy and reminiscence can benefit some people
- Promote good sleep hygiene (e.g. exercise, activity, and access to outside/daylight in the daytime; warm milky drinks, consistent night routine, avoiding caffeine at night time, try a warm bath at night)
- Ensure glasses / hearing aids are used when needed
- Review carer approach e.g. appropriate communication level, calm approach/body language
- Distraction, reassurance, or agreeing with the person can often help to de-escalate aggression rather than confronting, saying 'no' or asking lots of questions
- Consider limiting carers to those the person is most familiar and has a good relationship with

*Note sudden changes may resolve over the course of 4-6 weeks with the identification of causes and the above supportive approaches*

Medications may be used to help manage some symptoms and causes but should be used in conjunction with the above non drug approaches

## Step 3: review, reassess and escalate

### **Carer:**

Contact primary care for further review if no improvement

### **Social services:**

Contact your usual social worker to reassess as per usual contact numbers. If not currently known to social services, contact **01482 300300**

### **How to ask for help from specialist mental health services - to self-refer contact:**

**0800 138 0990** or if known to a mental health team contact as per the care plan

### **When to ask for help from specialist mental health services:**

- Moderate or severe distress
- Risk to self or others
- Risk of carer support breakdown
- Symptoms persist after consideration and treatment of **TIMEANDSPACE** and non-drug approaches