

Distress in Dementia

Resident distress and unmet needs toolkit for Primary Care and Care Homes in Hull

Step 1: Recognise distress

Examples of presentation requiring further assessment

DEPRESSION
Sad, Tearful
Hopeless
Irritable/Screaming
Guilty, Anxious
Suicidal

PSYCHOSIS
Hallucinations
Delusions
Misidentification
Suspicion

MANIA
Euphoria
Pressured
Speech
Irritable

APATHY
Withdrawn
Lacks interest
Lack of motivation

AGITATION
pacing
repetitive actions
dressing/undressing
restless/anxious
sleep disturbance

AGGRESSION
Physical aggression
Verbal aggression
Aggressive resistance
to care

Step 2: Report and Act

Is the behaviour change sudden / high risk / gradual?

Sudden change or risk to person or others:

Care home roles

(for funded and self funded residents):

- Access medical review (via usual GP or 111)
- Referral to Hull City Council Dementia care mappers via email - dementia.academy@hullcc.gov.uk
- For more information please visit -

<https://hull.connecttosupport.org/media/3bdn1nis/dementia-care-mapping-information-document.pdf>

please complete the referral form [here](#)

- Inform usual social worker of changes and to review/ reassess any additional short-term needs
- If details not known, contact **01482 300300** or see&solve@hullcc.gov.uk or socialcare@hullcc.gov.uk

- Start behaviour charts (eg ABC chart)
- Consider recent changes to circumstances (eg environment, bereavement, acute illness, medications)

Primary care (Usual GP / PCN team)

- Review diagnosis: delirium / acute delirium on top of existing dementia distress / worsening symptoms of dementia
- Review possible causes (TIMEANDSPACE) below
- Treat underlying causes

TIME AND SPACE

T - Toilet

I - Infection

M - Medication

E - Electrolytes

A - Anxiety/ Depression

N - Nutrition/ Hydration

D - Disorientation

S - Sleep

P - Pain

A - Alcohol/ Drugs

C - Constipation

E - Environment

Also consider: any acute neurological signs? Or exacerbation of chronic conditions or progression of cancer

Gradual change in behaviour:

Care home roles

(for funded and self funded residents):

- Highlight for review in weekly practice or PCN check in / MDT
- Referral to Hull City Council Dementia care mappers via email - dementia.academy@hullcc.gov.uk
- For more information please visit -

<https://hull.connecttosupport.org/media/3bdn1nis/dementia-care-mapping-information-document.pdf>

please complete the referral form [here](#)

- Inform usual social worker of potential review/ reassessment being required

If details not known, contact **01482 300300** or

see&solve@hullcc.gov.uk or socialcare@hullcc.gov.uk

- Start behaviour charts

Joint home and Primary care

(Usual GP / PCN team):

consider unmet needs, including PAIN pneumonic

P = physical / psychological pain

A = activity

I = iatrogenic (side effects of treatments)

N = noise and environment factors

Primary care:

Review diagnosis – if no diagnosis of dementia consider using **DiADEM** tool or refer to **MAS** (memory assessment services)

Treat underlying causes (**TIMEANDSPACE**)

Authors: Dr Anna Folwell, Consultant Geriatrician, CHCP and Dr Angharad Symes, Hull place Dementia Lead and GP with extended role frailty, CHCP

Contributors: Humber Teaching NHS Foundation Trust, Hull University Teaching Hospital Trust, Hull Local Authority and Hull Health and Care Partnership

Version 0.5 draft

Originally issued February 2023. Next review due February 2025

Person centred non-drug approaches – to be tried first or alongside pharmacological approaches if symptoms moderate to severe

Pharmacological approaches if symptoms moderate to severe or risk to the person or others

Care home

- 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.
- 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)
- Ensure glasses / hearing aids 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
- Ensure support is available for carers e.g. training, supervision, staff support structures
- 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

Primary care:

Consider causes and treatments as above

Refer to Mental Health Team

Consider trial of empirical pain treatments eg regular Paracetamol

The below is a guide to consider but not intended to replace prescribing guidance. For further details on monitoring and maximum doses see [Antipsychotic-Prescribing-Toolkit-for-Dementia.pdf](#) (england.nhs.uk).

Depression or apathy:

SSRI eg Sertraline

Consider **talking therapies** if able to participate

Agitation / anxiety:

1st line: SSRI eg Sertraline

2nd line: Trazadone (starting at 50mg ON) or Mirtazapine

AND ensure on Acetylcholinesterase Inhibitor or Memantine (refer to [Community Mental Health Team](#) or [ICC Frailty Team](#) if not currently prescribed)

Aggression:

Short term use with regular review and titration up or down according to response

1st line: Risperidone starting on 0.25mg od for frail, and titrate

Or Lorazepam starting on 0.5mg

Second line: refer to [Community Mental Health Team](#)

Sleep disturbance:

1st line: Zopiclone (starting at 3.75mg ON)

2nd line: Mirtazapine or Trazadone (starting at 50mg ON)

Psychosis:

Risperidone starting on 0.25mg for frail, 0.5mg for non frail, and titrate

Second line: refer to [Community Mental Health Team](#)

Parkinson's disease and Lewy Body Dementia:

As per above symptoms, or if antipsychotic required consider discussion with specialist PD team and in short term Quetiapine 12.5mg ON if frail, 25mg ON if nonfrail

Risperidone and Haloperidol should NOT be used in PD / LBD. Consider Lorazepam as alternative

Step 3: Review, reassess and escalate

If there is resolution consider continuance or titration of medications

Care home:

Contact primary care for further review, including discussion in PCN check in / MDT

If advice needed call frailty advice line on 01482 450078 (Monday - Friday 8-6pm)

Primary care:

reassess for other contributing causes, titration of treatments

If advice needed call frailty advice line **01482 450078**

Social services:

Contact your usual social worker to reassess as per usual policies and consider CHC/S117

If details not known, contact **01482 300300** or

see&solve@hullcc.gov.uk or socialcare@hullcc.gov.uk

When to ask for help from specialist mental health services:

- Moderate or severe distress
- Risk to resident or others
- Risk of placement breaking down
- Symptoms persist after consideration of TIMEANDSPACE, non drug approaches and first or second line medication
- Antipsychotics are being considered or commenced
- Resident known to Mental Health Team

How to ask for help from specialist mental health services:

Primary care:

Routine triage slot via the choose and book system with up to date referral form

Primary care:

Urgent referral call **01482 205520**

Care home:

Call **0800 138 0990**

When to refer to ICC Frailty Team for a holistic (comprehensive geriatric assessment) MDT review chcp.jeanbishopicreferrals@nhs.net

- New permanent resident
- Behavioural issues requiring MDT approach, including those being referred for 1:1 care within the home
- Multiple falls despite falls team intervention
- 3 or more ED attends or admissions in past 3 months
- Complex feeding issues or support for decision making
- Second opinion for complex advanced care planning or for diagnostic uncertainty