



**South East**  
Clinical Delivery and Networks

# Dementia and Older People's Mental Health

Guidance for Primary Care Networks and Care Homes

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# Introduction

## Background

- [Enhanced Health in Care Homes \(EHCH\)](#) is a proactive, integrated model of care which supports people who live in care homes. See [EHCH: A guide for care homes](#).
- Requirements for the delivery of EHCH by Primary Care Networks (PCNs) were included in the [Network Contract Directed Enhanced Service \(DES\) for 2020/21](#), and are now being delivered across the country. Corresponding requirements for providers of community services were included in the NHS Standard Contract.
- Through this service, every care home is now supported by a multidisciplinary team (MDT) in their aligned PCN.
- The MDT approach helps to support individuals with dementia and mental health conditions to access the right care when they need it. It improves care by taking a holistic view of mental and physical health and enables input from team members from multiple disciplines and service providers.
- It is crucial for all members of the MDT to understand dementia and mental health conditions due to the prevalence of both disorders in care home populations.

## Who is this guidance for?

Members of staff working in care homes and primary care, including [PCN care home clinical leads](#).



**Depression** is the most common mental health problem in older people, affecting up to **40%** of older individuals in a care home setting<sup>1</sup>

The average prevalence of people living with **dementia** in care homes is **69%**<sup>2</sup>



<sup>1</sup> <https://doi.org/10.1093/ageing/afu062>

<sup>2</sup> <https://www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-uk-report>

## Primary Care Network Multidisciplinary Teams



Primary Care Networks (PCNs) build on the core of current primary care services and enable greater provision of proactive, personalised, coordinated and more integrated local health and social care.

The NHS Long Term Plan makes a commitment to the expansion of community multidisciplinary teams (MDTs) aligned with PCNs. Through the Enhanced Health in Care Homes (EHCH) framework, every care home is now supported by an MDT in their aligned PCN.

Each PCN has a lead clinician for the care home(s) aligned to the network. The lead provides clinical leadership to staff delivering services in multidisciplinary care home teams and supports continuous improvement of the EHCH service.

MDTs are groups of professionals in the local health and social care system from a range of clinical and professional disciplines who together make shared decisions regarding recommended treatment of individual residents.

The teams comprise a range of staff such as care home workers, care home managers, doctors, practice nurses, care home nurses, clinical pharmacists, district nurses, dentists, geriatricians, psychiatrists, palliative care team, dementia workers/ advisors, physiotherapists, occupational therapists, dieticians, podiatrists/ chiropodists, social care practitioners and voluntary sector workers. MDTs also often include link workers or care navigators, who can support social prescribing by connecting individuals with local groups and community support services.

Care home workers know their residents extremely well, and this knowledge is fundamental to good, personalised care and support planning. As such, care home staff should be key members of your MDT.

## **Why are PCN MDTs important in supporting older people including those living with dementia?**

- Good quality care and support for older people, including those living with dementia, draws on the whole of the health, social, community and voluntary sectors.
- PCN MDT's can comprise a range of staff across health, social, community and voluntary sectors who help to:
  - build capacity across the system and increase resident access to services; and
  - deliver high quality care to residents, through drawing on the right expertise and ensuring they see the right professionals at the right time.
- The MDT supports the delivery of the EHCH service, which includes:
  - weekly 'home rounds' for every care home;
  - delivery of comprehensive assessments and development of personalised care and support plans for residents; and
  - provision of care to support delivery of those plans.
- MDT meetings are held to support the admission, assessment and ongoing case management of care home residents.

### **Example MDT meeting**

A lead clinician from the PCN aligned to the care home will usually lead and support discussion of residents and assist in diagnosis. The clinical pharmacist will ensure medicines optimisation and allied health care practitioners (e.g. occupational therapists, dieticians and mental health practitioners) will provide support in their area of expertise to diagnose and address any problems.

Care home staff will provide crucial insight through their knowledge of the residents and can advise on the likelihood of the implementation and success of recommended interventions. Social care workers will establish and assess any barriers to providing effective care, such as issues regarding safeguarding. In addition, the resident and their family/ carers will also participate.

## What can you do?

### To support MDT working

- Ensure you know who the key members of the MDT are and keep them informed of relevant changes within the care home. The table in Appendix B can be completed with contact details for MDT members.
- Agree how issues and urgent matters should be communicated effectively with the MDT.
- Develop an action plan using resources such as the '[We Check Dementia Care](#)' toolkit to support delivery of dementia care and engage appropriate MDT members in implementation.
- Ensure up-to-date and accurate information is available (including through shared IT portals) about residents to help with identification of their health needs generally and during review. This should include personalised care and support plans, advance care plans and palliative care reviews, information on behaviour, medication reviews, weight and nutrition, pain assessments and discharge letters and documentation. This information should be easily accessible in hours and out of hours and to paramedics, out of hours services and hospital staff.
- Identify and proactively share relevant information useful to inform clinician's visits. Ascertain any issues of individual residents in advance of the visit. Consider factors such as pain, sleep, mood, behaviour, swallowing reflex and nutrition. Raise discussion of medication timing and review medication risks and benefits, including refusal to take and the use of any medication to manage behavioural and psychological symptoms of dementia.
- When residents are admitted to hospital, ensure communication of transfer letters, personalised care and support plans, advance care plans, information on behaviour (e.g. triggers), communication and dietary needs, up-to-date medication information with any timing of dosages required (including when the last dose was given), any body maps of transdermal patches, contact details of residents' GP and other relevant items such as a [red bag](#) and 'This is me' form.
- When residents are discharged from hospital, nursing transfer letters should be made available in addition to discharge summaries. Appropriate supplies of medication should be provided in line with local protocols to ensure timely access to all medicines and a system should

be in place to prevent inadvertent restarting of discontinued medication. Any resident documentation and items shared with the hospital on transfer should also be returned. If any information is missing or unclear, this should be followed up with the hospital.

### In MDT meetings

- Identify which residents will be the focus of the meeting and in advance of the meeting, discuss with care home colleagues the key issues for each resident and prioritise them.
- Ensure that there is access to residents' care plans, outcomes from recent reviews, medication charts, test results and observations, upcoming appointment dates and any other relevant information such as discharge letters and documentation.
- Ensure the views and preferences of the resident are part of the discussion (as well as concerns of their family where appropriate). If the resident lacks capacity to make a decision around care and/ or treatment, a best interests decision needs to be made. See section on [best interests decisions](#) for more information.
- Provide insight on the likelihood of a recommended intervention succeeding where possible and advise on how realistic it is to implement.
- Ensure that actions agreed at the meeting are communicated to appropriate members of the care home team, the resident concerned and their family where appropriate, and implemented.

### **Links to guidance and further information**

[Royal College of GPs Multidisciplinary Team Working Toolkit](#)

[South East Clinical Network 'We Check Dementia Care' Toolkit](#)

[Multidisciplinary Team Working in a General Practice Setting: The practicalities of making it work](#)

[PrescQIPP: Care homes - Improving the effectiveness of multidisciplinary working](#)



# Structured Medication Reviews



The NHS Long Term Plan contained a commitment as part of the Ageing Well Programme to roll out the Enhanced Health in Care Homes (EHCH) model of care across England by 2024, commencing in 2020. Requirements for the delivery of EHCH by Primary Care Networks (PCNs) are included in the Network Contract Directed Enhanced Service DES for 2020/21. **This includes pharmacy supported provision of Structured Medication Reviews (SMRs) and Medicines Optimisation within multidisciplinary teams (MDTs) for care homes.**

A [Structured Medication Review](#) is a NICE approved clinical intervention designed to holistically review a person's medicines, undertaken by experts including clinical pharmacists, doctors or nurses with the resident (and family where appropriate) in the context of their clinical condition. PCNs are contractually obliged to undertake SMRs for residents in care homes.

The aim of an SMR is to improve the quality, safety and appropriate use of medicines, with the objective of optimising the impact of the medication being taken, minimising the number of medication related problems and preventing or reducing medication waste.

Conducting an SMR is a key part of the MDT approach to care. As a minimum, SMRs should be undertaken at least annually. In alignment with NICE guidance<sup>3</sup>, the frequency of these reviews should be determined by the health and care needs of the resident and recorded in personalised care and support plans.

SMRs are important, particularly for residents with dementia, and should focus on reducing polypharmacy and optimising all medicines including antipsychotic medication. SMRs should also consider nutrition related products such as oral nutritional supplements and fluid thickeners. It is important that these are undertaken regularly by the MDT working with the care home.

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<sup>3</sup> NICE Guideline 5: <https://www.nice.org.uk/guidance/ng5>

## Why are Structured Medication Reviews (SMRs) important?

- Medicines are prescribed to treat symptoms and diseases. The length of treatment can vary with different medication and can be short or long term. **It is good practice to regularly review medicines being taken to ensure that they are treating the condition properly** and that the dose is still correct, and that it is not causing any problematic side effects.

### SMRs provide opportunities for:

- The resident (and family where appropriate) to raise questions or highlight problems regarding their medication with an informed healthcare professional;
- Shared decision making ensuring that the clinician's experience and expertise, the clinical evidence and the resident's wishes and values are reflected in any decision to start or stop medicines;
- Considering changes in lifestyle and non-medicinal interventions that could be made to circumvent the use of medication e.g. weight loss to control hypertension or behavioural support to reduce or stop psychotropic medicines;
- Considering malnutrition and changes in body weight when considering medication doses; and
- Identification of unmet needs or new conditions that need treating, such as those that can increase in prevalence with age e.g. atrial fibrillation, heart failure and dementia.

## Polypharmacy

Older people, including those living with dementia, often have multiple conditions and require several medications to treat them. With this increased risk of polypharmacy there is an increased risk of adverse effects and potential for harm. For care home residents taking multiple medicines and those with a regular prescription for certain medicines (e.g. antidepressants or benzodiazepines), there is an increased risk of falling. These medications should be used only when absolutely necessary and discontinued as soon as possible. **Multiple drug-taking should be reviewed regularly and kept to a minimum<sup>4</sup>.**

## Anticholinergic medication

Medications with anticholinergic (Ach) properties are often used for the older population to treat conditions including urinary and gastrointestinal disorders,

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<sup>4</sup> <https://evidence.nihr.ac.uk/alert/care-home-residents-risk-falling-multiple-medications>

insomnia, respiratory disorders and dizziness. However, in cases where multiple medications are required, this can cause significant adverse effects including confusion, delirium and falls. The use of such medication should be avoided where possible, kept to a minimum, and taken for as short a duration as possible. **Regular SMRs are essential to assess the risks and benefits of anticholinergic medicines and reduce the use of anticholinergic medication where clinically appropriate and in partnership with the resident.**

### **Antipsychotic medication**

Antipsychotic medication can be used to help people manage severe symptoms of conditions such as psychosis and schizophrenia. Many people living with dementia experience behavioural and psychological symptoms of dementia which can include a variety of psychotic and behavioural symptoms such as hallucinations, delusions, aggression and agitation. However, for people living with dementia, antipsychotic medication can have serious adverse effects including an increased risk of stroke and mortality if taken for long periods of time (months rather than weeks). Quite often, antipsychotic medication is no longer necessary and can be carefully stopped.

NICE recommends that antipsychotic medication should only be used at as low a dose and for as short a time as possible, to help the resident if they are at 'risk of harming themselves or others, or if they are severely distressed', in tandem with exploring and implementing non-pharmacological methods of support. Furthermore, the use of **antipsychotic medication should be reviewed with the resident at least every six weeks and should be discontinued if it is not achieving the intended outcome, is causing unacceptable adverse effects or is no longer needed**<sup>5</sup>.

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<sup>5</sup> <https://www.nice.org.uk/guidance/ng97/resources/antipsychotic-medicines-for-treating-agitation-aggression-and-distress-in-people-living-with-dementia-patient-decision-aid-pdf-4852697005>

## What can you do?

In line with SMR [guidance](#) and NICE [recommendations](#), you can support the SMR by:

- Assisting with identification of residents who might need a more frequent review of their medicines and highlighting this to the GP, such as those:
  - entering the end-of-life phase;
  - with a recent diagnosis of a long-term condition;
  - needing frequent or complex monitoring;
  - who have been transferred to the care home, e.g. new resident or after hospital discharge<sup>6</sup>;
  - experiencing side effects potentially attributable to medicines, e.g. falls.
- Ensuring that SMRs involve the resident (and family where appropriate), and the appropriate MDT members working with the care home. Take a personalised approach, e.g. understanding the resident's wishes about current and new treatments. If the resident lacks capacity to make a decision around care and/ or treatment, a best interests decision needs to be made. See section on [best interests decisions](#) for more information.
- Confirming and communicating the purpose of the SMR with MDT members involved in the review.
- Ensuring that any changes to medication are recorded in the review. Record the date of the next SMR in the resident's care plan and note any support that the resident might need in taking any new medication.
- Ensuring that the resident's (and family where appropriate) views, concerns, questions or problems regarding the medication they are taking, are communicated during the review.
- Providing information on the monitoring of the effect of any medication on the resident, and whether there have been any side effects or reactions.
- Advising whether the resident can self-manage their medications, requires assistance or needs additional support, for example help to address swallowing difficulties or help to use an inhaler.

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<sup>6</sup> <https://www.nice.org.uk/guidance/sc1/resources/checklist-for-care-home-medicines-policy-pdf-13716829>

- Ensuring availability of information for the review including:
  - The resident's details, including their GP and other contacts defined by the resident and family (e.g. regular community pharmacist);
  - Known allergies and reactions to medicines or ingredients, and the type of reaction experienced;
  - All medication prescribed for the resident (name, strength, dose, form, timing, frequency and details of missed or omitted doses), the purpose of each medicine and how it is taken, and the resident's understanding of it;
  - Changes to medicines, including medicines started, stopped or dosage changed, and reason for change;
  - Date, time and target symptom of the most recent dose of any 'when required' medicine, or any medicine given less often than once a day (weekly or monthly medicines);
  - What information has been given to the resident and family members<sup>7</sup>;
  - Information on diet, fluid intake, urine output and stool consistency which can help clinicians make recommendations about some medicines (e.g. laxatives).
- **Ask for input from your MDT:** see Appendix B for contact details of your MDT members.

## Links to guidance and further information

[NICE: Reviewing Medicines](#)

[NICE: Implementing NICE guideline on managing medicines in care homes](#) - includes checklist for medication review

[NHS Confederation: Pharmacy's role in primary care network multidisciplinary teams supporting care homes](#) – best practice, top tips and resources

[Structured medication reviews and medicines optimisation: guidance](#)

[Polypharmacy: Getting it right for people prescribed many medicines](#)

[Polypharmacy Guidance Realistic Prescribing 2018](#)

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<sup>7</sup> <https://www.nice.org.uk/guidance/qs85/chapter/quality-statement-2-sharing-information>

# Recognition of Dementia



Dementia is not a disease itself. It is a collection of symptoms that result from damage to the brain caused by different diseases, such as Alzheimer's. These symptoms vary according to the part of the brain that is damaged. It is a progressive condition and can affect memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. Impairment in cognitive function can be accompanied, or preceded, by deterioration in emotional control, social behaviour, or motivation.

## Why is it important to get a diagnosis of dementia?

On average, 69% of care home residents are living with dementia<sup>8</sup>. People living in care homes tend to have more severe dementia than those living in the community.

Recognition that a resident has dementia is important because it helps to:

- enable the resident to access the right care and support, resources and information;
- explain changes in their behaviour to carers, family and friends: knowledge of the condition helps them to respond supportively;
- plan for future care needs to reduce any chance of reaching a crisis as the condition advances.

## What are some of the possible signs of dementia?

- Memory loss, such as remembering past events much more easily than recent ones;
- Loss of previously familiar skills, such as reading, writing or dressing;
- Problems thinking or reasoning, or finding it hard to follow conversations or tv programmes;
- Feeling anxious, depressed or angry about memory loss, or feeling confused, even when in a familiar environment;
- Change in social behaviour, such as emotional lability, irritability, apathy and coarsening of social behaviour;
- Unplanned weight loss and malnutrition, which can be one of the first signs of dementia.

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<sup>8</sup> <https://www.alzheimers.org.uk/about-us/policy-and-influencing/dementia-uk-report>

## What can you do if you think that a resident may have dementia?

- Ask other members of the team and family members if they have noticed any changes, as they may have noticed some that you have not. If this is a sudden change it may be due to delirium, so it is important to discuss with a clinician.
- Be aware of local patterns of dementia diagnosis rate and antipsychotics prescribing in dementia rates using the [NHS Digital dementia dashboard](#).
- **Ask for input from your MDT:** see Appendix B for contact details of your MDT members.

### Links to guidance and further information

The [New care models: Enhanced Health in Care Homes: Vanguard learning guide](#) provides support for implementation of high quality dementia care including resources for identification such as [DiADeM](#) (Diagnosis of Advanced Dementia Mandate in care homes), [DeAR-GP User Guide](#) and [Dementia Assessment Referral to GP Form](#)

[Alzheimer's Society support resources](#)

[Personalised care and support planning: resources for health and care staff](#)

[Dementia Support UK](#) offer a free Connect Consult service with dementia support consultants who provide advice and recommendations for caring for someone with dementia. They also have a range of online support resources.

[We Check Dementia Care and Know How Toolkit](#): developed to support care home managers and their staff to improve the identification of those with dementia, and enable quality dementia care to be provided to their residents.

# Delirium



Delirium is an acute transient confusional state that can happen when someone is ill, and in itself is not a mental health disorder. It is a **sudden** change over a few hours or days and tends to vary at different times of day. Delirium can also manifest with three different levels of consciousness: hyperactive, hypoactive, or mixed. People with dementia are more prone to becoming delirious.

## Why is it important to diagnose delirium?

- Delirium can be very distressing for the individual, other residents, relatives and members of staff;
- Delirium is life-threatening: people with delirium have high mortality and may be at increased risk of falls and other harm;
- People with prolonged delirium are more likely to develop dementia;
- Delirium can speed up decline in dementia.

## What are some possible signs of delirium?

The resident may:

- Become restless, agitated or aggressive;
- Be withdrawn, quiet or more sleepy;
- Be less aware of what is going on around them or where they are;
- Struggle to think clearly;
- Find it hard to concentrate, for example, keeping track of a conversation;
- Hear or see things that aren't there;
- Have vivid dreams;
- Be more confused at certain times of day, especially evenings and night-time;
- Feel an urge to wander around;
- Suddenly not be able to control their bladder or bowel movements.

If someone has dementia, the symptoms of delirium can sometimes be mistaken for the dementia getting worse, but it is important to recognise and treat delirium in its own right.



## To support someone with delirium:

- Keep calm and speak in short, easy to understand sentences;
- Remind them where they are and why they are there;
- Reassure, don't argue or disagree;
- Remind them of the date and time and make sure they can see a clock and calendar if possible;
- Make sure they have their usual glasses and hearing aids and use them;
- Encourage them to eat and drink - bring them food and drinks they like if this helps;
- Ensure they have some familiar photos or objects around them;
- Limit the number of visitors and reduce noise as much as possible - stimulating the resident too much can make things worse.



## What can you do if you think that a resident may have delirium?

- Delirium can be prevented by targeting the potential causes (see the PINCH ME diagram above). For example, avoiding unnecessary urinary catheterisation to reduce risk of infection; avoiding constipation and encouraging fluid intake and a nutrient dense diet. Any drugs that may be contributing to delirium should be reviewed. Ward and bed moves should be avoided wherever possible.
- If you suspect a resident has delirium, inform a doctor in order to treat any underlying cause, such as infection.
- **Ask for input from your multidisciplinary team (MDT):** see Appendix B for contact details of your MDT members.

## **Links to guidance and further information**

[THINK DELIRIUM materials](#)

[Delirium Awareness Video](#)

[Delirium dramas – video resources](#)

[Raising Awareness of Delirium E-Learning](#)

[Greater Manchester Community Delirium Toolkit](#)

[Recognising and preventing delirium: A quick guide for care home managers](#)

# Anxiety and Depression



Anxiety is something we all feel at times but when these feelings are constant, overwhelming or out of proportion to the situation, it can interfere with our everyday lives and relationships. This is also true for our residents. We may see changes in their physical feelings, emotions and behaviours.

Signs of anxiety include:

- Feeling tired, on edge, restless or irritable;
- Feeling a sense of dread;
- Being unable to concentrate or make decisions;
- Trouble sleeping including difficulty falling or staying asleep;
- Physical symptoms such as a racing heart, headaches, feeling sick, dizzy, sweaty, shaky, trembly, short of breath, pins and needles and having a dry mouth;
- Avoiding situations or putting off doing things;
- Repeatedly checking things or seeking assurance from others.

Anxiety disorders are very common in older people, most often coupled with a life-long history of anxiety which the factors associated with ageing may not have helped.

However, it is uncommon to see a new presentation with anxiety as the primary diagnosis. Anxiety can be a presenting feature of dementia, depression, and physical illness, and should always prompt investigations to exclude any underlying medical cause (especially new onset anxiety).

## What can you do if you think that a resident may have an anxiety disorder?

- Support the resident to identify what they are feeling anxious or worried about.
- Setting specific 'worry time' each day for the resident to go through their concerns can help them to focus on other things outside of this.
- Support the resident to problem solve, identifying solutions that may make the challenges they are facing more manageable.

- Some people find relaxation, mindfulness or meditation as they reduce tension and focus awareness on the present moment.
- It's easy to avoid situations, or rely on habits that make us feel safer, but these can keep anxiety going. By slowly building up time in worrying situations, anxious feelings will gradually reduce and the resident will see these situations are OK.

Depression is experienced by many people – some may have a single bout and recover well, others may have recurring periods of depression throughout their lives. It is the most common mental health disorder in older people<sup>9</sup> and, as such, may impact on residents directly. As with anxiety, we may see changes in physical feelings, emotions and behaviours.

Signs of depression include:

- Sadness, hopelessness, restlessness, guilt, despair;
- Numbness, losing interest or enjoyment in things;
- Loneliness – even if you are in company;
- Anger and irritability, often without provocation;
- Loss of confidence, thinking you hate yourself;
- Expecting the worst and having negative or gloomy thoughts;
- Poor memory or concentration;
- Difficulty in making decisions;
- Thoughts of suicide;
- Tiredness and lack of energy;
- Sleep problems;
- Feeling worse at a particular time of day, usually mornings;
- Changes in weight, appetite and eating;
- Disinterest in everyday tasks or not doing things you used to enjoy;
- Putting things off;
- Constant worrying;
- Cutting yourself off from others;
- Crying a lot or being unable to cry when a truly sad event occurs.

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<sup>9</sup> <https://www.england.nhs.uk/wp-content/uploads/2017/09/practice-primer.pdf>

It is important to remember that symptoms in older people can be distinctly different to depression in younger adults, and it is often missed. Certain symptoms of depression are more common in older adults and might be the only presenting features such as:

- Reporting physical rather than emotional symptoms (somatisation); Typical symptoms are faintness or dizziness, pain, weakness all over, heavy limbs, lump in throat, constipation;
- Health anxieties (hypochondriasis), especially if unusual for the resident;
- Prominent anxiety;
- Unusual behaviour;
- Slowing down of emotional reactions or agitation;
- Psychotic features: delusions of guilt, poverty or physical illness, or having no clothes which fit. Auditory hallucinations with derogatory or obscene content, provoking guilt and paranoia.

The risk factors for depression in older people include physical health problems, female gender, loneliness, life events (particularly bereavement) and loss of independence.

It is not always possible for a resident affected by anxiety or depression to recognise these symptoms in themselves. This can be even more challenging for someone who has dementia, who might find it hard to communicate clearly, so it is important for those caring for the resident to make a note of changes in their usual behaviour. Some physical illnesses can cause depression, so it is also important to rule out possible physical causes or side effects from any medication.

### **Why is it important to spot anxiety and depression as soon as possible?**

- Identifying anxiety and depression will help the individual to access appropriate support and treatment in a timely manner, improving all aspects of their life;
- Untreated, these conditions can become more severe, resulting in further distress or deterioration in both physical and mental health.

## What can you do if you think that a resident may be depressed?

- Support the resident to identify what they are feeling depressed about, talking to others can help when we are struggling.
- Support the resident to engage in important or enjoyable activities. They may find it helpful to list these and do some each day. It's important that they start with easier ones and, as they progress, their mood should improve.
- Encourage residents to break tasks down into manageable chunks and give themselves credit for the completion of each one.
- Encourage the resident to be more active, get better sleep and eat a balanced diet. All of these can help boost their mood and improve wellbeing.
- Consider talking therapies such as counselling or cognitive behavioural therapy.
- Be aware that changes in behaviour can be caused by triggered memories of previous trauma. With your MDT, ensure that all members of staff are aware of any residents' triggers so that they can be prevented.
- If a resident has an episode of self-harm inform your MDT immediately. All self-harm must be taken seriously. The resident should have a psychosocial assessment of need as well as assessment of their current risk of repetition or suicide.
- If a resident is distressed, always check their suicidal risk. Any resident who says they want to kill themselves must be taken seriously.
- Consider speaking to a doctor about medication to lift their mood and motivation, which might help them to engage in activities and begin other types of psychological therapies such as counselling. Make sure that you have plans in place to review the outcome of any new medication to treat depression or anxiety to prevent the inappropriate long-term use of these treatments.
- **Ask for input from your MDT:** see Appendix B for contact details of your MDT members.

## **Links to guidance and further information**

[British Geriatrics Society report: Depression among older people living in care homes](#)

[SCIE Promoting positive mental wellbeing for older people](#)

[NICE Quality Standard: Mental wellbeing of older people in care homes](#)

[A Practice Primer on Mental Health in Older People](#)

[NHS Every Mind Matters](#)

# Psychosis



People presenting with [psychosis](#) can suffer from a long-standing psychotic illnesses (chronic schizophrenia, schizoaffective disorder, delusional disorder), a mood disorder (particularly common is psychotic depression; bipolar affective disorder), early dementia, or a primary psychotic illness such as late-onset schizophrenia.

As in all psychiatric disorders, physical causes (especially delirium) and medication side effects need to be ruled out in older adults presenting with psychotic symptoms

## **Why is it important to diagnose psychosis?**

- It is important to ensure psychotic symptoms are addressed as early as possible;
- Physical causes (especially delirium) and medication side effects can cause older adults to present with psychotic symptoms which can be very distressing;
- Psychotic symptoms can lead to aggressive and disruptive behaviour. Persistent symptoms decrease quality of life and can lead to hospital admission.

## **Why is it important to support someone experiencing symptoms of psychosis using a personalised, non-pharmacological approach?**

- Use of medication could mask an organic cause (such as physical illness, medication side effects, dementia or delirium); a sensory deficit (missing hearing aid or glasses) or social isolation;
- Psychological approaches such as cognitive behavioural therapy or counselling can alleviate distress;
- Older people with persistent psychotic symptoms should be assessed by specialist mental health services;
- Pharmacological treatments should be reserved for people who are significantly distressed, and their functions are significantly affected. Antipsychotic medication should be used with extreme care, in the short-term and with regular review and consultation.



## What are the some of the possible signs that someone may be experiencing psychosis?

- The most common symptom is persecutory delusions (things that the resident believes despite reassurance and evidence to the contrary) and auditory hallucinations;
- People may also experience visual, tactile or olfactory hallucinations. These symptoms can be very distressing and may impact on their behaviour especially if they are frightened.

## What can you do if you think that a resident has symptoms of psychosis?

- Ask your colleagues if they too have noticed these symptoms and for how long.
- Psychosis in older adults can be associated with pain, polypharmacy, sleep disturbances, appetite disturbances and depression. A thorough and broad evaluation of possible underlying causes should be made before making treatment decisions. See the section on [Managing Distress and 'Behaviours that Challenge'](#) for information about non-pharmacological approaches to reducing distress.
- Listen and try to understand. It can help if the resident feels able to discuss their feelings and options with someone supportive and calm. Listen to their experiences and ask them what would help.
- Focus on feelings rather than experiences. If the resident sees, hears or believes something that you don't, instead of confirming or denying their experience it's usually more helpful to focus on how the person is feeling about what they are experiencing.
- **Ask for input from your MDT:** see Appendix B for contact details of your MDT members.

### Links to guidance and further information

[Rethink: psychosis information](#)

[Mind: psychosis information](#)

## Walking with Purpose



Walking with purpose is when a resident walks restlessly in their surroundings and seems unable or unwilling to stay still. This has previously been referred to as ‘wandering’ and it might not be clear why the resident is walking about. However, this suggests the walking is aimless whereas the walking often has a purpose and it could be a sign that the resident walking has an unmet need.

### **Why is it important to support someone who walks with purpose using personalised non-pharmacological methods?**

Use of medication:

- May place the resident at an increased risk of falls as they are still likely to continue to want to walk;
- Could cause a change in cognition, as well as the resident’s disposition, and impact their ability to participate in aspects of daily living; and
- Could lead to a negative change in behaviour such as aggression.

Reasons for walking with purpose could include that the resident simply enjoys walking or feels in need of exercise, or it might be that they are trying to cope with troubling emotions or physical pain, or they could be reliving an old routine.

There are several alternative ways to support someone walking with purpose without using medication. Suggestions are set out in ‘What can you do?’ below.

### **What are some of the possible signs that someone is walking with purpose?**

The resident may appear to be:

- Restless, unable to be still;
- Searching or looking for something;
- Anxious;
- Lost or curious, especially in an unfamiliar environment;
- In some discomfort or pain.

## What can you do if you think that a resident is walking with purpose?

- Be attentive, the resident will usually indicate either verbally or non-verbally, whether there is something that they need. Once their needs are understood they can be addressed to help manage walking with purpose behaviour and improve the resident's wellbeing.
- Walking with the resident can be a great way to interact with them and talk about the environment and what they can see, hear and smell, and can be a good way to reminisce with them about past memories.
- Ensure a daily routine is in place. Having a daily routine may help to identify if there are any common triggers, for example, if they are starting to feel hungry at lunchtime.
- Acknowledge that the increase in activity will increase the resident's nutritional requirements. Residents may not stay at a mealtime long enough to eat their meal or drink. Residents may also not be hungry but should be encouraged to eat and drink. It can help to provide finger foods and leave suitable foods around the home (with food safety considerations) that residents can access and recognise.
- Try to identify and record patterns or times of the day when and how often the resident is walking, and any reasons they give for why they are walking about. This might help you to identify and address any unmet needs early on and prevent any escalation in walking behaviour. It could also help you to predict when the resident is likely to walk and plan for activities to distract them with something they enjoy.
- Do not try to physically stop the resident from walking as this can cause distress. Instead, refer to their personalised care plan or '[this is me](#)' information (which might help you to understand the resident's unmet need or what might be causing them to walk with purpose) and try to distract them with an activity they might enjoy.
- Help to provide a safe and secure environment through ensuring it is clutter-free to reduce risk of falls and supporting the creation of secure areas where the resident can walk freely (wherever possible).

- Consider if the reason for the walking behaviour is due to:
  - **pain** – look at how this can be addressed. Can you help or does this need to be escalated? Refer to appropriate care home protocols.
  - **boredom** – can you engage them in an activity they enjoy? Refer to their personalised care and support plan or ‘this is me information’ for ideas.
  - **hunger** – have they eaten, or do they need a snack?
  - **searching for someone or something** – can you support the resident to find what they are looking for? Consider talking to the resident about their photographs and other treasured items.
- **Ask for input from your MDT:** see Appendix B for contact details of your MDT members.

### Links to useful guidance and resources

[Yorkshire and Humber SCN: Supporting People with Dementia who Walk with Purpose during the COVID-19 Pandemic](#)

[Northern Health and Social Care Trust: CLEAR dementia care](#)

[Dementia Friendly Environments \(SCIE\)](#)

[‘This is me’ Alzheimer’s Society](#)

[Dementia: Good Personalised Care and Support Planning](#)

# Managing Distress and 'Behaviours that Challenge'



As a resident's dementia progresses, they may develop behaviours that can be challenging to staff and other residents. This can include agitation and aggression. This behaviour is best viewed as an attempt to communicate an unmet need. If we can identify and meet this need, it will help to alleviate the resident's distress and any behaviours that challenge.

## **Why is it important to support someone showing distress and behaviours that challenge using a personalised, non-pharmacological approach?**

- Distress and behaviours that challenge are best treated by identifying and understanding the behaviours, and then addressing any unmet needs.
- Medication is rarely effective in reducing the behaviour and can have serious side effects such as increasing the risk of death, strokes, chest infections and falls.
- A personalised approach is essential to ensuring the wellbeing of the resident and positive outcomes from any actions we take. Suggestions are set out in 'What can you do?' below.

## **What are the some of the possible signs that might indicate a resident could become distressed or exhibit behaviours that challenge?**

- When a resident with dementia becomes distressed, they may become agitated, shout, start to pace or ask to go home. Or they might become withdrawn and uncommunicative.
- Reasons for their distress might include feelings of disorientation, anxiousness or fear because they might not recognise where they are as their home. They may also be trying to communicate that they are experiencing discomfort, pain, hunger or thirst, which need to be addressed.

## Physical issues that might contribute to distress behaviour: think FEET



**FEET:** painful toes/ tough nails, knees & hip joints

**EYES:** glasses, cataracts

**EARS:** wax in ears, hearing aids

**TEETH:** toothache, dentures

### What can you do if you think that a resident is distressed or exhibiting behaviour that challenges?

- If the resident is not themselves, distressed, agitated, shouting or withdrawn, lethargic or anxious try to identify the cause. This will help you to take actions to support them.
- Be aware that changes in behaviour can be caused by triggered memories of previous trauma. With your MDT, ensure that all members of staff are aware of any residents' triggers so that they can be prevented.
- Ensure you have information about the resident and their life through their personalised care and support plan, [this is me](#) form and [life story work](#) so that you can get a better understanding of their behaviour.
- Think about whether there are any specific triggers or circumstances which cause the resident to express any behaviours that challenge. Keeping a diary can help with this. For example, does the resident become irritable at a specific time of day or when carrying out a certain task?
- Maintaining a routine as close to 'normal' as possible is helpful as changes in daily activity can cause distress. For example, if going somewhere unfamiliar such as attending a hospital appointment.
- If change to routine is needed, to help reduce the possibility of distress, talk to the resident and explain as clearly as possible what is going to happen and when in a timely way. Use your knowledge of the resident to gauge what is right for them.

- To help manage distress, ensure as calm an environment for the resident as possible, consider encouraging [seated or walking exercise](#) where possible. [Music therapy](#), hand massage, counselling, cognitive behavioural therapy and acupuncture can also be very helpful. Keep in mind your knowledge of the resident and what they might respond to best.
- Aggression can be an expression of how someone is feeling, such as frustration at not being able to do something, or feeling they are not being understood. It might be that the resident is bored, frightened or anxious. To help calm and diffuse distress behaviour, speak to the resident using a calm tone of voice to find out what is troubling them and maintain eye contact. You could offer to sit with them with a cup of tea; bear in mind your knowledge of the resident and their preferences, needs, likes and dislikes, and what might give them reassurance.
- If any unmet needs have been addressed and they are still distressed consider distraction with social interaction, aromatherapy, animal therapy, music and dance therapy and massage or other activities they might enjoy.
- Malnutrition can increase syndrome severity and behaviours that challenge. Residents should be reassured that mealtime etiquette is not the priority (e.g. finger foods causing crumbs on the floor). Residents may lose perception of time and be hungry in the night and having a meal or finger foods available is supportive. For those unable to communicate, looking at behaviours at mealtimes can identify preferences. Cues that a mealtime is approaching can support behaviour conducive to eating (e.g. smell of foods, preparing for a mealtime - setting the table, washing of hands).
- There will be times when these initial approaches do not work. In this instance, acknowledge that the resident is upset and give them time. Re-engage them to see if you can establish the cause.
- If all these approaches do not help the resident and their symptoms are severe or distressing, ask the GP for advice about medication as a last resort.
- **Ask for input from your MDT:** see Appendix B for contact details of your MDT members.

## **Links to guidance and further information**

[Alzheimer's Society: Reducing and managing behaviour that challenges](#)

[Behavioural challenges when supporting a person with dementia \(SCIE\)](#)

[Northern Health and Social Care Trust: CLEAR dementia care](#)



# Best Interests Decisions



Mental capacity is the ability to make decisions. A resident might lack mental capacity to make one decision but not another. For example, a resident might be able to decide what colour top to wear but unable to decide one healthcare treatment over another.

Mental capacity is dynamic, and loss can be temporary; it relates to a specific decision that needs to be taken at any one time. It should be regularly assessed in relation to each decision taken, and accurately documented.

In the instance where it is assessed that the resident lacks capacity to make a decision around care and/ or treatment, a best interests decision needs to be made.

The Mental Capacity Act 2005 requires clinicians to start from an assumption that the resident has capacity, but this assumption may need to be tested if a person is unable to make a particular decision at a particular time because they are affected by illness or disability. The Act provides a framework for assessing capacity, and where this is lacking, for determining how a decision should be made. If the resident lacks capacity to make this decision (it is decision specific) and this assessment must be recorded in the notes.

## Key principles of the Mental Capacity Act 2005

1

Assume a person has the capacity to make a decision themselves, unless it's proved otherwise.

2

Wherever possible, help people to make their own decisions.

3

Don't treat a person as lacking the capacity to make a decision just because they make an unwise decision.

4

If you make a decision for someone who doesn't have capacity, it must be in their best interests.

5

Treatment & care provided to someone who lacks capacity should be the least restrictive of their basic rights & freedoms.

## Why is it important to involve the resident and those close to them in best interests decisions?

- When a decision is made on behalf of a resident who lacks the ability to make it themselves, it must always be made in the resident's best interests. This ensures that:
  - their rights are respected, they retain independence and choice; and
  - the decision is the best one for them.
- This is essential as just because someone cannot make a decision themselves, it does not mean that they don't have preferences and feelings about what they would like.
- Family, friends, and carers also have a right to be consulted and involved in the decision, where appropriate. This is important as they often know the resident best and can share what they feel is in the resident's best interests, as well as what the resident's preferences and views are.

## What can you do to support best interests decisions?

- Check whether the resident has appointed a [lasting power of attorney](#) for health care. If not, help [set up a best interest meeting](#).
- An [Independent Mental Capacity Advocate \(IMCA\)](#) should be appointed if there is no one independent of services, such as a family member or friend, who is able to represent the resident.
- Encourage the resident to participate in the meeting with appropriate [support](#).
- Find out and consider the resident's views (past and present wishes, preferences, beliefs and values) expressed verbally, or recorded in an [advance decision to refuse treatment](#) or [advance care plan](#).
- Identify all the circumstances relevant to the decision (clinical, social, psychological, spiritual).
- Consult others (within the limits of confidentiality) including family, friends, carers, those with [lasting power of attorney](#), IMCA or [Court Appointed Deputy](#) to determine what views they believe the resident with dementia would express if they had capacity.
- Weigh up all the factors in order to work out the resident's best interests.
- **Ask for input from your MDT:** see Appendix B for contact details of your MDT members.

## **Links to guidance and further information**

[Mental Capacity Act \(MCA\) in practice \(SCIE\)](#)

[NICE: Best interests decision making \(NG 108\)](#)

[SCIE: Best interests decisions: A COVID-19 quick guide](#)

# End of Life Care and Advance Care Planning



End of life care involves treatment, care and support for people who are nearing the end of their life. It's an important part of palliative care.

It's for people who are thought to be in the last year of life, but this timeframe can be difficult to predict. Some people might only receive end of life care in their last weeks or days.

End of life care aims to help people to live as comfortably as possible in the time they have left. It involves managing physical symptoms and providing emotional support for the resident and their family and friends<sup>10</sup>. To deliver the best end of life care it is important to understand what is important to the resident themselves.

## Why is it important to talk about future needs, preferences and wishes regarding end of life care as early as possible?

- Ensuring that residents have opportunities to talk about their future needs, preferences and wishes as early as possible (advance care planning) is **vital to support their right to make choices about their care, and a personalised approach to their future care and treatment**. It can also provide the resident with a sense of reassurance that their wishes and preferences will be addressed.
- Time is a key factor. It is better to have the Advance Care Planning (ACP) conversations when the resident concerned can express their views about the possible options.
- ACP is about the provision of ongoing opportunities/ conversations to enhance the choice and control a resident has over their future treatment and care needs/ preferences. Each resident is an individual whose needs and preferences must be taken account of. Blanket policies are wholly inappropriate, particularly in respect of do not attempt cardiopulmonary resuscitation (DNACPR) policies.
- Conversations should take place on a regular basis to check, with sensitivity, whether the resident is ready to speak about their future

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<sup>10</sup> <https://www.mariecurie.org.uk/>

needs, preferences and wishes. Some people will be ready to have an ACP conversation before others and it should not be forced.

- This supports the resident to think about, talk about and write down their concerns and wishes when they are ready to do so.

### **What are some of the possible signs that someone is approaching the end of their life?**

In the last weeks and days, people might experience<sup>11</sup>:

- Feeling weak and tired;
- Sleeping more, being drowsy;
- Feeling hot or cold;
- Cold hands or feet;
- Eating and drinking less;
- Bladder or bowel problems;
- Breathlessness (dyspnoea);
- Pain;
- Nausea or vomiting;
- Weight loss;
- Difficulty swallowing;
- Being confused or delirious;
- Being restless or agitated;
- Talking or communicating less.

### **What can you do to support end of life care and Advance Care Planning??**

- Consider [My future wishes: advance care planning for people with dementia in all care settings](#) which highlights key actions from the point of diagnosis to the advanced condition to prompt **best practice in ACP conversations**. It also considers situations where it has not been possible to initiate ACP conversations and provides some tips on how to manage this.
- Check if the resident has an ACP and/ or has made advance decisions or statements. If the resident does not have an ACP, facilitate this process if possible. If the resident lacks capacity to make a decision around care and/ or treatment, a best interests decision needs to be made. See section on [best interests decisions](#) for more information.
- Ensure that the information is shared with the GP (and on shared IT portals) and that staff involved in the care of the resident know where the information is and what it says.
- Speak to the resident to establish their wishes and preferred place of care and what element of treatment is important to them (e.g. feeding tubes, treatment of infections, cardiopulmonary resuscitation).

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<sup>11</sup> <https://www.mariecurie.org.uk/help/support/being-there/end-of-life-preparation/signs-of-dying>

- Often, the most important therapeutic agent for residents is their carer, so it is important to involve them as much as possible in treatment decisions and in the resident's care.
- To help alleviate anxiety, agitation and distress in the last weeks and days of life try to ensure that the resident's environment is calm. Making sensory connections through hearing, touch, sight or smell can provide comfort. The most important thing is to engage with the resident, talk to them and make use of the senses focusing on what you know about them. Use their personalised care and support plan/ ACP and their life story work or 'this is me' documentation to help you decide what might best support the resident.
- Consider using the resource from [National Council for Palliative Care: How to help someone with dementia who is in pain or distress](#) which includes tips on the identification and management of pain and distress.
- Provide support for visitors in the resident's last phase/ last days of life.
- **Ask for input from your MDT:** see Appendix B for contact details of your MDT members.

## Links to guidance and further information

[Advance Care Planning: A quick guide for registered managers of care homes and home care services](#)

[National Council for Palliative Care: How to help someone with dementia who is in pain or distress](#)

[BGS COVID-19: End of life care and dementia](#)

[End of life care for care home residents during the pandemic](#)

[Visiting arrangements in care homes for the period of national restrictions](#)

[Care Provider Alliance: Care Homes and Palliative and End of Life Care](#)

# Frailty



“Frailty is a syndrome that combines the effects of natural ageing with the outcomes of multiple long-term conditions, a loss of fitness and reserves”<sup>12</sup>. It refers to a resident’s mental and physical resilience, or their ability to recover from events like illness and injury.

## Why is it important to address frailty needs as early as possible?

- Frailty and physical health difficulties increases the likelihood of co-morbid mental health difficulties such as depression.
- For people living with frailty, relatively minor health problems, such as infection, can have a severe long-term impact on their health and wellbeing.
- People living with frailty are at highest risk of adverse outcomes such as falls, disability and admission to hospital.
- Frailty can be identified early and there are interventions that can slow decline and prevent crises.
- Early identification coupled with targeted support can help older people living with frailty to stay well and live independently for as long as possible.

## What are the some of the possible signs of frailty?

- Falls (e.g. collapse, legs gave way, ‘found lying on floor’).
- Immobility (e.g. sudden change in mobility, ‘gone off legs’ ‘stuck in toilet’).
- Delirium (e.g. acute confusion, ‘muddledness’, sudden worsening of confusion in someone with previous dementia or known memory loss).
- Incontinence (e.g. change in continence – new onset or worsening of urine or faecal incontinence).
- Susceptibility to side effects of medication (e.g. confusion with codeine, hypotension with antidepressants).

However, it is possible for the resident to experience any of the above without having frailty. A review of the resident is needed.

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<sup>12</sup> <https://www.ncbi.nlm.nih.gov/pubmed/26402213>

## What can you do to support identification and management of frailty?

- Support a comprehensive review of residents:
  - develop a of personalised care and support plan within seven working days of admission to the home and within seven working days of readmission following a hospital episode<sup>13</sup>;
  - base the personalised care and support plan on the principles and domains of a Comprehensive Geriatric Assessment<sup>14</sup>.
- Support regular assessment of residents:
  - delivery of a weekly home round with the MDT;
  - document the assessment by updating the personalised care plan for each resident;
  - monthly malnutrition screening.
- Carers support for residents:
  - carers to provide support to achieve activities of daily living;
  - senior carers or managers to provide a care needs assessment for residents and refer to specialised expertise to ensure needs are met.
- Targeted interventions include enhancing or maintaining nutrition status, minimising polypharmacy, ensuring regular exercise and providing support for cognitive function.
- Malnutrition is commonly found in people living with frailty and can manifest as both a cause and effect. It is important to identify and manage malnutrition in combination with strength building exercise.
- **Ask for input from your MDT:** see Appendix B for contact details of your MDT members.

### Links to guidance and further information

[British Geriatrics Society Frailty Hub](#)

[Royal College of Nursing: Frailty in older people](#)

<sup>13</sup> <https://www.england.nhs.uk/publication/enhanced-health-in-care-homes-framework/>

<sup>14</sup> <https://www.bgs.org.uk/resources/resource-series/comprehensive-geriatric-assessment-toolkit-for-primary-care-practitioners>



## Appendix

### **Appendix A:** List of Contributors (alphabetical order):

Alistair Burns; Vicky Cartwright; Nisha Duggal; Claire Fry; Joanna Gavins; Joanne Greengrass; Rakesh Koria; Helen Martin; Bikram Raychaudhuri; Sian Roberts; Emma Self; Mark Thaxter.

### **Appendix B:** Infographic

The infographic on the next page shows some signs of dementia and mental illness in care home residents. The page can be printed out and displayed as a poster.

## Symptoms:

Memory loss

Loss of skills (e.g. reading, writing)

Change in social behaviour



Consider....

# DEMENTIA

## Symptoms:

Agitated OR excessively sleepy

Hearing or seeing things that aren't there

Fluctuating awareness of goings on around them

Consider....

# DELIRIUM

# Does your resident have signs of dementia or a mental illness?

## Symptoms:

Persistent low mood

Reduced enjoyment

Constant worry or phobia



Consider....

# ANXIETY OR DEPRESSION

## Symptoms:

Delusions that harm is occurring or going to occur to them

Hearing or seeing things that aren't there

Consider....

# PSYCHOSIS



Walking with purpose and 'behaviours that challenge' could be signs of any of the conditions above.

### Appendix C: MDT Contact Details

There are several roles that should form part of the multidisciplinary team (MDT) in order to support the health and wellbeing of care home residents. The table below should be completed with contact details for each role.

IMPORTANT – make sure to include contact details for out-of-hours/ night teams where available.

Contact	Contact details
Advanced Clinical Practitioner	
Advanced Nurse Practitioner	
Bowel and Bladder Team	
Care Home Liaison Team	
Community Matron	
Dementia Support Workers/ Advisors	
Dentist	
Dietician	
District Nurse	

Contact	Contact details
GP or Geriatrician	
Hospice	
Improving Access to Psychological Therapies (IAPT) service	
Independent Mental Capacity Advocate (IMCA)	
Memory Service Team	
Mental Health Nurse/ Practitioner	
Occupational Therapist	
Palliative Care Team	
PCN Clinical Pharmacist	
Physiotherapist	
Podiatrist/ Chiropodist	

<b>Contact</b>	<b>Contact details</b>
Practice Nurse	
Social Link Prescriber	
Speech and Language Therapist	

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