

End of life care for people with dementia

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Who developed the guide?

This guide was created as part of a research project funded by Marie Curie and Alzheimer's Society, led by Dr Nathan Davies and Prof Steve Iliffe.

It was developed by an experienced team of researchers and health and social care professionals, including GPs and Psychiatrists, from University College London and King's College London, and a group of family carers.

The research team included Prof Liz Sampson, Prof Jill Manthorpe, Dr Kethakie Lamahewa, Dr Rammya Mathew and Ms Jane Wilcock.



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How was it developed?

To create this guide, we consulted the latest evidence from research and clinical practice, together with the views and experiences of family carers and healthcare professionals.

This guide has been reviewed by GPs, palliative medicine doctors, nurses, geriatricians, psychiatrists, and social care professionals. It was evaluated in a research study across five settings.

Contents

Who's this guide for?	3
What does end of life mean?	3
Who should be involved in care decisions?	3
Rules of thumb	
Eating or swallowing difficulties	4
Agitation or restlessness	8
Reviewing treatment and interventions at the end of life	12
Providing routine care at the end of life	15

Who's this guide for?

This guide has been created for any healthcare professionals providing care and support for people with dementia at the end of life. It can be used for training, to support decision-making, and help you have discussions with family members and advocates.

What does end of life mean?

The researchers behind this guide have taken the view that end of life isn't a period of time limited to the final days, hours or weeks of life, but a period when the person, their family or healthcare professionals recognise that the person might be in the last phase of their life. This will vary for different people.

Who should be involved in care decisions?

Whenever possible try to include the person with dementia in any new decisions, at each stage of their care. Continue to reassess whether they're able to make these decisions.

If the person is able to make decisions, consider advance care planning (if this hasn't already been done). They may want to involve their

family and others in these discussions. Ask about their preferences for health and care treatment, their wishes, values or aspects of life that are important to them.

If the person with dementia isn't able to make a decision, you should involve their family member or advocate. Make sure you know who, if anyone, has lasting power of attorney (or deputyship) powers covering health and welfare. Decisions should be made in the best interests of the person living with dementia.

If the person with dementia has no family or friends, identify someone to advocate on their behalf. For major decisions, this may be an Independent Mental Capacity Advocate (IMCA).

Rule of thumb: eating or swallowing difficulties

In an emergency, follow first aid principles and call for help or dial 999.

1 Have a conversation with the person living with dementia and their family or advocate around the time of diagnosis, so that problems with eating or swallowing difficulties don't come as a surprise.

Also consider discussing this in advance care planning, so the person can decide what they'd want if they were to develop these difficulties.

2 Is dementia the cause of the eating or swallowing difficulties?
You may need to consult a specialist to answer this.

Yes

Convert their oral medication to another form, eg liquid, and try comfort feeding.*

No

Stop feeding them promptly.**

3 Is the cause reversible?

Yes

Discuss options for specialist care with them and their family or advocate – these should be considered on an individual basis.

No

Try comfort feeding.*

*This may carry associated risks of aspiration.

**Closely observe their intake, especially if changes to their swallow function are suspected.

Eating and swallowing difficulties

Eating and swallowing difficulties can occur at any time and shouldn't come as a surprise. They're particularly common if the person becomes unwell or weaker. For example, if they have a chest infection.

As part of the advance care planning process, consider asking the person what they'd want to happen if they were to develop eating or swallowing problems.

What if the person isn't eating, is having difficulty swallowing, or choking?

A judgement needs to be made as to whether this is an emergency or not. If it's considered to be an emergency, for example if the person is choking, then apply the principles of first aid and call for help. This may include calling 999.

If the person's difficulties with swallowing aren't acute, then you'll need to assess whether they're due to the progression of dementia. To make this assessment, you may need to consult a specialist, such as a Speech and Language Therapist (SALT). Alongside this, make sure that all vital medication is converted to another form, eg liquid, so the person can still take it.

Is this being caused by dementia?

If it's judged that these difficulties are due to the progression of dementia, or if it isn't considered to be reversible, then you can offer comfort feeding (see below).

If the person's difficulties with eating and swallowing aren't due to the progression of dementia, stop feeding them and assess whether the difficulties are reversible. Closely observe and document their intake, particularly if changes to swallowing are suspected.

What should I do if there's a reversible cause?

Discuss options with a specialist, eg a geriatrician or GP, including the potential use of a time limited nasogastric tube (NG) for feeding.

Conversations with family members or advocates should clearly specify that there's a defined time period for which NG feeding will be trialled, during which the response to the treatment will be monitored. If it seems not to be working, or brings other problems, tell the family or advocate that NG feeding is likely to be withdrawn at the end of this trial period.

What's comfort feeding?

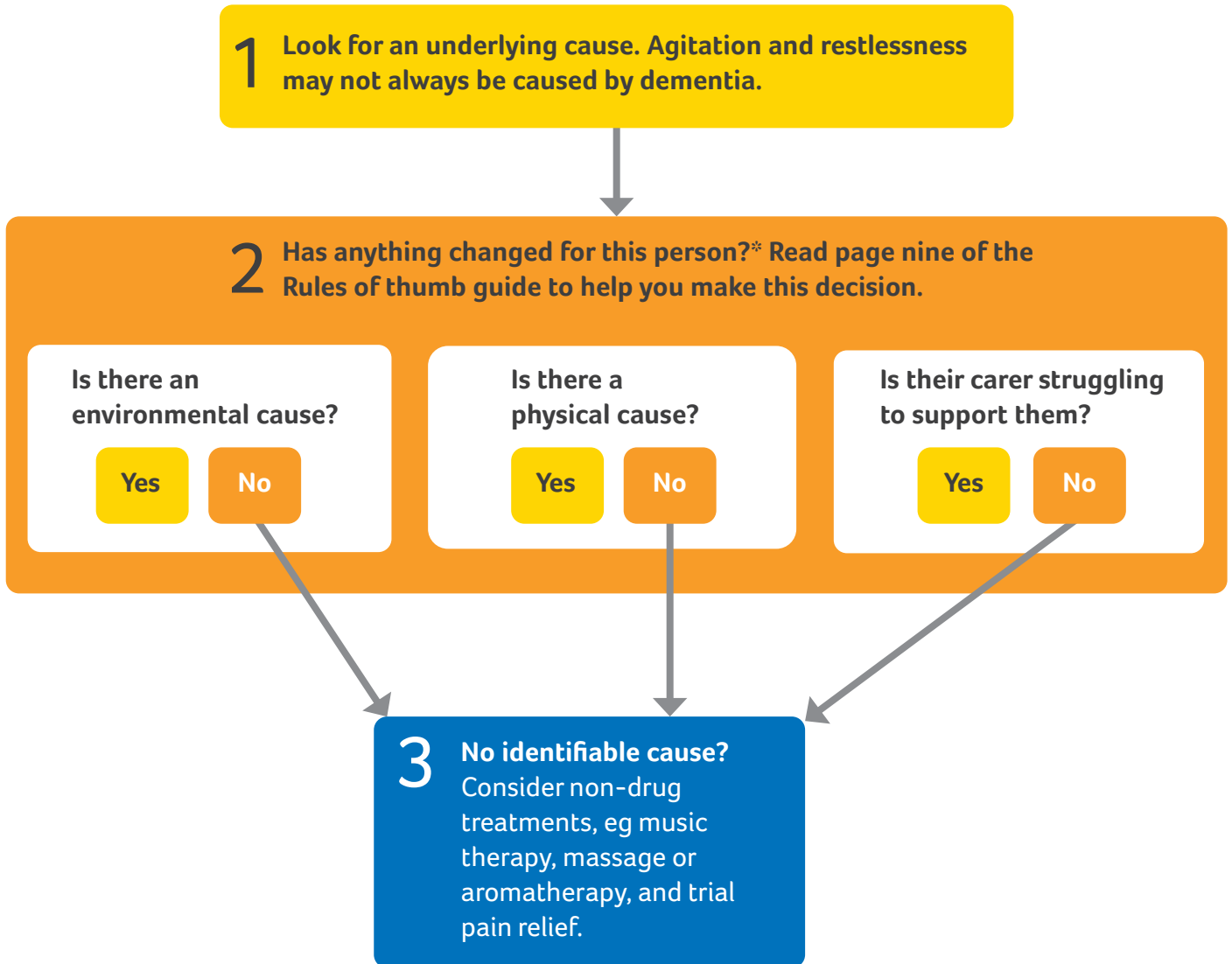
Comfort feeding means eating for pleasure. It involves providing the person with small amounts of food or drink that the person likes.

Comfort feeding can carry associated risks, such as aspiration. In some settings it's referred to as 'risk feeding'. You'll need to balance the risks of feeding the person this way with the potential comfort and pleasure that eating may provide.

To begin comfort feeding, you should:

- Identify the person's favourite foods and drinks – and what they don't like – to create a food passport. You can include information like how many sugars they prefer in tea or coffee.
- Assess how much assistance the person will need with feeding.
- Follow any recommendations from the Speech and Language Therapist, eg the texture, consistency or quantity of food, or specific strategies for feeding. Seek clarification if these no longer seem appropriate.
- Allow for flexibility in the person's eating patterns.
- Check that the person is sufficiently awake and alert enough to be offered food and drink.
- Support the person to sit as upright as possible, preferably out of bed and in a chair.
- Follow the person's pace to make sure they're relaxed when you're feeding them and check their mouth for residue at the end of meals.
- Reduce distractions or background noise so the person can focus on eating and drinking.
- Consider asking someone the person knows to help feed them.
- Make sure the person gets regular, thorough mouth care to maintain oral hygiene.
- Closely observe all their intake, particularly if changes to their swallow function are suspected.
- If swallowing difficulties persist or worsen, seek guidance from specialist colleagues.

Rule of thumb: agitation and restlessness



*You might want to speak to their family or advocate. to help establish this.

Consider throughout this process whether the person is a risk to themselves or the people around them.

Agitation and restlessness

Agitation isn't necessarily caused by dementia. There could be several reasons why someone with dementia is agitated.

You should look for an underlying cause. Has there been a change for this person? Consider the following three areas and checklists:

Is there an environmental or social cause?

- The temperature or noise may not be comfortable for them.
- It may be a result of unfamiliarity with their surroundings.
- They may be bored.
- Their cultural values, beliefs or spiritual needs may not be being met.

Is there a physical cause?

The person living with dementia may:

- be hungry or thirsty.
- be constipated – treat them with laxatives.
- have urinary retention – if so, consider catheterization.
- have a pressure sore or be uncomfortable in their position.
- have soiled underwear – address their personal hygiene.
- have an infection or other underlying illness – treat as appropriate or control the symptoms.
- be in pain. This could be because of arthritis, badly fitting dentures or something else.
- have an alcohol, nicotine or drug withdrawal.
- be experiencing side effects from any drugs or medication they're taking.

Is it related to the health or wellbeing of their carer?

- If their carer is struggling to cope or is ill themselves, this may have an indirect effect on them.
- Do they have a new or existing condition which is making it harder for them to provide care?
- Do they feel supported? Do they have enough support?
- Are they experiencing side effects from any drugs or medication?
- Consider a carer assessment or review for the family member or advocate providing care.

Agitation may have several causes, which fall into different areas, so you should consider them all equally at any time. You may also have to return to all three areas.

It's ok if you can't identify a cause for the agitation or restlessness. In this case, you should consider non-drug treatments, then a trial of pain relief. If these aren't effective, seek specialist help and consider the use of medication.

If the person with dementia remains agitated despite making these changes, then it may be part of the dying process.

At all times, consider if the person is a risk to themselves or others around them and if so, how this can be managed.

Rule of thumb: reviewing treatment and interventions

1 Towards the end of a person's life, you should only continue medication or interventions that are likely to maintain their comfort and quality of life. The same goes for starting them on any new medication or interventions.

2 Is the current treatment or intervention contributing to their comfort or quality of life?

You'll need to discuss this decision with the person's family or advocate.

Yes

Continue the current care.

No

Stop the treatment.

3 Regularly review the person's comfort and quality of life after any change in treatment. Be prepared to restart treatments if necessary, as it's not always clear whether they're helping the person feel comfortable or improving their quality of life.

Reviewing treatment and interventions at the end of life

Interventions can include regular measurements, physical observations, blood tests, cannulation, blood pressure monitoring and other invasive processes.

Who should be involved in this decision?

Decisions to continue or stop treatment or interventions should be discussed in a multi-disciplinary team meeting. You'll need to adhere to any decisions made in the person's advance care plan, if they have one, and consult the person who holds lasting power of attorney (LPA) or their deputy.

Any decisions to stop treatments or interventions should also involve frequent discussions with the person's nominated family member or advocate.

Reviewing current treatments

Consider whether the current treatment or intervention is still needed. Does this treatment or intervention help to maintain the person's quality of life?

Ensure that the family or advocate is aware that stopping intrusive treatment is not an indication of 'giving up' on the individual; we will just offer a different type of care that focusses on comfort or quality of life.

If the treatment or intervention is still considered to be needed, then continue with the current care.

Continually review comfort of the person and their quality of life. There may be occasions when a treatment needs to be restarted as it may be having a positive effect on their quality of life and/or the comfort

As their disease progresses

Later in the course of the person's disease, you should review all treatments, including those that were originally thought of as symptomatic treatments.

Symptomatic treatment is any medical treatment which only addresses the symptoms of the disease and doesn't treat the cause.

Rule of thumb: routine care in the last days and hours

1 Discuss routine care with the person's family or advocate to decide on an acceptable level and the best way to provide it.

2 Is routine care causing the person distress?
You may need to consult a specialist to answer this.

Yes
Can the way the care is being provided be adapted to better suit the person's needs?

No
Provide routine care with the goal of maintaining the person's comfort and dignity.

3

Yes Make any necessary adaptations.	No Try again later.
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4 Is this a recurring issue?

Yes Go back to 1.	No Continue as normal.
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Consider referring to the rules of thumb for agitation and restlessness.

Providing routine care at the end of life

These rules concerning routine care are to be used in the final hours to days of life.

What's routine care?

Routine care includes oral (mouth) care, washing and bathing, changing the person's bed sheets and turning them to prevent pressure sores or skin irritation.

Some types of routine care are essential, as they add to the comfort of the person, and shouldn't be stopped. This includes changing soiled or wet bed sheets or clothing and providing mouth care.

Who should decide the level of routine care that's provided?

An advance care plan should always be respected if the person with dementia has one. Other existing legal authorities should be documented and understood.

You should talk about routine care with the nominated family member or advocate in advance, before issues arise. Make sure you understand what they believe to be an acceptable level of care and how it should be provided.

If routine care does not cause distress, then continue to provide routine care to maintain the comfort and dignity of the individual, but let your colleagues know what you're doing and why.

What if routine care is causing distress?

For some people with dementia and their family or advocates, routine care may become distressing.

If routine care is causing distress for the person with dementia, see if the way it's being delivered can be adapted. For example, can you change the way you hold or touch the person when you move them?

Consider giving anticipatory pain relief to the person prior to providing essential care, if it's likely to cause them distress or discomfort.

If the adaptations don't help then try again later, when it may be possible to provide that care.

Distress from routine care may be a recurring issue. If this is the case, discuss it with the person's nominated family member or advocate and decide on an acceptable level of care.

Some family members or advocates may not prioritise routine care at the end of life, as it can also take away from the valuable and limited time they have left with their relative. This needs to be discussed. Minimum care may be a kindness to the person with dementia at the end of life, and their dignity should be maintained.

Notes

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