



After the Liverpool Care Pathway Study

Rules of Thumb for End of Life Care for People with Dementia



Message from the project leads



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Dementia is one of the biggest health concerns facing older people and health and social care systems across the world and has become an international public health priority.

Typically, as people with dementia approach the end of life they develop symptoms which can be distressing and create dilemmas for practitioners and family members. Currently practitioners lack a framework for providing end of life care for someone with dementia, subsequently some feel they lack confidence.

This led us to think “how do we fill this gap?”

This study has developed with the help of family carers and practitioners, four rules of thumb covering: eating and swallowing difficulties; agitation and restlessness; reviewing treatment and interventions at the end of life; and providing routine care at the end of life. These have been trialled in five different clinical settings in England and are presented below.

We would like to thank all of the family carers, the practitioners and sites involved in this study as well as the hard work of all the research team.

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Rules of Thumb for End of Life Care for People with Dementia

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Care and support
through terminal illness



End of life care

For this study we have taken the view that end of life care is not a period of time limited to the final days, hours or weeks of life, but more a period when the person, their family or practitioners recognise that they might be dying. This will vary for individuals.

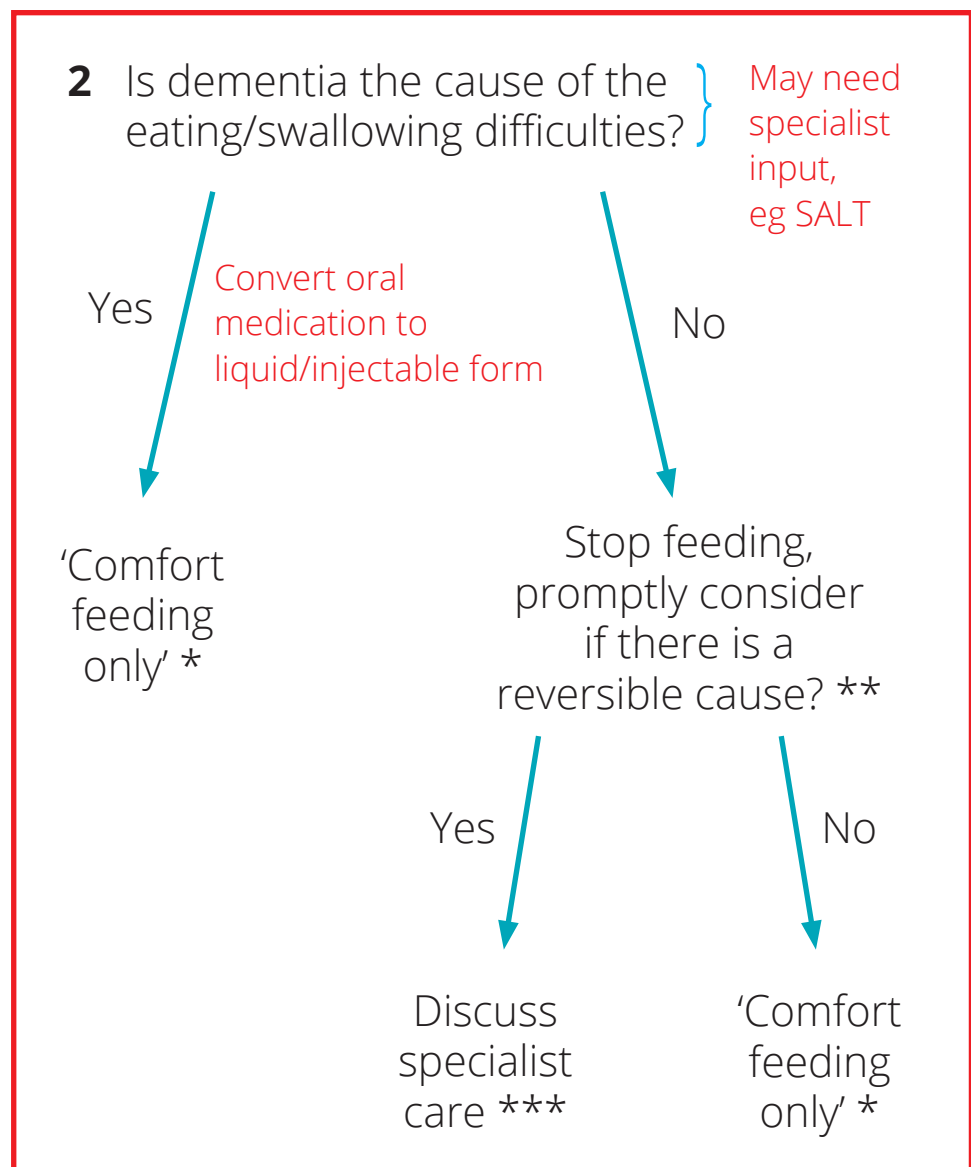
Who should I talk to?

- Always try to involve the person with dementia, whenever possible. Continue to reassess capacity of the person with dementia and try to involve them in their care and in each new decision, and at all stages.
- If the person has the ability to make decisions, consider advance care planning (if not already done). The person may want to involve family and others in these discussions. Ask about the person's preferences for health and care treatment as well as their other wishes.
- If the person with dementia does not have the ability to make a specific decision, ensure decisions involve any nominated family or advocate and know who, if anyone has lasting power of attorney (or deputyship) powers covering health and welfare.
- If the person with dementia has no family/friends, then identify someone who is able to advocate for them on their behalf. This may include an Independent Mental Capacity Advocate (IMCA) for major decisions.

Eating/swallowing difficulties

- 1 Don't let eating/swallowing problems come as a surprise (ensure conversation has occurred with the person with dementia and family or advocate early, around the time of diagnosis). Consider advance care planning (ACP).

If it is an emergency follow principles of first aid



*Comfort feeding may carry associated risks of aspiration

**Closely observe all intake particularly if changes to swallow function are suspected

*** Consider appropriateness on individual basis

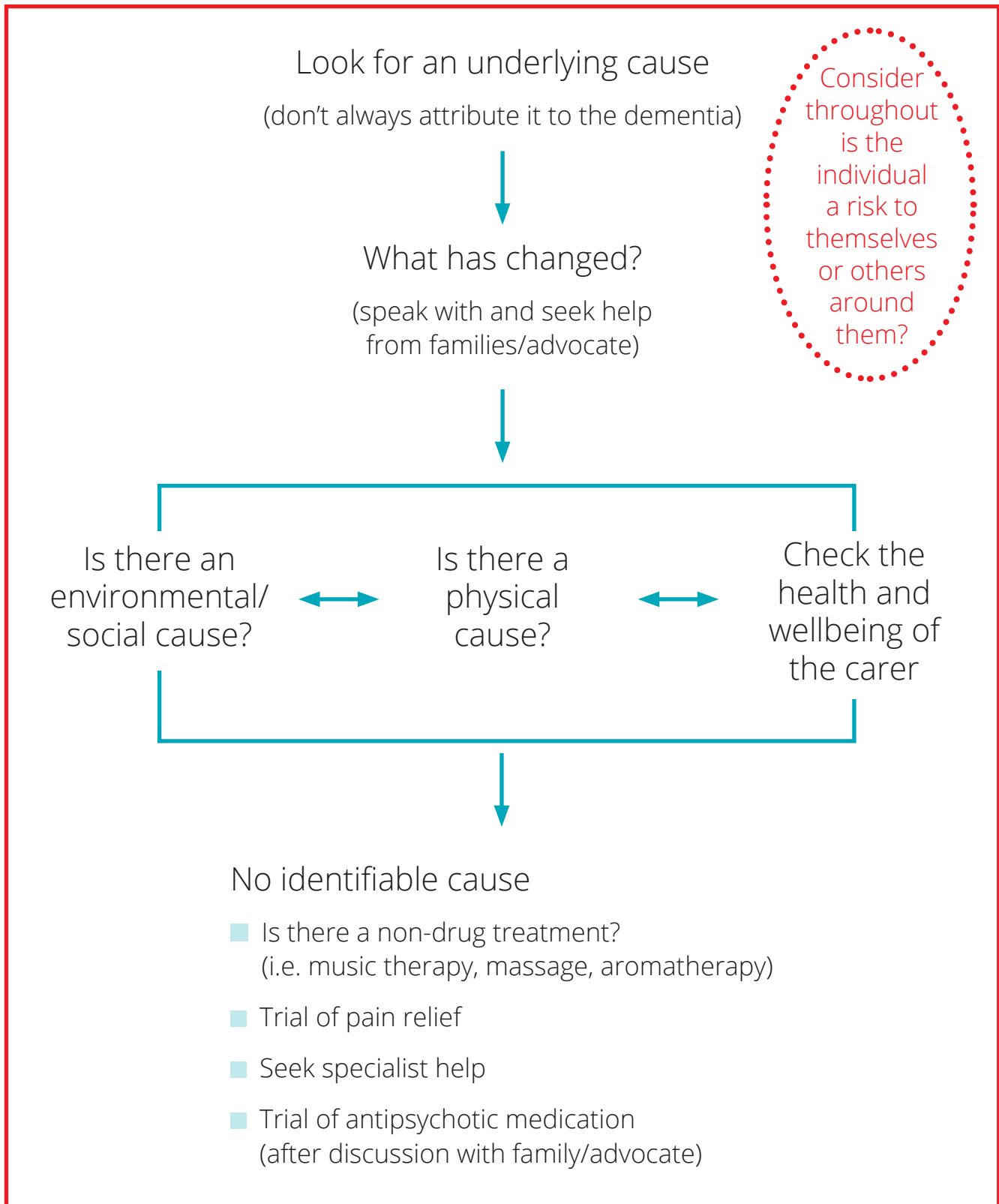
Eating/swallowing difficulties (continued)

- Eating and swallowing difficulties may occur at any time and should not come as a surprise. As part of the advance care planning process, consider discussing what the person would want if they were to develop eating/ swallowing problems.
- If a person with dementia is not eating, having difficulties swallowing or choking, a judgement needs to be made as to whether this is an emergency or not. If it is considered to be an emergency for example if the individual appears to be choking, then apply principles of first aid and call for help. This may include dialling 999. If it is not an emergency, then move to rule 3
- If difficulties with swallowing are not acute, then you need to consider whether it is due to the progression of dementia. In order to make this assessment you may need to consult a specialist, such as a Speech and Language Therapist (SALT). Alongside this, ensure that all necessary medication is converted to liquid or injectable form so that it may still be taken by the person.
- If it is judged to be due to the progression of dementia, then provide comfort feeding* only. Comfort feeding refers to the process of eating for pleasure, providing small amounts of food and may carry associated risks such as aspiration. In some settings the term risk feeding may refer to the same concept as comfort feeding. Practitioners need to balance the risks of feeding with the potential comfort and pleasure that eating may provide.
- If difficulties are determined not to be due to the progression of dementia, stop feeding the person and consider if the cause of the eating/ swallowing difficulties is reversible. Closely observe all intake, particularly if changes to swallowing are suspected.
- If there is a reversible cause, then discuss with a specialist (i.e. geriatrician- this may vary in your area) or GP about options and the potential of time trialled nasogastric tube (NG) feeding. Conversations with family/ advocates should clearly specify that there is a defined time period for which NG feeding will be attempted, during which the response to treatment of the underlying condition will be monitored. If treatment seems not to be working or brings other problems, tell the family/advocate that NG feeding is likely to be withdrawn at the end of this trial period.
- If no reversible cause is identified, then revert to comfort feeding* only.

*Comfort feeding

- ❖ Identify the degree of assistance someone needs with feeding and facilitate this
- ❖ Allow for flexibility in eating patterns
- ❖ Check the person is sufficiently awake and alert to be offered food and drink
- ❖ Consider asking someone known to the person, to help with feeding
- ❖ Promote regular thorough mouth care to optimise oral hygiene
- ❖ Support the person to sit as upright as possible, preferably out of bed and in a chair
- ❖ Follow any existing or new SALT recommendations (e.g. modified textures, quantities, specific strategies); seek clarification if these no longer seem appropriate.
- ❖ Follow their pace to ensure slow relaxed feeding, check their mouth for residue at the end of meals
- ❖ Reduce distractions/background noise to allow the person to focus on eating and drinking
- ❖ Closely observe all intake particularly if changes to swallow function are suspected
- ❖ If swallowing difficulties persist or worsen, seek guidance from specialist colleagues

Agitation/restlessness



Agitation/restlessness (continued)

- Don't always assume that agitation is due to the dementia, there may be many reasons why the person with dementia is agitated. Look for an underlying cause.
- Think about change, has there been a change with this person? Consider the following three areas and checklists:

Is there an environmental/ social cause?

- ❖ Consider the environment
e.g: temperature or noise
- ❖ Attempt to engage the
person in activities of
interest to them
- ❖ Unfamiliarity
- ❖ Boredom
- ❖ Consider if cultural values/
beliefs/spirituality are
unmet

↔ Is there a physical cause? ↔

If so, then treat the cause.

Consider:

- ❖ Hunger/thirst – offer food
and drink
- ❖ Constipation – laxatives
- ❖ Urinary retention –
catheterise
- ❖ Pressure sore/
uncomfortable positioning
– wound care and
repositioning
- ❖ Soiled underwear –
address personal hygiene
- ❖ Infection or other
underlying illness – treat
as appropriate/ symptom
control
- ❖ Pain (consider causes
such as arthritis/ill fitting
dentures)
- ❖ Alcohol/nicotine/ drug
withdrawal
- ❖ Consider drug/medication
side effects

↔ Check the health and wellbeing of the carer

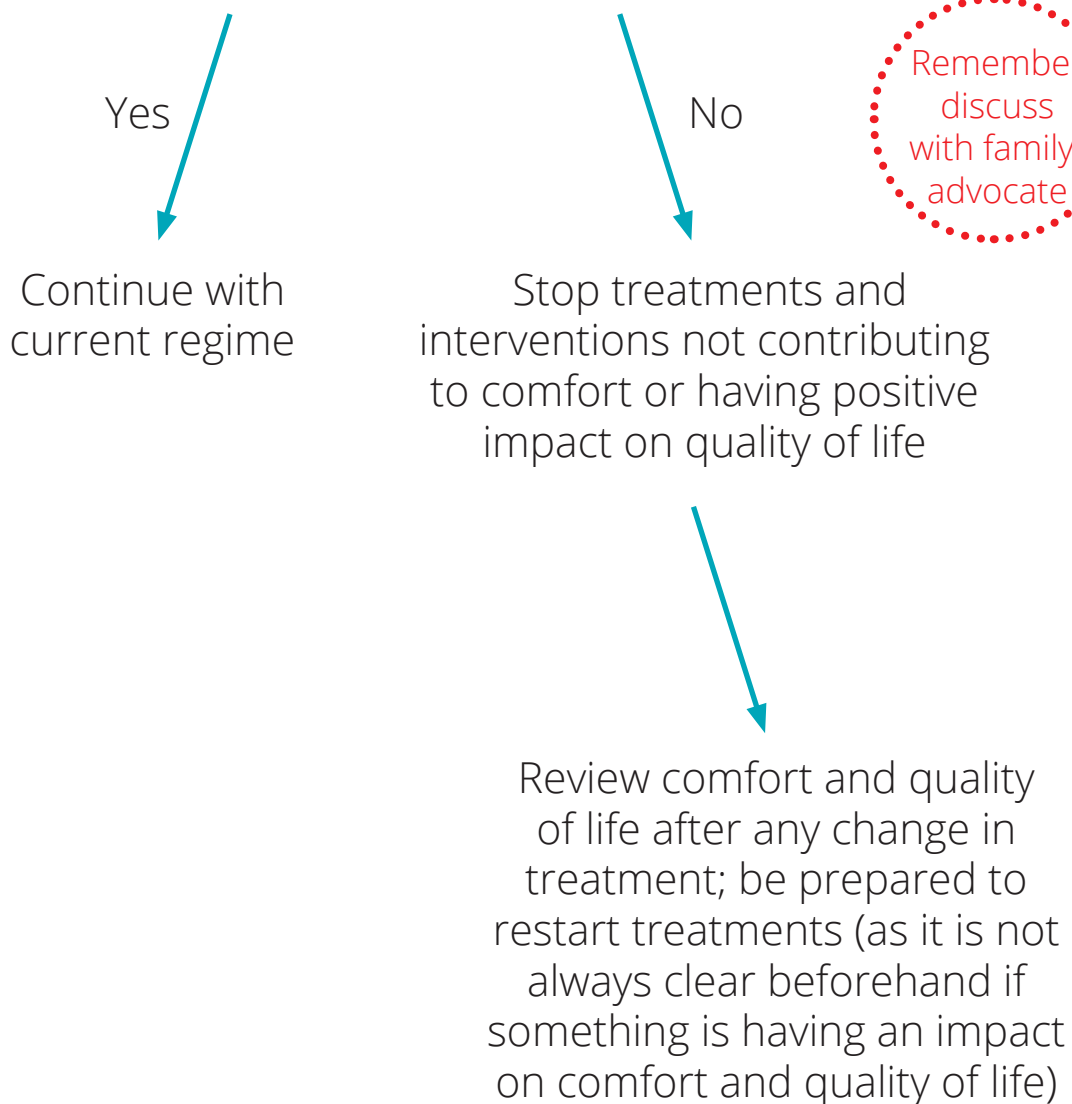
- ❖ Consider a carer
assessment/review for
family/advocate providing
care
- ❖ Do they have a new
or existing condition
complicating their ability to
provide care?
- ❖ Do they feel supported/
have enough support?

- If the person with dementia remains agitated despite excluding other causes, then this may be part of the dying process.
- These three areas should be considered equally at the same time, these are not separate and agitation may be a result of all three. The bi-directional arrows in the rule indicate that you may have to come back and reconsider each area at any point and these are not linear.
- The assessment of the carer/person providing care is included because if they are struggling to cope or ill, this may have an indirect effect on the person with dementia.
- It is ok if you are not able to identify a cause for the agitation or restlessness. Consider non-drug measures, then a trial of pain relief. If these measures are not effective, then seek specialist help and consider the use of antipsychotic medication.
- At all times, consider if the individual presents a risk to themselves or others around them and assess how can this be managed?

Reviewing treatment and interventions at the end of life

- 1 Towards the end of life, only continue or initiate medication or interventions that are likely to maintain comfort or have a positive impact on quality of life

- 2 Is the current treatment/intervention still needed?



Reviewing treatment and interventions at the end of life (continued)

- Decisions around continuing or stopping treatment or interventions should be discussed in a multi-disciplinary team meeting, if appropriate. Professionals should be aware of the need to abide by any advance decisions made and the role of the person holding lasting power of attorney (LPA) or deputy. Interventions include regular measurement of observations, blood tests, cannulation, blood pressure monitoring and other invasive processes.
- These decisions should also be discussed with the nominated family or advocate. If an advance care plan or decision has been made, consult this. Consult the LPA/ deputy/advocate if applicable.
- Question whether the current treatment or intervention is still needed. Does this treatment or intervention help to maintain quality of life for the individual? Any decisions to stop treatments or interventions should involve frequent discussions with a nominated family member or if a family member is not available, then with someone who can advocate on behalf of the person with dementia (see page 5). Ensure that the family or advocate is aware that stopping treatment is not an indication of 'giving up' on the individual.
- If the treatment or intervention is still considered to be needed, then continue with the current care.
- Continually review comfort of the individual and their quality of life. There may be occasions when treatment needs to be reinstated as it may be having a positive effect on the quality of life and/or the comfort of the individual.
- Later in the disease course, also review other treatment, including those that were originally thought of as symptomatic treatment*.

* Symptomatic treatment is providing any medical treatment which only addresses the symptoms of the disease and does not treat the cause

Providing routine care at the end of life

1 Discuss with family or advocate regarding what is an acceptable level of care and how best to provide it?

2 Is routine care causing distress?

Yes

No

Can the way that care is delivered be adapted to better suit the persons' needs?

Provide routine care with the goal of maintaining comfort and dignity

Yes

No

Make adaptations

Try again later

3 Is this a recurring issue?
If yes go to rule 1

Consider referring to rules of thumb for agitation/restlessness

Providing routine care at the end of life (continued)

- These rules concerning routine care are to be used in the final hours to days of life. Routine care encompasses oral/mouth care, washing/ bathing the individual, changing bed sheets, turning the patient to prevent pressure sores and skin irritation. Some types of care that comfort the person with dementia are essential and should not be stopped. These include changing soiled or wet bed sheets/ clothing and providing mouth care.
- An advance care plan should always be respected if the individual has one. Other existing legal authorities should be documented and understood.
- Talk about routine care with the nominated family member or advocate in advance before there is an issue. Understand what they believe to be an acceptable level of care and how it should be provided. For some people with the dementia and their families/advocates, routine care may become distressing. Some families/advocates may not prioritise routine care at the end of life as it can also take away from valuable and limited time that families have to spend with their dying 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.
- If routine care is causing distress, consider if the way in which it is being delivered can be adapted. For example, can you change the way you hold/touch a person when you move them? Consider anticipatory pain relief to the person prior to providing essential care, if it is predicted to cause distress or discomfort to the person. If you cannot make adaptations then try again later, when it may be possible.
- 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 are doing and why.
- Distress from routine care may be a recurring issue, if this is the case then refer back to rule one and discuss with the nominated family member or advocate what is an acceptable level of care.

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