Facilitator's support and guidance

Welcome to the Rules of Thumb

Background to the Rules of Thumb guide

The Rules of Thumb guide was developed by a team of researchers from University College London and Kings College London and a group of family carers. The latest evidence from research and clinical practice, together with views and experiences of family carers and healthcare professionals (HCP). It was updated in 2020.
It is aimed at any HCPs 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 with discussions with family members and advocates.
It has been adapted, with full permission to become the base for this programme.

Overview of the programme

The programme is made up of 6 mini-sessions:

- Introduction
- Rule One: eating or swallowing difficulties
- Rule Two: agitation and restlessness
- Rule Three: reviewing treatment and interventions
- Rule Four: routine care in the last days and hours
- Conclusion

Case study – Peter
Peter is a fictional character, but draws upon the knowledge and experience of a clinician who has worked with people with dementia and reflects real life situations that they have come across within their practice. You may wish to adapt or change some of Peter's background to fit with different client groups, family members, religions, needs etc. of the delegate groups that you are working with.

Activity sheets
There are a number of activity sheets that can be used with delegates. They can be given individually or worked within a group. If there is a mixed professional group, it can be advantageous for the groups to mix up and work together.

Evaluations
As you know, evaluation is an important part of everything we do. As a new programme, it is important to understand what works well, what doesn't and what makes a difference to delegates. There is a standardised evaluation form for you to use after sessions, but during

the pilot phase there is an online version and we would ask if you could encourage delegates to complete.

Modes of delivery

Flexibility

Each mini-session can be delivered in approximately 45 minutes. Some sections need to be carried out quite quickly, but there are the ones where delegates are being 'refreshed'. There are recurring themes throughout the programme such as advance care planning, so these tend to be touched on quite lightly. The mini-sessions can be extended if preferred, and additional resources have been suggested to make up these sessions. All resources can be found on the Six Steps website. The mini-sessions may also be delivered all together within an extended half day format. Another option would be to include parts of the mini-sessions to extend an existing programme, an example would be the Six Steps programme.

Virtual or face to face

This programme or the mini-sessions can be delivered as either virtually or within and in-person session. There are a few slides (within the pre-session section) that introduce delegates to the virtual environment, however, this may need to be adjusted according to the platform being used. It is possible to use the activities in either situation. However, you would need to consider how you would share these with delegates. You could show them on the screens (or within break out groups) or they could be emailed to delegates ahead of the sessions.

Other resources for facilitators

There is a section on the Six Steps website for facilitators. This has three areas at the moment: Supporting the programme, Evidence and evaluation of the programme and accreditation of the programme. You may find the first section useful as it has resources for delivery of the programme and some resources for virtual delivery. As with all Six Steps resources, it is free to access, but you do have to register as a facilitator to access this section.

Dementia Training Standards Framework

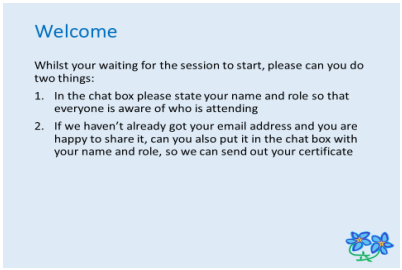
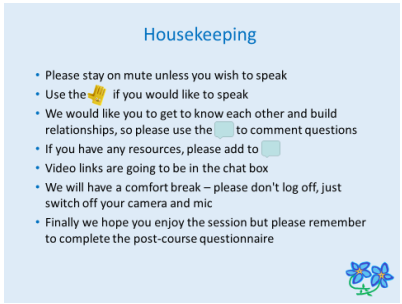
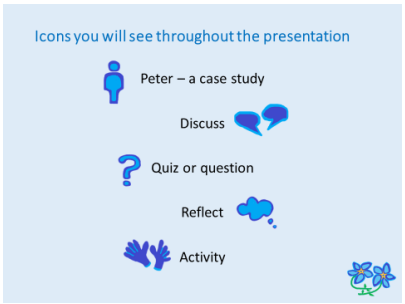
Each element of the programme has been mapped to the Dementia Training Standards Framework (Department of Health, Skills for Health, Health Education England and Skills for Care, 2018). These are presented in more detail in appendix iii.

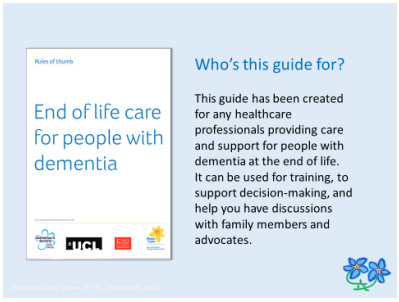
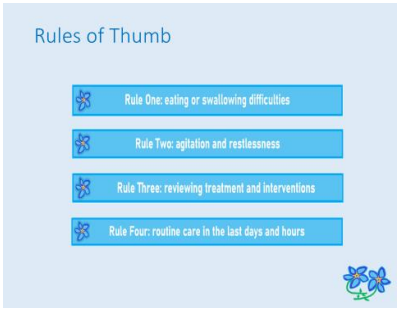
Contents

PRE-SESSION

Overview of session

The aim of this part of the programme is to welcome delegates, and show the different elements of virtual delivery. These can be amended if the session/s are being delivered face to face. If the mini-sessions are being delivered separately, it can be used prior to each session as a useful reminder. It also briefly introduces the Rules of Thumb guide to delegates.

	Notes for slides and activities
	
	
	
	

	**Some suggested ground rules. You may wish to write them up as you discuss or have them on screen as a 'given', but check everyone agrees with them** Treat everyone with respect Open communications Give constructive feedback Allow everyone to participate/share the time Listen with an open mind Maintain good timekeeping Keep camera on and microphone muted while not speaking
	**About Rules of Thumb…** Developed by a team of researchers from University College London and Kings College London and a group of family carers. The latest evidence from research and clinical practice, together with views and experiences of family carers and healthcare professionals (HCP). It is aimed at any HCPs 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 with discussions with family members and advocates.
	Comprises of four 'Rules' We are adding in two extra parts: Introduction and Conclusion to expand upon the Rules.

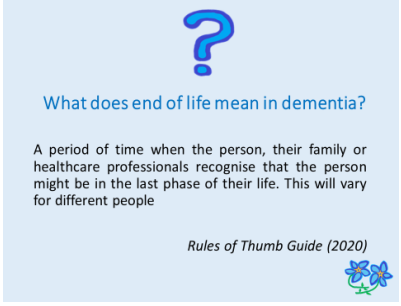
INTRODUCTION

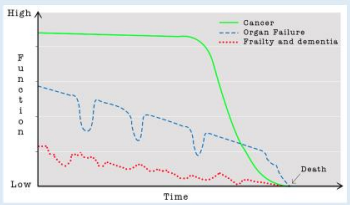
Outcomes

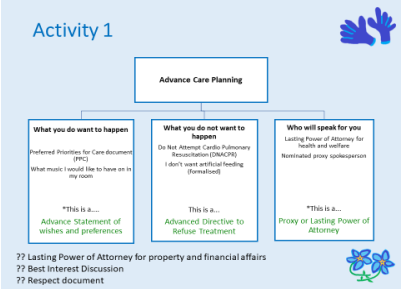
1. Be able to distinguish the key aspects of recognising the end of life in people with dementia
2. Identify the process of Advance Care Planning
3. Understand and appreciate the value of communicating with the wider multi-disciplinary team

Example session plan

Time	Content	Activity	Resources for facilitators
00.00	What is end of life care in dementia?	Ask for ideas of what defines EOL in PWD, what are the signs of progression	PP slide
00.10	Why is it difficult to identify dying in people with dementia?	Take the ideas from above to highlight why it is difficult	PP slide (summarise feedback)
00.25	Who should be involved in care decisions?	Do we know what the person wants? Who else 'decides'? Complete a blank flowchart/ diagram of ACP Discussion	Overview flowchart/ diagram of ACP PP slide (Completed flowchart)
00.40	The importance of communicating decisions and plans with others	Show or hand out 'Let's talk about death shall we3	Document Download link
00.45	Finish	End of session/break	PP slide

Slides	Notes for slides and activities
	
	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.

Why is it difficult to identify dying? • The person is likely to have difficulty in communicating any issues, relying on external judgement of their condition • The variable nature of the progression of dementia Deterioration can be sudden and unpredictable OR… A decline can happen so gradually that people do not link the person's eventual death with dementia (…see next slide)	Use the previous slide to draw out the difficulties
The course of illness  *Based On Lynn & Adamson, 2003*	Based on the work of Lynn & Adamson, this slide shows the trajectory of different diseases: **Cancer –** function levels stay mostly the same, once they do start to change then they usually continue to change **Organ failure –** COPD/Renal/Heart failure function levels may fluctuate and deteriorate over time, and often have acute episodes where they will require treatment and recover **Dementia –** much trickier to predict as their function levels and abilities will gradually decline, but for these you can see that they may well have a series of illness episodes such as infections that will sign that they are approaching end of life, and actually they may even appear they are in their last days or hours, and then rally around and stabilise for a time, and this is what makes it so difficult for carers and families
What does this mean? • The average life expectancy from diagnosis to death for dementia is 4.5 years[1] but many people live for 8 years and some for 20 years after diagnosis • Half of people with advanced dementia will die within 1.3 years • One quarter of those with advanced dementia will die within 6 months • Most people with advanced dementia do not die from devastating acute events, such as heart attack KEY MESSAGE… "Consider needs vs. prognosis"	1. BGS (2020) End of Life Care in Frailty: Dementia. https://www.bgs.org.uk/resources/end-of-life-care-in-frailty-dementia Rest of figures come from: Mitchell, S. L., Teno, J. M., Kiely, D. K., Shaffer, M. L., Jones, R. N., Prigerson, H. G., et al. (2009). The Clinical Course of Advanced Dementia. New England Journal of Medicine, 361 (16), 1529-1538.6 **Needs vs Prognosis**: The style of care as dementia progresses cannot be prognosis based, as we do not know the prognosis. It must therefore be needs based, with sensible and appropriate care provided according to need and the ability to participate in care and also to benefit from it
How do we identify when the very end of life is approaching? 	Ask group to share their ideas before showing the slide
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. • If the person is able to make decisions, consider advance care planning. If this is not the case, have they completed and advance care planning previously…. *Complete activity 1*	**Activity 1** Ask individuals (or smaller groups) to complete the chart from the text provided. The idea of this session is to quickly refresh the knowledge of ACP, not to provide a comprehensive session. If delegates don't have an understanding of the process, they will need directing to further reading/study. Mixed professional groups should be mixed up to promote discussion.

	Quickly summarise this chart ACP is NOT a legal document BUT professionals have to give sound reasoning as to why they are going against the patient's wishes Basically ACP is not legally binding and captures everything you would want ADRT IS legally binding but has to be very specific
	This document provides a pictorial and rapid refresh of the value of communications. Delegates could be asked what things they would take from this.

Additional resources (can be used to extend session if required)

Resource	Suggested use to extend session
Proactive Identification Guidance Supportive and Palliative Care Indicators Tool (SPICT™)	Use these tools to consider relevance for people with dementia. Enhances the discussion about the challenges of recognising end of life
Advance care planning for people who may lack capacity to make decisions in future	Helpful for those who don't understand ACP. It can be used to discuss situations where a person lacks capacity to make a decision, particularly around end of life decisions
Defining EOL in dementia – systematic review Browne etc. (2021)	A very current evidence based review that highlights the challenges in defining end of life
Understanding dying	Can be used for less experienced staff who require further understanding about approaching end of life
End of Life Care	As above
My future wishes for people with dementia	A guide that can support staff to have discussions and use appropriate documentation to record these
"I didn't want that" video Advance care planning for people who may lack capacity to make decisions in future	An emotional video that shows the impact of not having discussions. It is only just over 6 minutes long, but allow time for discussion after watching it.
"What's Best for Lily?" teaching video	This can be used to support staff working in care homes. The video gets across end of life care very well and helps staff to relate to it

Rule One: eating or swallowing difficulties

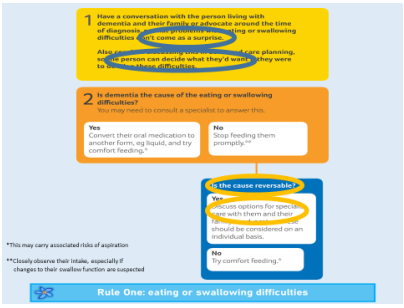
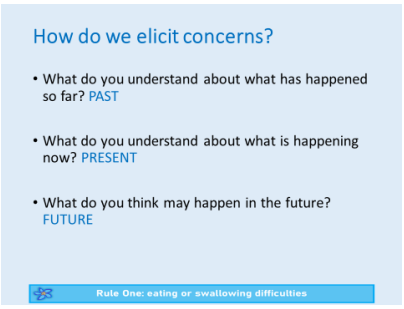
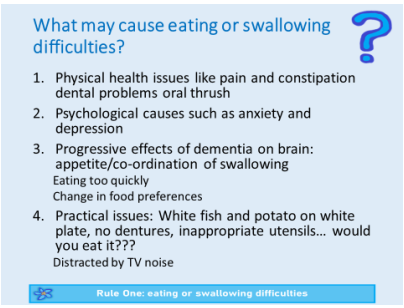
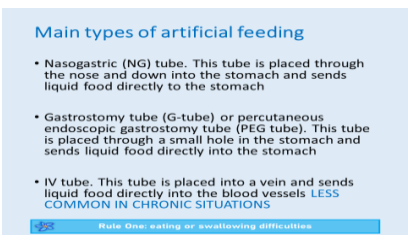
Outcomes

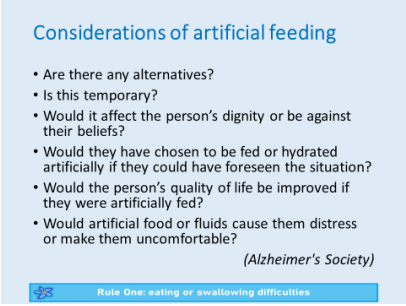
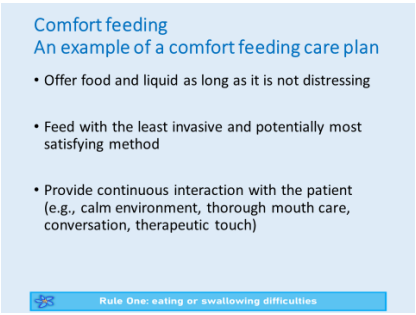
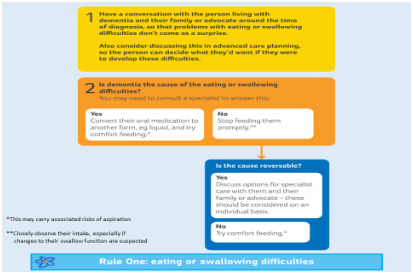
1. Understand why eating and swallowing difficulties causes surprise, and the impact that has on families and professionals
2. Be able to list the key reversible causes for eating and swallowing difficulties
3. Identify different forms of feeding and their advantages and disadvantages
4. Describe ways to support the person, families and carers

Example session plan

Time	Content	Activity	Supporting resources for facilitators
00.00	Case study Introduce Rule One	Meet Peter Talk through PP slide with rules flowchart	Case study Rules of Thumb document – share/have available to take away
00.05	Don't let it be a surprise (Early conversations)	Why does it come as a surprise? How does it feel for families and professionals? How can we elicit information/ concerns?	Figures re recognition of inability to swallow PP slide - Examples of Qs that may be used to elicit information/ concerns etc.
00.15	Reversible causes – Is it caused by dementia?	What may these be? – ask group to identify White food activity with unexpected noise over the top	PP slide (summarise) Crowdnoisehttps://freesound.org/people/pushtobreak/sounds/18684/
00.20	Types of feeding	Different types of artificial feeding Considerations of artificial feeding	PP slide
00.30	What do we know about Peter?	Use flow chart from introduction session – what do we know about Peter's wishes? Comfort feeding – how to support this	PP slide (completed flow chart) Case study
00.45	Finish	Show rules flowchart End of session/break	PP slide

Slides	Notes for slides and activities
	
	This is an introduction to Peter, a case study that will recur throughout the programme. There is an additional case study information sheet for facilitators with further information and guidance for the case study.

	This comes directly from the Rules of Thumb guidance. These are the aspects that we will focus on through the session. Ensure that delegates know that the Rules of Thumb also contains additional information to support this chart.
	Alagiakrishnan K, Bhanji R, Kurian M. Evaluation and management of oropharyngeal dysphagia in different types of dementia: A systematic review. Archives of Gerontology and Geriatrics. 2013;56(1):1-9 Arcand M. End-of-life issues in advanced dementia: Part 2: management of poor nutritional intake, dehydration, and pneumonia. Can Fam Physician. 2015;61(4):337-341.
	Gaining an understanding from past, present and future can very quickly allow us to elicit concerns, although further probing is likely to be needed
	Ask delegates to give you their ideas before revealing the responses
	**This activity can be explored with delegates.** First, ask them how they would feel about eating this food, then how it feels if they cannot properly see it? A further layer can be added by playing the crowd noise over the top (noisy dining room). Is this conducive to eating?? The crowd noise track is available on the website
	**Risks and harms associated with feeding tubes in those with advanced dementia** The following are among the risks and harms of tube feeding: Pain and other complications (e.g., infection, bleeding) directly associated with placement of tube Increased risk of aspiration Increased risk of pressure ulcers

	Gastrointestinal symptoms from feeding (e.g., diarrhoea, constipation, reflux) Physical and chemical restraints to prevent patient from pulling out feeding tube Fluid overload leading to increased pulmonary or peripheral oedema, upper airway secretions Can increase the perception of hunger (Ying, 2015)
	
	So ACP/LPA and ADRT's must be completed when the person has capacity, what do you do if the person does not have the capacity to do this? What does this mean for Peter
	There is an additional case study information sheet for facilitators with further information and guidance for the case study.
	This is a very brief list and more can be added if needed
	This comes directly from the Rules of Thumb guidance. These are the aspects that we will focus on through the session. Ensure that delegates know that the Rules of Thumb also contains additional information to support this chart.

Additional resources (can be used to extend session if required)

Resource	Suggested use to extend session
Eating and drinking - Information for family and friends as dementia progresses towards the end of life	This booklet has been designed for family or friends. This can be used as a discussion point for staff dealing with families who are struggling with this issues (or indeed themselves)
Attitudes of people with mild dementia: very individual (Ananatapong)	A study to explore how people living with mild dementia understand possible future eating and drinking problems and their perspectives on assistance. This helps to promote discussion around the emotional aspects of eating and drinking
White and red plate examples	This gives an option of exploring the white food/white plate activity in the mini-session.
Talking about dementia and dying - A discussion tool for residential aged care facility staff	As we touch very briefly on how to have conversations, this guide expands on this area to help to give confidence to staff when speaking about dementia and dying

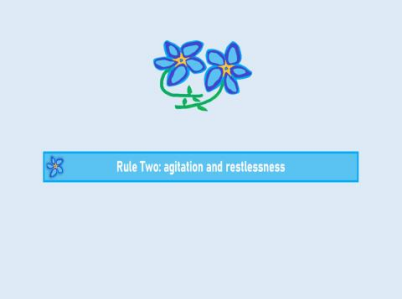
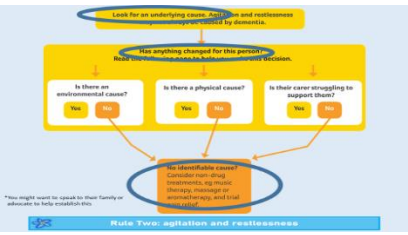
Rule Two: agitation and restlessness

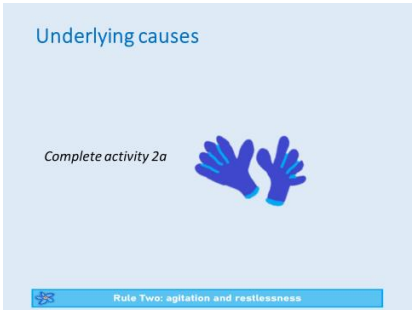
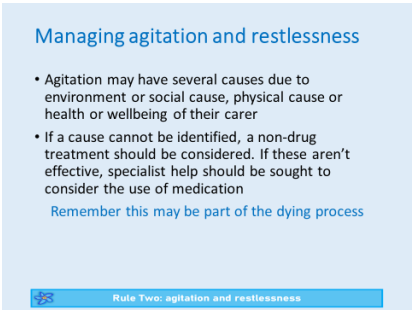
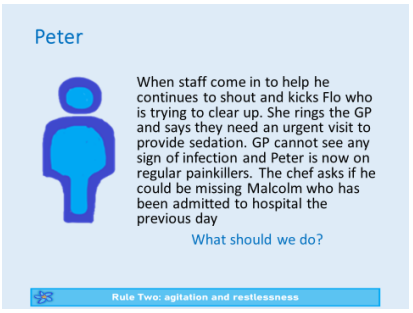
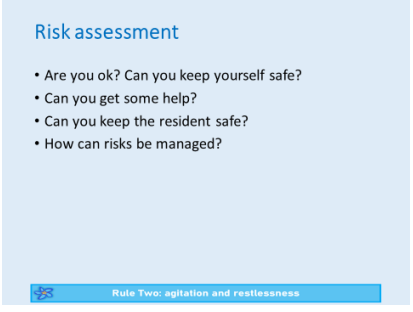
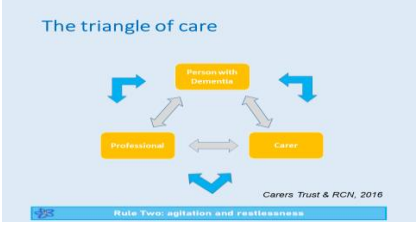
Outcomes

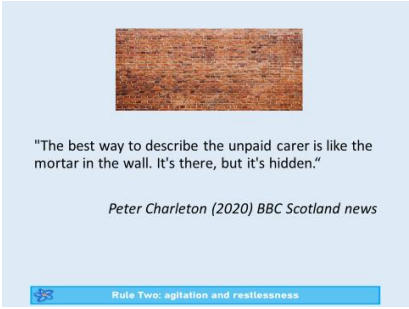
1. Define the key underlying causes of agitation and restlessness
2. Summarise the main approaches to managing agitation and restlessness
3. Understand the importance of risk assessment and identity the steps to carrying out a risk assessment
4. Appreciate the need to support the health and wellbeing of carers

Example session plan

Time	Content	Activity	Supporting resources for facilitators
00.00	Case study Introduce Rule Two	Talk through PP slide with rules flowchart	Rules of Thumb document share/have available to take away
00.05	Understanding underlying causes (not always caused by dementia)	Peter What may they be? Include environment and physical causes. Use activity to draw these out	Case study Activity sheet 2a
00.15	Managing agitation/ restlessness	Which approaches to choose to manage – pros and cons	PP slide Case study
00.25	Risk assessment (person with dementia/ others)	Use a situation to discuss	PP slide. Use case study to illustrate
00.35	Health and wellbeing of carers	Where do carers 'fit in' Listen to carers story Activity - revise Age UK carer's check list for someone at end of life	The triangle of care https://www.youtube.com/watch?v=g6rk88V-TvM&pp=sAQA Cure the care system Activity sheet 2b - blank check list
00.45	Finish	Show rules flowchart End of session/break	PP slide

Slides	Notes for slides and activities
	
	This comes directly from the Rules of Thumb guidance. These are the aspects that we will focus on through the session. Ensure that delegates know that the Rules of Thumb also contains additional information to support this chart.

	There is an additional case study information sheet for facilitators with further information and guidance for the case study.
	**This activity** encourages delegates to think more broadly about behaviours. It's not always an obvious cause, or it may be more than one thing that is provoking the behaviour. Ask delegates if they are labelling residents/clients at times?? Stress that it is not always caused by dementia Aggression is a reaction and unlikely to be deliberate, more likely fear or desperation
	Assessment is key in order to try and find a cause (not always possible) When would medication be indicated? Is it over used in their setting?
	There is an additional case study information sheet for facilitators with further information and guidance for the case study.
	Does risk assessment get carried out? What about a daily shower? Does the risk of doing this outweigh the consequences? There may be times when the risk outweighs any input, this may mean a resident/client moving to a different unit/home – how does this feel?
	So, family carers and professional carers are the key to their loved ones care The Triangle of Care approach is aimed at bringing together carers, service users and professionals & was developed to address the clear evidence from carers that they need to be listened to and consulted more closely.

	This approach was originally developed for use in mental health services but the 6 standards of care that are key to achieving better collaboration & partnership with carers can be applied to other care settings including dementia care.
	Discussion about the potential impact on carers
	
	This activity is to highlight the many issues that *may* affect carers. It can also be applicable to professional carers as well.
	This comes directly from the Rules of Thumb guidance. These are the aspects that we will focus on through the session. Ensure that delegates know that the Rules of Thumb also contains additional information to support this chart.

Additional resources (can be used to extend session if required)

Resource	Suggested use to extend session
Aggressive behaviour from people with dementia	This can be used to further the consideration of different aspects in relation to aggressive behaviour
End of Life Care in Frailty: Dementia	Aimed at clinicians, this can help to support their understanding of managing distress in dementia

A carer's story VIDEO	This further enhances the understanding of the role of the carer of a person with dementia
A decision aid to support family carers of people living with dementia towards the end-of-life: Coproduction process, outcome and reflections	An evidence- and theoretical-based process for developing a decision aid. This may be used for those who wish to think more about supporting family carers

Rule Three: reviewing treatment and interventions

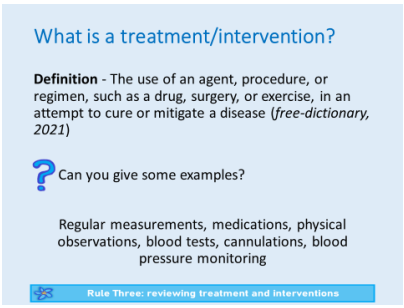
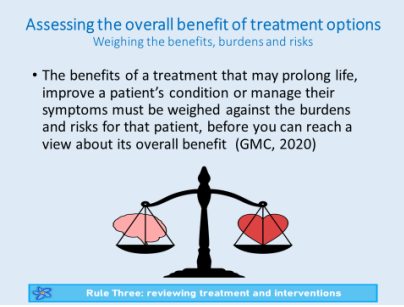
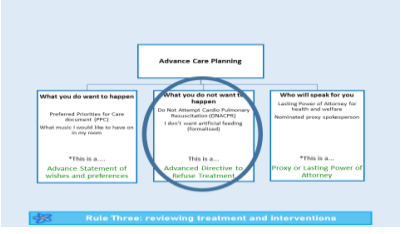
Outcomes

1. Consider different treatments associated with end of life care
2. Understand the influence of advance decisions on end of life decision making
3. Explain what a Treatment Escalation Plan is
4. Recognise the importance of Multi-Disciplinary Team involvement

Example session plan

Time	Content	Activity	Supporting resources for facilitators
00.00	Case study Introduce Rule Three	Talk through PP slide with rules flowchart	Rules of Thumb document share/have available to take away
00.05	What are treatments/ interventions? Making decisions re: continuing/ stopping	Define treatment/ intervention – group to give some examples Making decisions – benefits vs risks vs burden Consider benefits vs risks vs burden	PP Slide (definition from RoT) Provide examples Case study Activity sheet to make list of benefits, risks, burdens
00.20	Advance Decisions	Revisit diagram from session 1– where does AD fit in	Overview flowchart/ diagram of ACP PP slide (Completed flowchart)
00.25	Continuous review and assessment	Group to reflect on the situation for Peter and how might TEP change over time	Case study and update on PP
00.35	The role of the Multi-Disciplinary Team	Discussion - How do team work together?	PP slide
00.45	Finish	Show rules flowchart End of session/break	PP slide

Slides	Notes for slides and activities
	
	This comes directly from the Rules of Thumb guidance. These are the aspects that we will focus on through the session. Ensure that delegates know that the Rules of Thumb also contains additional information to support this chart. Once all reversible causes (in best interest) have been ruled out and the decision is that they may well be actively dying, then you need to review current treatment and interventions. Medications should be rationalised and interventions such as routine bloods discussed as to their need v distress and outcomes

	If it's still needed then carry on but review if there are any further deterioration or causing discomfort Commence the Individual Plan of Care for the Dying person if used in your area Ask families and carers if they have any concerns or questions, it's much better for you to answer them that it is to let them google or ask the neighbour!! If you don't know the answer just tell them you will ask the GP/DN or SPCN but don't let it put you off asking about concerns
	Provide the definition and ask group to give examples of what they think are treatments/interventions Cure or mitigate is a key point
	There is an additional case study information sheet for facilitators with further information and guidance for the case study.
	For example, it may be of no overall benefit to provide potentially life prolonging but burdensome treatment in the last days of a patient's life when the focus of care is changing from active treatment to managing the patient's symptoms and keeping them comfortable Treatment and care towards the end of life: good practice in decision making (GMC, 2020)
	This activity ties in with the case study and requires the careful balancing of benefits, risks and burdens. The case study document includes a range of these for discussion. If you have a mixed professional groups, there are often different perspectives, but this is about encouraging delegates to see each other's points of view.
	This is here to remind delegates about the importance of ACP and ADs rather than a lengthy discussion.

	There is an additional case study information sheet for facilitators with further information and guidance for the case study.
	If the group is mixed, it may be useful to take them back to the case study and consider the different perspectives. How do we ensure that we work together??
	This comes directly from the Rules of Thumb guidance. These are the aspects that we will focus on through the session. Ensure that delegates know that the Rules of Thumb also contains additional information to support this chart.

Additional resources (can be used to extend session if required)

Resource	Suggested use to extend session
"Supporting people with dementia to have a good death" VIDEO	A thoughtful 11 minute film to help develop thinking around we can help people with dementia to die how they wish to
Treatment and care towards the end of life guidance	If delegates wish to understand more about making benefit based decisions, this resource is really helpful
ReSPECT	Helpful to provide information for those who want to know more about ReSPECT
Sample Treatment Escalation Plan	Can be used to demonstrate a hospital based TEP
How to create a document - Dementia - value of an Advance Decision	A practical opportunity to create an advanced decision
NHS Structured medication reviews and medicines optimisation: guidance	Not everyone is familiar with structured medication reviews, so this could be used to provide clarity

EHCH framework	This can be used to consider how homes work within the framework and what it means to them

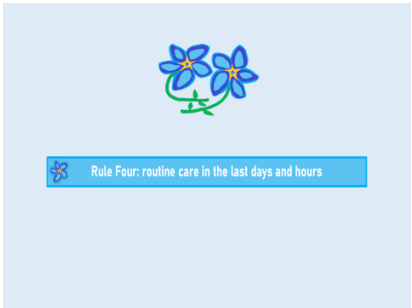
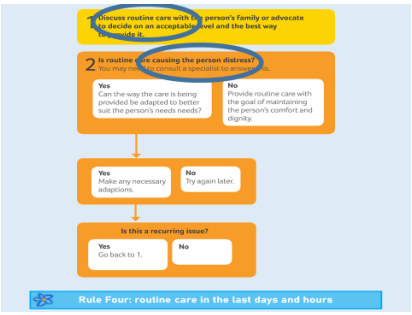
Rule Four: routine care in the last days and hours

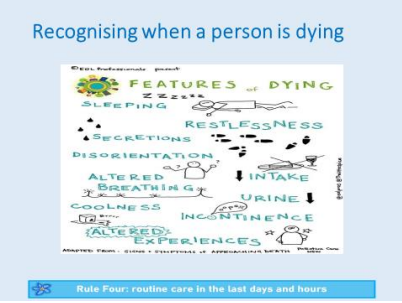
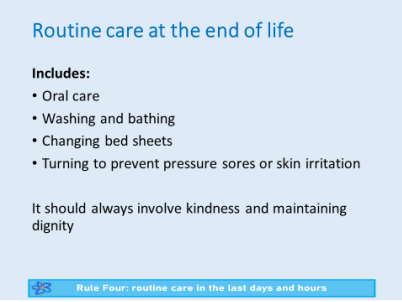
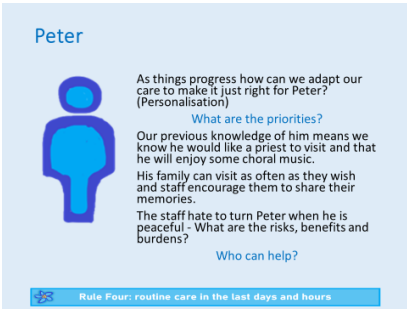
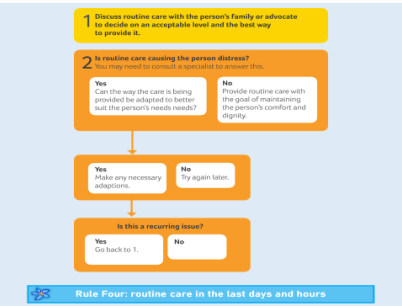
Outcomes

1. Be able to identify the key aspects of recognising the end of life in people with dementia
2. State the major characteristics of personalised, quality and acceptable care at the end of life
3. Discuss ways of providing personalised, quality and acceptable care at the end of life

Example session plan

Time	Content	Activity	Supporting resources for facilitators
00.00	Case study Introduce Rule Four	Talk through PP slide with rules flowchart	Rules of Thumb document share/have available to take away
00.05	Recognising when a person is dying	Link back to intro, mini-session 1 Discussion – how does this feel now – what have we learnt?	PP slide (shown in session 1)
00.10	Care at end of life	Group discussion -what are the key elements **AND** what do delegates do to provide care? **Routine care** to provide comfort and dignity (Oral/ mouth care, washing / bathing, turning, pressure area care)	PP slide
00.25	**Adapting care** (Person Centred Care) Advance Care Plan Acceptable levels of care	What are the priorities? How can we support?	Case study
00.45	Finish	Show rules flowchart End of session/break	PP slide

Slides	Notes for slides and activities
	
	This comes directly from the Rules of Thumb guidance. These are the aspects that we will focus on through the session. Ensure that delegates know that the Rules of Thumb also contains additional information to support this chart. Must be balanced against risk i.e. find alternative ways to clean mouth, use baby toothbrush, pressure relief a little less often, give analgesia ½ hour prior to moving.

	Involve the family in care-giving: Ask the family if they would like to be involved. Use Rule of thumb for guidance. Rule out reversible causes – discuss with MDT. Manage the symptom - ? pain ?isolated ?need comfort. Discussion with family.
	How do the group feel about this now? What have has been learned?
	Group discussion If the group is mixed, are there different priorities? Are the priorities equal? How do we meet the needs of the client/resident as a team?
	This list is not exhaustive – is there anything missing? What is the 'minimum' care required? For who? Carers, the family, the care home manager? Does this cause a challenge when the client/resident is distressed receiving 'care'?
	There is an additional case study information sheet for facilitators with further information and guidance for the case study.
	This comes directly from the Rules of Thumb guidance. These are the aspects that we will focus on through the session. Ensure that delegates know that the Rules of Thumb also contains additional information to support this chart.

Additional resources (can be used to extend session if required)

Resource	Suggested use to extend session
Development of a caregiver-reported measure to support systematic assessment of people with dementia in long-term care: The Integrated Palliative care Outcome Scale for Dementia	For those who want to support a systematic way of assessing people, this can provide further guidance
Webinar - A Measure to Assess Symptoms and Concerns in Advanced Dementia	A webinar that could be included in the session to support the information above
What you can do to practically care for someone who is in their last days and hours of life	Helps to have further discussions about key aspects of end of life care

CONCLUSION

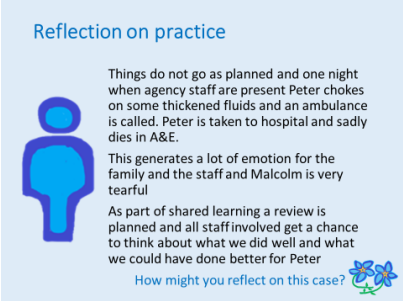
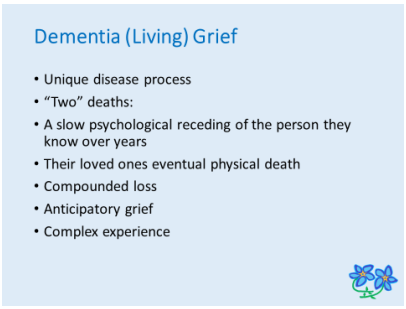
Outcomes

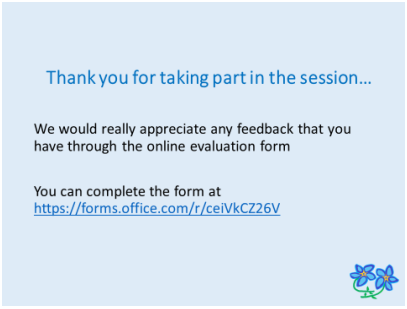
1. Recognise the major impactors on and of bereavement
2. Understand ways in which people can be supported post bereavement
3. Identify ways in how this programme can be utilised in individual's own practice

Example session plan

Time	Content	Activity	Supporting resources for facilitators
00.00	What is reflective practice?	Provide definition Reflection on practice– what went well? What didn't? What if things hadn't gone to plan?	PP slide
00.05	Reflection on event	How might you reflect on this case?	Case study
00.20	Bereavement – what is it and what is the impact Supporting others after bereavement	Definition of bereavement Listen to Emma Scattergood's story: My bereavement journey Summary quote	PP slide Emma's story PP slide
00.30	Using the programme in practice	What have you learnt? Reflecting on how this may be applied	Reflective personal action plan (activity sheet no 5)
00.45	Finish	End of session/evaluation	Evaluation form

Slides	Notes for slides and activities
	
	Consider the value of this. Does this take place on a regular basis? If there is a mixed group, how do we work to reflect well together (instead of in silos/our own professional groups)? How do we avoid the 'blame culture' if something has been perceived to have not gone well? See Six Steps for more information about SEA

	There is an additional case study information sheet for facilitators with further information and guidance for the case study.
	Bereavement is what happens to you due to a loss and includes grief and mourning. Bereavement care is an integral part of good care, and is relevant both before and following the death of a person. Lasting memories of what happened around the time of death can stay with those who have been bereaved for many years and can support or hinder them in their adjustment to the death. Preparing people to face the approaching death of a loved one will help them to cope after the death has occurred.
	Dementia causes a unique situation to occur where the carer experiences 2 Deaths: The 1st death is slow psychological receding of the person they know over years The 2nd death is the person's eventual physical death. However, Dementia is a unique disease process that creates an unusual situation: the person with dementia gradually recedes from their loved ones while still alive. The family loses the person they loved bit by bit before their physical death.
	**Read out Emma's story** Don't let fears about saying or doing the wrong thing stop you from reaching out Acknowledge the loss Let the person know that you're there to listen Understand that everyone grieves differently and for different lengths of time Offer to help in practical ways Maintain support and contact after the funeral
	
	This activity is to encourage delegates (while they are still framing the programme) to consider the changes they need to make in their own practice. But it's also about them recognising their own skills too. Advice to delegates – keep it simple and manageable (SMART!!)

	Please encourage delegates to complete the evaluation form. They will be asked if they are happy to be contacted via phone for a short interview about this programme

Additional resources (can be used to extend session if required)

Resource	Suggested use to extend session
Together in dementia everyday	A video of Natasha, daughter of a women who has dementia, speaking about the impact that her Mother's condition has had on her and her family. A good discussion point with staff and carers
Bereavement, loss and dementia	This leaflet raises a number of issues that can be further discussed with delegates
Re-framing Conversations around End of Life	A video to watch and discuss showing the perspectives on death and dying from people with dementia and carers. A very frank video to observe
End of Life Care and Post Bereavement Support - Shifting the Conversation from Difficult to Important	A document in relation to the above video
Video Q&A with an Admiral Nurse: Bereavement and memory loss	An Admiral Nurse does a Q&A with person with dementia. An opportunity to watch and discuss with delegates
GM syllabus for EOLC and those with dementia	A Greater Manchester resource that can be used as a talking point for supporting care homes with training

Appendices

Appendix i - Peter – a case study

	Case study	Considerations
Within PP	Peter is an 85 yo gentleman who has recently moved into a care home He has dementia and Type 2 diabetes and had a heart attack 5 years ago. He had been living at home with his family until his wife fell ill and he came to the care home for respite before converting to a permanent residential placement	
Rule One: eating or swallowing difficulties		
Within PP	He has lost weight over the last 6 weeks and isn't eating very much. Despite the best efforts of the chef and his family, he still seems disinterested in his food. He is diagnosed with depression and things do improve when he starts sertraline. He is observed laughing together with another resident, Malcolm. In spite of this the volume that he eats reduces gradually and his daughter is frightened he will starve to death	Why do people have difficulties with eating and swallowing? Symptom of dementia progression Natural part of the body shutting down Reversible causes
	Decision: Comfort feeding	
Rule Two: agitation and restlessness		
Within PP	Peter seems really settled for a few months and even joins in with the visiting choir and church services. One day he refuses breakfast and when his daughter comes with some lunch for him he pushes the plate onto the ground. Over the next few days he is very noisy and causing distress to other residents. He seems angry and everyone is on edge	What is agitation and restlessness? A means of communication
Within PP	When staff come in to help he continues to shout and kicks Flo who is trying to clear up. She rings the GP and says they need an urgent visit to provide sedation. GP cannot see any sign of infection and Peter is now on regular painkillers. The chef asks if he could be missing Malcolm who has been admitted to hospital the previous day	What can you do? How do you keep yourself and other staff safe? Who can help? Don't overlook our social and emotional needs
Use this information to update group	This new thought helps staff to understand what Peter is trying to express and they feel better able to look after him.	

	Peter continues to have altercations with other residents, going into their rooms at night and eventually it is agreed to try a small dose of risperidone in the evening. This is done because of balance of risk to peter and the other residents. Keeping ourselves safe and balancing risk. Frequently reviewed: after six weeks Peter's risperidone is reduced and stopped and he returns to his usual self.	
Rule Three: reviewing treatment and interventions		
Within PP	Peter's swallowing difficulties continue and he starts to choke when trying to swallow his atorvastatin capsule. What are the options? Covert medication? Review goals of treatment and stop atorvastatin? How can we make these decisions? Benefits risks and burdens Best interests	**Carers** emotions: sense of sadness and worry, we are doing our very best and he is still losing weight **Family** emotions: Don't let him starve to death Prior knowledge of his wishes and preferences **GP:** factual knowledge and personalised medical risk assessment too frail for procedure and r/o aspiration pneumonia and increased distress, prolongs dying process **OT:** practical help…try altering his position or using a smaller spoon **Dietician:** other ways to increase his calorie intake: fortifying the food he does eat, adding supplements **SALT:** there are risks with every option
	Complete activity 3	
Use this information to update group following discussion of activity 3	It is agreed to stop most of his prevention medications A Treatment Escalation Plan is drawn up (Respect) which reflects his ACP and his previously known wishes Preferred Place of Death = care home DNACPR For hospital admission if appropriate but not for ICU (ward level care)	
Within PP	As the months go by, Peter continues to lose weight and becomes more frail His swallow worsens and he is bed bound; GP and care home feel he is reaching the end of his life. His family find this hard to take on board. All of his medications are discontinued and we start to focus on symptom management: for example pain relief, regular turning and good mouth care His Treatment Escalation Plan is adjusted to reflect the new priorities of care: not for hospital admission (except for fractures, serious head injuries or intractable symptoms)	
Rule Four: routine care in the last days and hours		
Within PP	As things progress how can we adapt our care to make it just right for Peter? (Personalisation) What are the priorities?	

	Our previous knowledge of him means we know he would like a priest to visit and that he will enjoy some choral music. His family can visit as often as they wish and staff encourage them to share their memories. The staff hate to turn Peter when he is peaceful What are the risks benefits and burdens? Who can help?	
Conclusion		
Within PP	Things do not go as planned and one night when agency staff are present Peter chokes on some thickened fluids and an ambulance is called. Peter is taken to hospital and sadly dies in A&E. This generates a lot of emotion for the family and the staff and Malcolm is very tearful As part of shared learning a review is planned and all staff involved get a chance to think about what we did well and what we could have done better for Peter. How might you reflect on this case?	Communication? Did we get the right skill sets at the right time? Did we personalise our care for Peter? Did we look after his physical social environmental and spiritual/emotional needs? How can we involve the family? What about Malcolm?

Appendix ii - Activity sheets

All activity sheets are available for download on the Six Steps website. List of activity sheets available:

Activity sheet 1 – Advance Care Planning
Activity sheet 1 – Advance Care Planning WITH RESPONSES

Activity sheet 2a – Underlying causes
Activity sheet 2a – Underlying causes WITH RESPONSES

Activity sheet 2b – Carers checklist
Activity sheet 2b – Carers checklist WITH RESPONSES

Activity sheet 3 – Benefits, risks and burdens
Activity sheet 3 – Benefits, risks and burdens WITH RESPONSES

Activity sheet 5 – Reflection and personal action plan

Appendix iii - Mapping to Dementia Training Standards Framework

The Rules of Thumb programme (all sessions) has been cross mapped to the Dementia Training Standards Framework to support delegates and facilitators to check the tier and the learning outcomes of the programme.

Subject no	Subject	Tier and key learning outcomes
1	Dementia awareness	**T1, T2, T3** a, g, h, j, k, f
2	Dementia identification, assessment and diagnosis	**T2** d
3	Dementia risk reduction and prevention	-
4	Person-centred dementia care	**T2** a, b, c, d, e
5	Communication, interaction and behaviour in dementia care	**T2** a, l, m, n, o, p
6	Health and well-being in dementia care	**T2** h, i, k
7	Pharmacological interventions in dementia care	-
8	Living well with dementia and promoting independence	**T2** g
9	Families and carers as partners in dementia care	**T2** a, c
10	Equality diversity and inclusion in dementia care	**T2** a
11	Law, ethics and safeguarding in dementia care	**T2** b, d, e, f
12	End of life dementia care	**T2** a, b, d, f, h **T3** b, c
13	Research and evidence-based practice in dementia care	-
14	Leadership in transforming dementia care	-