

Final Report - The Rules of Thumb Project

July 2022

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This report describes and shares ideas and early learning from a project in Greater Manchester and Eastern Cheshire Strategic Clinical Networks (GMEC SCN), which facilitated the development and delivery of an educational programme, addressing the palliative and end of life care needs for people with dementia. The programme is based on ‘The Rules of Thumb’ and is aimed at professionals working in care homes and Primary Care Networks (PCNs). The aim of this project is to enhance the delivery of palliative and end of life care to people living with dementia in GMEC to improve their experience, and that of their families. Greater Manchester and Eastern Cheshire Strategic Clinical Networks Palliative and End of Life Care Team undertook this project and Dr Helen Martin lead the programme as the dementia clinical lead

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INTRODUCTION

Mortality rates for Alzheimer’s disease and other dementias have increased over the last decade (Alzheimer’s Research 2021). In 2020, dementia and Alzheimer’s accounted for 11.5% of all deaths. Although this is a decrease from the previous year’s figures, summing together the deaths caused by dementia and the number of people with dementia who died from COVID-19 accounts for 14.5% of total deaths in the UK in 2020 (Office of National Statistics). Despite this, dementia is still not universally recognised as life limiting and when people are in the dying phase, they are often no longer in contact with dementia specialists. Fifty eight percent of people with dementia will die in the care home setting and 29% will die in hospital (Public Health England, 2019). Dying with dementia brings unique challenges that can be difficult to manage without appropriate training for those professionals providing end of life care.

BACKGROUND

Phase one of the programme development

[Dementia United](#) made a decision to fund and develop a bespoke dementia end of life training package for Primary Care Networks and care home teams, based on the Rules of Thumb work created by Nathan Davies and the University College London. This guide was created as part of a research project funded by Marie Curie and Alzheimer's Society and was developed by an experienced team of researchers and health and social care professionals, including GPs, psychiatrists and a group of family carers. The following first steps were taken:

- Engagement with Greater Manchester Hospices
- A Greater Manchester syllabus for dementia end of life training with a big focus on the University College London's rules of thumb guide
- St Anne's Hospice and Springhill Hospice educators translated the syllabus into a lesson plan and slide set designed to be delivered to Primary Care Network and care home teams
- A training webinar was tested with a Trafford team and adjustments were made accordingly
- Educator Packs were created to support interested educators to plan, deliver content and evaluate training consistently across Greater Manchester and Eastern Cheshire. There is a constant programme content, but the programme allows a flexibility of delivery according to locality needs

Phase two

For the next phase of the programme development, the collaboration between Dementia United and Greater Manchester and Eastern Cheshire Strategic Clinical Network's Palliative and End of Life Programme continued, and the responsibility for piloting and delivering the programme moved to the Palliative and End of Life Care Programme Team on the 1 April 2021.

The project took a pump-prime approach with interested locality educators delivering a small number of sessions in their locality. Primary Care Networks (PCNs) and care homes were the focus of the training audience, as 58% of people with dementia will die in a care home setting (Public Health England, 2019). Moving forward, PCNs will need to work closely with care homes, through initiatives such as the Enhanced Health in Care Homes Framework to provide optimum care for people with dementia approaching end of life.

Programme Objectives

- To trial the 'Practical ways of supporting care homes and PCNs to collaborate and share learning to support people with dementia at the end of life', based on the Rules of Thumb guide, learning programme
- To enhance ways of working together through small group learning in newly forming Multidisciplinary Teams (MDTs) in care homes, thus fostering a local and personalised approach
- To actively engage with the PCNs to support the delivery of this work and provide feedback to the Strategic Clinical Networks on the delivery of the package which may enhance the quality of the learning package
- To support active engagement between the leading training organisation and the PCN
- To support education for the MDT and care home staff

DEVELOPING THE PROGRAMME

The purpose of the programme development was to work with the Rules of Thumb guide to transform it into a deliverable education programme that offered facilitators a comprehensive set of resources that would be flexible enough to adapt to a diverse group of delegates. The programme requires a multi-disciplinary approach to include MDT education and collaborative working with care homes.

A small amount of funding was offered, to the sum of £1000 per locality wishing to pilot the package, in return the Strategic Clinical Networks (SCNs) were keen to learn from the delivery sites so as the package could be updated on the early implementers feedback.

A requirement of delivering the package was that there would be active engagement between the leading training organisation and the PCN to support education for the MDT. There was also a need to create working opportunities where the MDT can work collaboratively with care home staff to enhance the care for people with dementia approaching or at end of life.

The SCN worked with Springhill Hospice, St Ann's Hospice, Dr Helen Martin (Clinical Lead) and the End of Life Partnership to design the programme. It may be delivered in a single session, as an extended half-day session, across several sessions or incorporated into other programmes, such as the Six Steps end of life care home programme.

The Rules of Thumb guide already provided a clear structure for the sessions, so the four rules¹ remained in its' original order, with the addition of introduction and conclusion sessions resulting in six mini-sessions'. Each mini-session had a PowerPoint presentation, a range of resources and activities, links to document, videos and audio resources. The activity sheets are an important element as a key emphasis of the programme is its' interactive design. At some points, activities are linked from one mini-session to another to promote continuity between the four 'Rules'. A case study (with facilitator notes) was written by a clinician to ensure links to clinical practice. Finally, a full facilitator guide was developed to support facilitators to become familiar with the delivery and content.

All resources are provided for the programme free of charge and available on the [Six Steps website](#)

¹ The four Rules of Thumb are: Eating or swallowing difficulties; Agitation and restlessness; Reviewing treatment and interventions; Routine care in the last days and hours

The package of support

A small project team, including the Clinical Lead, project manager and programme designer were available to support each locality in delivering the objectives and engaging with key partners and stakeholders. The project team were keen to support early implementers and offered a programme of virtual support sessions to the educators of the locality delivery sites.

Project offer and requirement of localities:

Project offer

- Web based package and resource materials
- Support for delivery teams via a programme of virtual sessions and engaging key partners
- Financial contribution to support localities coming forward to be part of the initial delivery

Requirement of localities






- Collaboration with Dementia services and PCN regarding delivery
- Completion of an agreement to release the funding
- Delivery of the programme
- Contribute to evaluation measures
- Feedback on programme package

Outline of the virtual support sessions for the educating teams

Session	Actions	Timeline
Session One Set up	Initial set up meeting between delivery teams and the SCN project team to help clarify the aims of the project, and to walk through the programme and resources	September 2021
Session Two New ways of working with PCNs	A session to explore new ways of working with PCN'S and the opportunities, to share ideas/ learning on what works well in terms of the delivery of multi-disciplinary training. Progress updates from localities and troubleshooting	September 2021
Session Three Progress and Problem solving	Individual Sessions with each Rules of Thumb delivery team to review progress and problem solve	October 2021

Session Four Evaluation	Individual meetings between the programme designer and each delivery team to learn more about each of the delivery teams experiences and feedback from delivering the programme	January 2022
Session Five Reshaping the programme	Delivery Teams and project team come together to discuss summary of findings from the Rules of Thumb GMEC programme evaluation, and to use the expertise of the delivery teams to check the planned changes resulting from their feedback	February 2022

Geographical location of delivery sites and different modes of delivery

Organisation and locality	Format	Structure of delivery	Delivery team
 Bolton Hospice caring from the heart Bolton	Virtual	1 full day	2 hospice educators
 Confidence to Care Eastern Cheshire	Face to face	1 full day Have also used content in other shorter sessions	1 EoLC facilitator and 1 Admiral Nurse
 Manchester Local Care Organisation Leading local care, improving lives in Manchester, with you Manchester	Face to face	One afternoon session to MDT	2 EoLC educators and 1 GP
 SPRINGHILL HOSPICE Making every moment count Heywood Middleton and Rochdale	Face to face	1 full day (included additional 'what is dementia' session) Also used core resources in other half day dementia and EoLC training	2 EoLC educators
 Wigan & Leigh Hospice Wigan and Leigh	Virtual	Content included in existing training which includes 90 minute sessions and half day training	1 or 2 EoLC educators

EVALUATION OF THE PILOT SESSIONS

The process

The programme evaluation took place from two different perspectives:

- 1) Evaluation and feedback from delegates who attended the locality sessions
- 2) Feedback from the education delivery teams

1) Evaluations from delegates attending sessions

1. A post-course evaluation form was included in the resources (See Appendix I) and facilitators asked delegates to complete the forms following the session. Post completion, the SCN Programme team compiled the returned forms.
2. On the evaluation form, delegates were asked if they could be contacted four to eight weeks following the session. If they consented, delegates included their email address and a link to a Microsoft Forms evaluation containing five questions was sent
 1. Where did you attend the session or what was the name of the educators/facilitators who led the session? (this was only used as an identifier)
 2. Did you enjoy the session?
 3. On a scale of 1 to 10, how useful did you find the session (1 being the least useful)
 4. If you could change anything about the session, what would it be?
 5. If you would like to discuss anything about this course, please put your email address below and we will get in touch to arrange a call to speak with you

Summary of results from the evaluations

1. Forty evaluation forms were completed and returned. The following table reports on the results

	Pre session	Post session
Q1a. Please can you rate your levels of knowledge before and after today's session?	3.5*	4.4*

Q1b. Please can you rate your levels of skills before and after today's session?	3.3*		4.2*		
Q1c. Please can you rate your levels of confidence before and after today's session?	3.3*		4.3*		
Q2a. How would you rate the content of the speakers? (on a scale of 1 – 5)	4.6*				
Q2b. How would you rate the presentation of the speakers? (on a scale of 1 – 5)	4.5*				
Q3. As a result of attending today's event, how likely are you to make a change to your future actions and behaviours?	Not at all	Unlikely	Quite likely	Most likely	Highly likely
	0#	3#	3#	19#	15#
Q4. If you have answered 'likely' above, what change/s will you make?					
Q5. How likely is it that you would recommend this event to a friend or other person? (on a scale of 0 – 10)	8.8*				
Q6. Please feel free to make any further comments					

* Average score of all 40 delegates

Total number of responses under each category

The evaluations demonstrated an increase of 26% in delegate's knowledge, 27% in skills and 30% in confidence. Delegates conveyed a high level of satisfaction in relation to the sessions' content and the educators' presentation, with a likelihood of 8.8 (out of 10) that they would recommend the session to a friend or other person. Ninety-three per cent of delegates are likely to make a change to their future actions and behaviours due to attending the course, with 85% rating the likelihood as most likely or highly likely.

The qualitative feedback from delegates was very positive and included comments such as...

"I feel the session was very informative, i also feel it is good to be working with the Hospice, it offers that peer support"

"The assessment process and being able to prioritise a person's needs. The discussion and talking about this with others reinforces how important it is to work together with others and families to ensure best care"

"Well presented. Completely relevant information. Interesting course, well delivered"

2. In relation to the follow up evaluation, 38 requests were made. The response was five undeliverable notices and five forms returned (16%) with the following responses.

Did you enjoy the session? (Yes /No/ Somewhat)	Yes – 5 [#]
On a scale of 1 to 10, how useful did you find the session (1 being least useful, 10 most useful)	9.2 [*]
If you could change anything about the session, what would it be?	"I really enjoyed the session, I wouldn't change anything" "Nil" "No very well presented and delivered" "Nothing. As a newly qualified Nurse I found this session very helpful and informative for future practice"
If you would like to discuss anything about this course, please put your email address below and we will get in touch to arrange a call to speak with you	There were no requests for follow ups

[#] Total number of responses under each category

^{*} Average score of all five delegates

All delegates responding to the follow up questionnaire enjoyed the session and when asked about the session's usefulness rated it 9.2 out of 10.

2) Evaluations from education delivery teams running the sessions

Following their delivery of the session, facilitators from the pilot sites were asked to complete a Microsoft Forms questionnaire comprising of 30 questions (See Appendix II for questions).

An informal follow up interview took place with the facilitators once the questionnaires were completed. This used a semi-structured approach, with the questions mainly used to clarify any responses from the questionnaires. With permission from the facilitators, the interviews were recorded and transcribed (solely for ease of capturing the responses).

All five pilot sites involved with the pilot completed the questionnaire and subsequently took part in an interview. The interviews took between 13 mins and 25 mins. The common features from both the questionnaires and the interviews were identified and grouped together and are presented below:

What went well?

- The programme and resources were flexible enough to be used with different groups and different localities
- The localities were keen to engage with Rules of Thumb process, and with each other for shared learning and future development
- There was found to be a great overarching programme and structure, in addition, it would work well in smaller chunks or as stand-alone sessions
- The content links in well with the Six Steps programme
- The additional resources were useful to support delivery or to personalise sessions for different groups
- The case study 'Peter' provided strong links to practice
- There is a further opportunity to support homes with medical anticipatory management plans

What should/could be changed?

Short term

- The ending to the case study 'Peter' was quite discouraging in that Peter dies in hospital. Having a more flexible approach to the ending could enhance learning, for example, if "A" happened, he could have died in hospital, however, if "B" happened, he could have died in a care home/other place of care
- There was a lack of an introduction/ background to dementia which would have been helpful for setting the scene
- Some elements of the programme, particularly Rule 3, 4 and the conclusion felt to be more focussed on end of life than dementia
- The video re: social care was reported to take a very negative view of social care (this was a limited feedback)
- Offering the session via a virtual delivery approach lead to some challenges
- The name of final session is 'conclusion', but it was felt that it was a stand-alone session rather than concluding the programme
- The section on feeding was felt to either a) focus too much on artificial feeding or b) not include enough information about artificial feeding

Longer Term

- For many areas it was challenging to link the programme into the wider PCN agendas
- There is no reference to pain management in the programme. Some facilitators felt that this was an important area that should have been covered
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- The project team review the programme with the GMEC pilot sites acting as a steering group over the coming months, adapting content as required and aligning the website with new changes

Changes to Rules of Thumb post-evaluation

Following on from the feedback from both the delegates and the educators, several changes and adaptations are being made to the programme. The educators working within the pilot sites discussed the changes with the programme team to gain their opinions. The short-term actions have virtually all been carried out and the longer-term actions are underway.

Short-term actions

You said...	We did...
Add in a 'what is dementia' section	<ul style="list-style-type: none"> • New mini PowerPoint supplement session to be added to website and facilitator's guide that may be used if needed • To recommend co-delivery with Dementia Specialist (e.g. Admiral Nurse, Facilitator/Educator with special interest in dementia) <i>(Added to facilitators guide)</i>
Add in additional resources	<ul style="list-style-type: none"> • Improved signposting to additional resources • Produce a reference list with all additional resources • Add in link to 'Gladys Wilson' video • Add information about 'Bubble machine' <i>(Added to Rule One: eating or swallowing difficulties resources and facilitator's guide)</i> • Add in Orange clip (Samuel L. Jackson) <i>(Added to new 'what is dementia' session)</i> • Caveat has been added that additional resources are optional, and everything doesn't need to be included
Case study 'Peter', links to practice	<ul style="list-style-type: none"> • Case study reviewed and 4 different flexible endings/options added for facilitators to use • Guidance for use will be added to handbook and website
Maintain the flexibility of the programme	<ul style="list-style-type: none"> • Ensure it is easy to align with different localities, i.e. RESPECT not used by all <i>(Reinforced in facilitators guide, look for other examples)</i>
At times its feels more end of life than dementia	<ul style="list-style-type: none"> • Programme/content checked for dementia-based resources – the majority of resources and references used are dementia specific • Ensure links to Peter and the case study to keep focus on people with dementia <i>(Reinforce in facilitators guide)</i> • Darkness in the afternoon (Sterling University) included as additional resource in 'What is dementia' supplement session

Change name of 'conclusion' session	<ul style="list-style-type: none"> • Suggestion - 'The final session'
Section on feeding what happens in your area needs to be flexible	<ul style="list-style-type: none"> • Review – not enough about artificial feeding, covers AF too much when it's not used much in some settings
Good structure of RoT	<ul style="list-style-type: none"> • Keep flexible - Information added to support use of sections when delivering smaller sessions, or within shorter time scales (<i>Reinforced in facilitator's guide</i>)
Video re: social care can be perceived as negative	<ul style="list-style-type: none"> • TRIGGER warning added to balance the video (<i>Added to facilitators guide</i>)

Longer-term actions

You said...	We are doing...
Engagement with care homes (esp. due to Covid)	<ul style="list-style-type: none"> • Share activities and approaches from different areas wider than Rules of Thumb promotion of EOLC options at GM level
Linking into PCNs Challenging need a link in (EOL Champion) Links to Six Steps	<ul style="list-style-type: none"> • To consider how to offer support and guidance and promotion of programme • To identify specific guidance on how to inter-relate Rules of Thumb and Six Steps programmes. The guidance will be added in both Six Steps and Rules of Thumb programme
No reference to pain management	<ul style="list-style-type: none"> • Nathan Davies and colleagues are currently working on specific guidance around pain management. This will be incorporated as soon as it is available
Shared learning and future development	<ul style="list-style-type: none"> • Working group to review revisions of changes and updated documents. • Further discussion with localities to identify any potential buddying up requirements
Virtual delivery	<ul style="list-style-type: none"> • To offer clearer guidance/alternative approaches to delivery of Rules of Thumb such as virtual delivery and possible hybrid delivery

CONCLUSION

This web-based, free to access programme offers a flexible way to address some of the challenging aspects of care that professionals come across when working with people with dementia at the very end-of-life. There is a set of comprehensive resources that educators and facilitators can utilise to lead full sessions or mini-sessions, that are flexible enough to allow local variations to be addressed. The sessions are interactive and engaging and focusses around a case study based on real life clinical situations.

The programme evaluation showed an increase of 26% in knowledge, 27% in skills and 30% in confidence. Delegates conveyed a high level of satisfaction in relation to the sessions' content and the educators' presentation, rating it 8.8 (out of 10) in regard to recommending it to a friend or other person. Ninety-three per cent of delegates indicate that they will make changes to their future actions and behaviours due to attending the course. Qualitative feedback from delegates and facilitators was very positive and provided a foundation to be able to make selective improvements to the programme.

Delivering this programme aims to strengthen the partnerships between the Primary Care Network and care home teams and support a shared conversation between the multidisciplinary team. This in turn provides a consistent framework to help professionals caring for people with dementia at end of life be more confident in meeting the unique needs of those dying with dementia and supporting those close to them.

RECOMMENDATIONS

1. More initiatives directly related to very end of life care for people with dementia are required as this group of people are less likely to receive palliative care, due to the complex and unpredictable disease trajectory (Browne et al, 2021).
2. Multi-Disciplinary Teams are still newly forming in care homes, and ways of encouraging the teams to work together are required. By supporting small group learning, local and personalised approaches can foster the importance and impact of relational working (NIHR, 2021).
3. Education and training are 'absolutely essential parts of providing palliative care' (Ingleton et al, 2013). As many areas have limited numbers of palliative and end of life care educators and facilitators, providing free to access, evaluated and relevant resources can support their roles and enable them to focus on the delivery of high-quality education and support. These resources need to be updated and relevant to ensure they offer the most current and up to date practice.
4. There are many projects and programmes such as the Rules of Thumb programme, but there are few opportunities to promote in practice. There is a need to invest in research to embed these in practice. Evaluating and supporting initiatives such as the Rules of Thumb is crucial to gain ongoing investment by commissioners and engagement from practitioners (Goodman et al, 2017).
5. Promotion and campaigns to increase people's awareness of resources such as The Rules of Thumb is necessary to increase visibility and uptake. By opening lines of communication also improves the quality of resources and increases user satisfaction.
6. Promotion of initiatives to identify people living with dementia who are likely to be entering the last year of life, so encouraging personalised advance care planning much earlier in order to deliver elements of what matters to people as they approach the very end of life.

ACKNOWLEDGEMENTS



Dementia United



University College London



Alzheimer's Society



Kings College



Care and support through terminal illness

Marie Curie

The pilot sites



Bolton Hospice



End of Life Partnership



Manchester Local Care Organisation



Springhill Hospice



Wigan & Leigh Hospice

APPENDICES

Appendix I - Post course evaluation form for delegates attending Rules of Thumb

Name:

Email Address:

We may like to contact you in 4-8 weeks' time via email to find out if today's session has made a difference in any way. If you are happy to be contacted, please add in your email address. **For future events, we would welcome your feedback on today's content, presentation and speakers**

Q1. Please can you rate your levels of Knowledge, Skills and Confidence before and after today's session?

Pre-Event	Not applicable to role 0	None 1	Very little 2	Some 3	Good level 4	High level 5	Post-Event	Not applicable to role 0	None 1	Very little 2	Some 3	Good level 4	High level 5
Knowledge							Knowledge						
Skills							Skills						
Confidence							Confidence						

Q2. How would you rate the content and presentation of the speakers?

	Rating Score					Comments
	Very poor				Very good	
Content	1	2	3	4	5	
Presentation	1	2	3	4	5	

Q3. As a result of attending today's event, how likely are you to make a change to your future actions and behaviours? (Please circle one)

Not at all	Unlikely	Quite likely	Most likely	Highly likely
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Q4. If you have answered 'likely' above, what change/s will you make?

Q5. How likely is it that you would recommend this event to a friend or other person? (Please circle one)

Not at all										Definitely	
0	1	2	3	4	5	6	7	8	9	10	

Q6. Please feel free to make any further comments below

Thank you for taking the time to complete this evaluation

Appendix II - Questions for facilitators completed post-delivery of session

1. Email
2. Name
3. Your name
4. Your role
5. Your organisation
6. Delivery: How have you delivered the sessions?
7. Delivery: Who have you partnered with to deliver?
8. Preparation: Were there any challenges with engagement?
9. Preparation: What worked, and what didn't work in engaging with the care homes?
10. Preparation: Any ideas for the future?
11. Content: How did you use the programme?
12. Content: Did you follow the core programme as mini sessions?
13. Content: Did you follow the core programme in an extended session?
14. Content: Did you use any of the additional resources for further targeted learning so extending the core programme, if so which did you use?
15. Content: Did you add or delete any content?
16. Content: Has it been integrated into the Six Steps Programme or any other training?
17. Programme: 'Introduction' - Is there anything you want to feedback about this section?
18. Programme: Rule One - Is there anything you want to feedback about this section?
19. Programme: Rule Two - Is there anything you want to feedback about this section?
20. Programme: Rule Three - Is there anything you want to feedback about this section?
21. Programme: Rule Four - Is there anything you want to feedback about this section?
22. How long did it take you to deliver the programme?
23. Has this programme created new ways of working, are care homes more linked in with the MDT discussion? (Delegates action plan may help inform this)
24. Have there been any operational changes been within the care home and the PCN?
25. Has this programme created new opportunities?
26. Have your knowledge skills and confidence increased in delivering end of life care to people living with dementia as a result of the programme?
27. Will you do further training with the PCN?
28. What worked and didn't work about the learning programme?
29. Were there any resources missing?
30. Are you able to share any stories (case studies) quotes from staff, families, people receiving care and support to capture impact of the difference made by the approach?