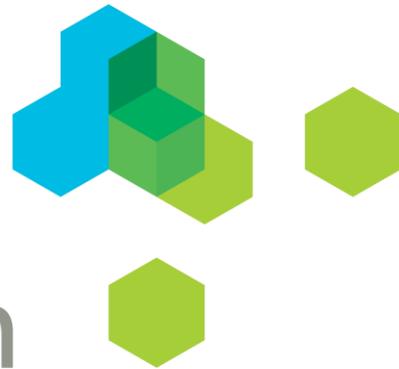


Maudsley  
Simulation



**Starting the Conversation- advance care  
planning and end of life care in Dementia  
Course Report  
Feb- March 2018**

***A training course to improve confidence in having difficult conversations  
across the Dementia pathway***

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## BACKGROUND

NHS England – in their guidelines **Dementia - Good Care Planning** recommend the importance for people with dementia and their carers to be supported with advance care planning and expression of future wishes in preparation for when capacity might be impaired at the end stages of dementia.

The Mental Health of Older Adults Clinical Academic Group (MHOA) now known as Psychological Medicine and Older Adults (PMOA) set up a working party to review current practice in advance care planning (ACP) and end of life care (EOL). They were also tasked to scope training available and to complete a training needs analysis which was mapped against the Dementia Care Skills framework. This multi professional working party with a special interest in this area of dementia care outreached to specialist agencies to review good practice across all palliative care services and completed a literature review.

In relation to practice in “advance care planning” the working party concluded that:

***‘Everyone thinks everyone else is doing it’***

People who are therefore living with dementia are more at risk of disenfranchised dying.

***‘It's everyone's business to do this’.***

Regardless of where we work within mental health there are opportunities for discussion of this at varying levels of our work and to different degrees of detail in the discussions.

The working party also identified the need to de stigmatise speaking about death and dying in dementia and that a conversation should happen early in the person’s care following dementia diagnosis if the person so wishes. The need for development and integration of ACP/EOL discussion into the Dementia Care Pathway in local services was identified.

To support this development, the working party identified the need for high fidelity interactive training package to support good communication skills and best practice in advance care planning and other conversations towards the end of life.

A joint bid was made between Maudsley Simulation and the PMOA end of life care working party to obtain funding for the development of a simulation package to support the developments across the pathway. We were delighted to have been successful in our application for a Health Innovation Network Award to support this project.

A simulation based training package has the advantage over more traditional educational packages and offers participants the opportunity to practice these often difficult conversations in an environment as close to real life as possible using age appropriate trained actors.

The benefits of simulation as an educational intervention have been well described (Cook et al 2011, Zendejas et al 2013). Specific benefits include increased knowledge and confidence, improved efficacy in technical skills, as well as improved non-technical skills, such as: teamwork, communication, and interprofessional collaboration (Cook et al 2011, Miller et al 2012).

Inter professional education has been shown to enable the learning of knowledge and skills necessary for collaborative working (Hammick et al. 2007), whilst interprofessional simulation has been shown to lead to improved confidence, leadership, teamwork, communication and collaborative care (Fay-Hillier et al 2012; Goldfarb & Gorrindo 2013; Naeem et al 2007; Robertson & Bandali 2008). Mixtures of staff from clinical and third sector organisations attended the training allowing the opportunity to network and learn from each other during the course of the day.

## COURSE DESIGN

### Aims

For participants: to support and encourage best practice and facilitate early conversations in advance care planning and end of life care. The scenarios covered difficult conversations that happen across the dementia care pathway.

After completing this course those attending will:

- Communicate effectively and openly with people with dementia and their carers about sensitive issues
- Understanding best practice in supporting early conversations about advance care planning and end of life decisions with patients with a diagnosis of dementia and their carers
- Feel confident in initiating conversations about advance care planning and end of life decisions with patients with a diagnosis of dementia and their carers
- To feel confident in asking about a person's wishes and preferences
- Support physical ,psychological and spiritual needs across the care pathway
- Use a range of resources to support the conversation.

### Design

As part of the course design- Members of the design team met with Service Users and Carers Advisory Group (SUCAG) which is well established group within PMOA. They were able to put forward their ideas for what they wanted covered in the scenarios and suggestions for course materials. They were also very keen to come and view the training day which we agreed to arrange. We also asked if anyone would be prepared to tell their story to camera, two volunteers kindly offered to do this. The videos story would frame the day for the participants.

The scenarios were designed to incorporate two patient's stories across the care pathway from diagnosis to end of life – The cases and background were based on Patients that clinicians had worked with in practice.

## Delivery

This full-day course ran on 4 occasions during Feb- March 2018 at the Maudsley Simulation centre at Lambeth Hospital. The course used the full simulation suite to run scenarios based on the real life environments in the home, hospital and community settings.

### Participants came from:

CMHT	11
Memory Services	8
Specialist Care	6
Inpatient Services	4
Liaison	3
Care Home Intervention	2
Other Dementia Services	8
Total	42

### Professional Groups:

Doctor	3
Social Worker	3
RMN	18
Occupational therapist	8
Psychologist	2
Other (dementia advisors )	8
Total	42

Participants were invited to complete a consent form and a pre-course questionnaire at the start of the training day. They were introduced to the principles of simulation as a training tool via a PowerPoint presentation, ground rules and safe environment were established. Due to the sensitive nature of the topics being discussed permission for “time out” was given to participants if things became difficult. A course facilitator or expert was nominated to provide participant support on each simulation day as well as an allocated quiet place for participants if needed.

Participants were invited to participate in scenarios to suspend disbelief and perform as they would as if in a real situation. Care was taken to allocate the most suitable participant for each scenario. Participants were involved in a series of simulated scenarios using highly trained older actors simulating patients with symptoms of a specific dementia related condition or a carer of a person with dementia. Each scenario involved one or two participants acting in their actual professional capacity to initiate conversations as set out in each task. (See below)

Course attendees who were not taking part in the scenario observed in the debrief room via video-link. The whole group was then debriefed by trained facilitators using a new debrief model that was designed to support participants’ reflection on the emotional, cognitive, and behavioural elements of clinical practice, as well as introduce psychologically-informed concepts relevant to care. This model was suitable to deepen learning for participants around core subject matter of this course and it’s emotionally

laden focus. In order to address technical questions, Senior Nurses from the Mental Health of Older Adults attended each course date.

During the course of the day there were opportunities to look at specifically selected resources that can be used to support patients and carers at diagnosis and throughout the Dementia Pathway.

The table below summarises the content of the scenarios throughout the day.

**Mr Eric Matthews and Wife Megan Matthews** - Eric is a 75 year old retired police officer he was referred following deterioration in his memory noticed by wife. GP has ruled out all physical causes. MRI scan has shown changes in his brain structure –in keeping with Alzheimer’s disease.

- Having a conversation about a Dementia Diagnosis - Husband and Wife attend clinic appointment.
- Follow up meeting – Starting a conversation about advance decisions – focus on financial planning
- Carer Conversation – Wife attends the team base wanting to speak about her husband’s care

**Mrs Peggy Spencer and Carer Carol Bright**-Peggy has a diagnosis of Vascular Dementia following a small stroke. She currently lives at home and is well cared for by her Foster daughter Carol and other family members. Peggy has very strong opinions about how she wants to be cared for at the end of life

- Planned home visit to discuss end of life decisions with service user and carer.
- Liaison conversation -Patient Peggy has been admitted the Acute Hospital -carer concerned as she feels her wishes aren’t being met
- Difficult phone call - Peggy is now receiving care at the end of life- Her condition suddenly deteriorates and her carer needs contacting.

## Debrief model

The course used the recently developed Psychologically Informed Debriefing Framework created by Maudsley Simulation. The highly skilled facilitators adopted this approach to allow for deeper reflection and learning in participants by exploring the emotional, cognitive and behavioural impact on them relating to end of life care conversations. Psychological and psychotherapeutic concepts were brought into debriefs to improve participants psychological literacy, self-awareness, and clinical psychotherapeutic skills.



Peggy and Carol at home

## MEASUREMENT

A self-report course evaluation form was administered to all participants. This comprised of free text questions assessing their experience, learning, perceived benefits, and potential impact on workplace practice as well as Likert scales assessing various course components. An additional self-report questionnaire was administered pre- and post-course. This comprised two scales; the first assessing confidence (0-10 Likert scale) regarding symptom recognition, decision making, the role of non-technical skills, processes and protocols, and inter-professional collaboration; and the second assessing knowledge and confidence of managing difficult conversations about advance care planning and end of life care in Dementia.

All measurement tools were carefully designed to assess the course learning objectives, with reference to both clinical expertise and relevant literature.

## DATA ANALYSIS

As the quantitative data set met the required assumptions, a paired-samples t-test was used to establish if the simulation training had had any effect on the confidence and attitudes of participants.

## METHODS

The Human Factors Skills for Healthcare Instrument was administered pre and post-course to all participants (n=37) to assess the impact of training on healthcare skills. Attached were course-specific questions assessing the impact of the training specifically on confidence and knowledge.

A self-report course evaluation form was administered to all participants. This comprised of free text questions assessing their experience, learning, perceived benefits, and potential impact on workplace practice as well as Likert scales assessing various course components.

## FINDINGS

Paired samples t-tests found **statistically significant improvements** to the participants' human factors and healthcare skills ( $p < .05^*$ ). Participants' scores on course-specific questions on confidence and knowledge also showed **statistically significant improvements** ( $p < .05^*$ ).

Table 1. Total pre and post-course scores as percentages and with significance level

	Pre-course total (%age)	Post-course total (%age)	Percentage change	<i>p</i> value
Human factors and healthcare skills	75	84	9%	<.05*
Course specific skills	67	85	18%	<.05*

Total pre and post-course scores as percentages



Analysis of individual statements on the Human Factors Skills for Healthcare Instrument found that the largest improvements were reported for the items: *'prioritising when many things are happening at once'*; *'monitoring the 'big picture' during a complex clinical situation'*; *'using effective coping strategies when experiencing stress in a clinical environment'*.

Analysis of individual statements on the confidence and knowledge questions found that the largest improvements were reported for the items: *'I am able to initiate conversations about advance care planning and palliative care in dementia'*; *'I am aware of the processes and procedures around end of life'*; *'I am aware of how I can support people with dementia and their carers to make financial arrangements for end of life'*; *'I understand the legal considerations for advance care planning'*.

## THEMATIC ANALYSIS

Data was provided by participants (n=37) through course evaluation forms. These collected participants' views and experiences on the impact of the training, with the subsequent thematic analysis identifying the themes of *'starting the conversation'*, *MDT working*, *dealing with emotions*, and *service user perspective*.

### - **'Starting the conversation'**

Participants reported an increased likelihood, ability, and confidence to start end of life care conversations with service users, as the most significant change to clinical practice following the course. Participants highlighted specific techniques that they had learned and would use with their clients, from structuring conversations, focusing on reassurance rather than

problem solving, and agenda setting with service users. Participants' feedback means that more end of life care conversations should be happening in clinical practice.

- **Service user perspective**

A focus on the needs, wishes, and prioritising issues dictated by service users and carers was reported by participants, above those of the clinician and service. The importance of this person-centred approach, and enquiring about and respecting the wishes of clients was stressed as a key takeaway from the training.

- **Dealing with emotions**

Many participants highlighted that the training has supported them to know how to and be confident in managing the difficult emotions that surface in service users and carers around end of life care, decisions, and planning. Tactics to support clients in expressing and coping with these emotions were highlighted, such as listening skills, and reassurance or normalising of emotions.

- **MDT working**

Participants reported an increased appreciation of the benefits of including an MDT approach around end of life care and conversations. This varied from using the skills of all different professions involved, to coordinating between professionals and services, to including all staff and professional backgrounds in team meetings and training.

## **Service User Feedback Event –**

A Service User feedback event was arranged on the last training day. The service users and carers, with the participants consent, viewed the afternoon scenarios and gave their written feedback on the training provided. They were supported by the Research Lead for Maudsley Simulation and the Participant Lead for PMOA. The feedback was very positive with the group reflecting how “well informed and realistic” the actors were playing the roles and how true to life the scenarios were. There was also feedback for the facilitators which included “encouraging all participants to participate” in the debrief discussion and how helpful the summing up at the end of the debrief was for the participants.



Sucag viewing the simulation

## SUMMARY

This course is a novel and innovative training for staff that have contact with service users and carers along the Dementia Pathway. Evidence shows this course can help build confidence in staff facilitating these conversations earlier in the dementia trajectory and aligns with service users views of the importance of discussing ACP early.

This course is the starting point from which wider changes in trust policy will be made. As part of the planning for the course a trust resource pack has been developed including a new patient information leaflet. Work is also underway to review the end of life policy to highlight and encourage good practice in advance care planning with the service users and their carers.

There will be an on-going evaluation of this course at 3 months to see how the knowledge has been implemented into practice.

The Author would like to thank everyone who contributed to the smooth running of this project including, All the members of the End of Life working party and the carer and service user group at PMOA. Thank you to Josh Brewster -Project Manager at the Health Innovation Network and Josie Turner- Work Transformation Lead, Health Education England for their support and encouragement throughout the project.

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# APPENDICES

## Appendix 1 – Timetable

### STRUCTURE OF DAY

**08:45-09:00** Sign in and coffee

**09:00-09:30** Introductions

09.30 – 9:45 Set up for the day – Film

**10.00-10.15** Scenario 1 simulation – Conversation dementia diagnosis

**10.15-10.50** Scenario 1 debrief

**10:50-11.00** Break – Tea & coffee

**11.00-11.15** Scenario 2 simulation – Starting a conversation about advanced decisions – financial

**11.15-11.50** Scenario 2 debrief

**11.50-12.05** Scenario 3 simulation – Carer conversation

**12.05-12.40** Scenario 3 debrief

**12:40-13:15** Lunch

**13.15-13.30** Scenario 4 simulation – Planned meeting EOL decisions

**13:30-14:05** Scenario 4 – debrief

**14.05-14.20** Scenario 5 simulation – Care Discussion Acute Hospital

**14.20-14:55** Scenario 5 – debrief

**14:55-15.10** Break – Tea & coffee

**15.10-15.25** Scenario 6 simulation – Conversation at end of life

**15.25-16.00** Scenario 6 – debrief

**16:00-16:30** Feedback and close.

## Appendix 2 – Pre and Post Questionnaires

Human Factors Skills for Healthcare Instrument											
Please rate how confident you are that you can manage the following effectively:											
<div style="display: flex; justify-content: space-between; width: 100%;"> <span><b>Definitely cannot do</b></span> <span><b>Moderately can do</b></span> <span><b>Definitely can do</b></span> </div>											
<div style="display: flex; justify-content: space-between; width: 100%;"> <span>1</span> <span>2</span> <span>3</span> <span>4</span> <span>5</span> <span>6</span> <span>7</span> <span>8</span> <span>9</span> <span>10</span> </div>											
		1	2	3	4	5	6	7	8	9	10
1	Constructively managing others' negative emotions at work										
2	Requesting help from colleagues in other professions										
3	Communicating effectively with a colleague with whom you disagree										
4	Prioritising when many things are happening at once										
5	Speaking up as part of a team to convey what you think is going on										
6	Involving colleagues in your decision making process										
7	Dealing with uncertainty in your decision making process										
8	Asking other team members for the information you need during a busy clinical environment										
9	Recognising when you should take on a leadership role										
10	Monitoring the 'big picture' during a complex clinical situation.										
11	Anticipating what will happen next in clinical situations										
12	Working effectively with a new team in clinical situations										
13	Re-allocating tasks between members of your team as required										
14	Summarising critical information for a structured handover										
15	Making critical clinical decisions under pressure										
16	Using effective coping strategies when experiencing stress in a clinical environment										
17	Providing constructive feedback to colleagues about their performance										
18	Acting with compassion towards patients even when stressed										

## Course Specific Skills Questionnaire

Please read each of these statements carefully.  
Then **tick ONE box** that best describes how much you agree with each statement:

**Totally Disagree**
**Neither agree or disagree**
**Totally Agree**

**1**
**2**
**3**
**4**
**5**
**6**
**7**
**8**
**9**
**10**

		1	2	3	4	5	6	7	8	9	10
<b>1</b>	I am able to communicate effectively with people with dementia about sensitive issues										
<b>2</b>	I am able to initiate conversations about advance care planning and palliative care in dementia										
<b>3</b>	I am able to assess a person's strengths, care needs, wishes and preferences										
<b>4</b>	I am able to support physical, psychological and spiritual needs in a range of environments										
<b>5</b>	I understand a range of interventions to support people with dementia and their carers										
<b>6</b>	I am aware of how I can support people with dementia and their carers to make financial arrangements for end of life										
<b>7</b>	I am aware of the processes and procedures around end of life										
<b>8</b>	I am aware of the need to have conversations about advance care planning and end of life care										
<b>9</b>	I am able to demonstrate compassion when having conversations about end of life care										
<b>10</b>	I understand the legal considerations for advance care planning										