Network Recording Declaration

During this ECHO session discussions will be recorded so that people who cannot attend will be able to benefit at another time. Filming is regarded as ‘personal data’ under the Data Protection Act 2018 General Data Protection Regulations (GDPR), under that law we need you to be aware that:

• This Data will be stored with password protection on the internet.
• This Data will be available for as long as your network continues to meet and will then be taken down from the internet and either stored securely at the Superhub or deleted.

Your ongoing participation in this ECHO session is assumed to imply your agreement to the use of your data in this way.

If you are NOT willing for your data to be used in this way, please LEAVE the session at this point.
# Agenda

<table>
<thead>
<tr>
<th>Time</th>
<th>Item</th>
<th>Presenters</th>
</tr>
</thead>
<tbody>
<tr>
<td>14:00</td>
<td>Welcome and Introductions</td>
<td>Julia Russell, Senior Clinical and Quality Improvement Manager, Hospice UK</td>
</tr>
<tr>
<td>14:05</td>
<td>Empowering decision making in dementia care: Resources and support</td>
<td>Dr Nathan Davies, Associate Professor Ageing and Applied Health Research, UCL</td>
</tr>
<tr>
<td></td>
<td>for health and social care professionals and families</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Questions and Group Discussion</td>
<td></td>
</tr>
<tr>
<td>14:45</td>
<td>Shared decision making with people living and dying with dementia</td>
<td>Rachel Daly, Practice Development Admiral Nurse Consultant, Dementia UK</td>
</tr>
<tr>
<td></td>
<td>Questions and Group Discussion</td>
<td></td>
</tr>
<tr>
<td>15:15</td>
<td>Breakout Rooms: Questions on Decision Making</td>
<td>All</td>
</tr>
<tr>
<td>15:30</td>
<td>Group feedback</td>
<td>All</td>
</tr>
<tr>
<td>16:00</td>
<td>Session Close</td>
<td>Julia Russell, Senior Clinical and Quality Improvement Manager, Hospice UK</td>
</tr>
</tbody>
</table>
Empowering decision making in dementia care: Resources and support to help decision making for health and social care professionals and families

Dr Nathan Davies
Associate Professor Ageing and Applied Health Research

@nathandavies50
n.m.davies@ucl.ac.uk
Overview

- Setting the scene
- Supporting professionals with rules of thumb
- EMBED-Care
- Covid-19
Possible journey

Managing uncertainty and complexity

- What’s the alternative to another pathway or another guideline?

- Are rules of thumb the answer?

*Taken with permission from stroke.org.uk


Building rules of thumb
Co-design approach with three phases:

Phase 1) Literature review and previous interviews

Phase 2) Groups interviews and individual interviews with practitioners and family carers.

Phase 3) Field testing in 5 sites including:
- 1 general practice
- 2 palliative care community teams
- 1 care of the elderly ward
- 1 community nursing team

Refined through a series of workshops with an expert user group, using nominal group in an iterative co-design process


Agitation and restlessness

1. Look for an underlying cause. Agitation and restlessness may not always be caused by dementia.

2. Has anything changed for this person? Read page nine of the Rules of thumb guide to help you make this decision.

   - Is there an environmental cause?
     - Yes
     - No
   - Is there a physical cause?
     - Yes
     - No
   - Is their carer struggling to support them?
     - Yes
     - No

3. No identifiable cause? Consider non-drug treatments, eg music therapy, massage or aromatherapy, and trial pain relief.
Agitation and restlessness

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

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

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

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

Is it related to the health or wellbeing of their carer?
- If their carer is struggling to cope or is ill themselves, this may have an indirect effect on them.
- Do they have a new or existing condition which is making it harder for them to provide care?
- Do they feel supported? Do they have enough support?
- Are they experiencing side effects from any drugs or medication?
- Consider a carer assessment or review for the family member or advocate providing care.
1. Discuss routine care with the person’s family or advocate to decide on an acceptable level and the best way to provide it.

2. **Is routine care causing the person distress?**
   - You may need to consult a specialist to answer this.
     - **Yes**
       - Can the way the care is being provided be adapted to better suit the person’s needs?
     - **No**
       - Provide routine care with the goal of maintaining the person’s comfort and dignity.

3. **Yes**
   - Make any necessary adaptations.

4. **No**
   - Try again later.

4. **Is this a recurring issue?**
   - **Yes**
     - Go back to 1.
   - **No**
     - Continue as normal.
Evaluation and where are we now?

Six Steps to Success in End of Life Care

Rules of Thumb

Introduction to the Rules of Thumb

This programme has been based on the Rules of Thumb, a guide for end of life care for people with dementia.

The programme aims to offer a flexible way to address some of the aspects of care that professionals come across when working with people with dementia at the very end-of-life.

The programme can be delivered in a single session as an extended half day session, across several mini-sessions or it may be incorporated into other programmes, such as the Six Steps programme. All resources are provided for the programme and can be found below. There is a facilitator guide to support the delivery, a PowerPoint presentation for each mini-session, activity sheets for group work. A range of additional resources have been included to enhance the delivery or to enable facilitators to extend the mini-sessions, although the use of these is optional and will depend on the audience.

It is suggested that facilitators firstly download or view the facilitators guide which provides a comprehensive overview of the programme.

Key programme resources

- Pre-session Information
- The Rules of Thumb guide
Programme summary

WS 1 Policy & guideline reviews inform model palliative dementia care

WS 2 Large data examine transitions and inequalities in care

WS 3 Cohort study palliative care needs, outcomes and costs

WS 4 Data synthesis of knowledge creation with actions to inform model of integrated palliative dementia care

WS 5 Co-design intervention/framework of integrated palliative dementia care in health and social care – assessment, management, person-centred care

WS 6 Feasibility and pilot trials of integrated palliative dementia care at home and in care homes

Network for Excellence in Palliative Dementia Care

Sampson et al. EMBED-care protocol. Int J Geriatric Psychiatry 2019
RAISING A CONCERN

(1) In care homes: Alerts and decision support tools may prompt staff to raise concern(s) to senior staff/RN and to link in with family member(s).

(2) At home: discuss with the person and/or the family carer about the next steps to take

CONTEXT
Palliative dementia in care homes or at home

FREQUENCY
Repeat monthly, or more frequently as required (e.g., if clinically indicated, and on a case-by-case basis). Flexible alerts will remind all to complete the assessment in the appropriate time frame

IPOS-DEM ASSESSMENT
Check main symptoms and concerns such as pain or low mood experienced by people with dementia over the past week
Each item rated from 0 (no problem) to 4 (very severe)

ALERTS
Automatically generated if items score 3 and above on the assessment or if items suddenly change and score outside of the individuals' normal range

PRIORITY OF CARE
Using a priorities of care list or a summary of discussions, the PwD/family carer (or both) and practitioner agree on the priorities of care. This informs care plans. Priorities of care are adaptable to settings and existing processes

DECISION SUPPORT TOOLS
Follow step-by-step guidance in the form of a flowchart to determine the appropriate course of action for the assessment item. RoTs help to break down complexity, manage need and enable carers to provide support.

TRAINING & SUPPORT (FOR APP USE, IPOS-DEM ASSESSMENT AND DECISION SUPPORT TOOLS)

1. Introduction to EMBED-Care intervention booklet.
2. Face-to-face training for health and social care professionals (champions), including how the EMBED-Care intervention is to be used in care homes at home and potential benefits of EMBED-Care intervention and interacting with the EMBED-Care app
3. Video training (including an introduction to the EMBED-Care app and intervention, shared decision-making, and RoTs). Weekly drop-in support sessions, email/telephone helpline for people with dementia and family carers

(1) In care homes: Alerts visible to care home staff in the form of an online dashboard. Signal for the care home to ring the family. Staff will have the ability to communicate about alerts via chat boxes. The system can be linked with a named contact e.g., care home matrons, and GPs

(2) At home: Alerts visible to clinical team ‘holding’ the intervention in the form of a dashboard (on a provided tablet).

(1) In care homes: Alerts can inform priorities of care in the form of e.g., a job list as needed.

(2) At home: Alerts can link in with concerns of the PwD and family care which are then the priorities for care and treatment

(1) In care homes: RoTs available for review by care home staff, family member(s) and PwD. Family member(s) to support the management plan based on the RoTs

(2) At home: RoTs available for review by healthcare professionals, family member(s) and PwD. Family member(s) to support the management plan based on the RoTs

RoTs will be stored alongside guidance videos which explain the IPOS-Dem and RoTs, the training manual, and links to further information and support.
Please write clearly

Person's name: __________________________
Person's number: ________________________
Date (dd/mm/yyyy): ________________________

What has been his/her main problems over the past week?

1. ______________________________________
2. ______________________________________
3. ______________________________________

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Severely</th>
<th>Overwhelmingly</th>
<th>Cannot assess</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shortness of breath</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weakness or lack of energy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea (feeling like being sick or vomiting)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vomiting (being sick)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor appetite</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Constipation</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Decision support tools

12 decision areas:
- Overarching principles
- Pain
- Mobility
- Spirituality
- Emotional wellbeing of person with dementia
- Emotional wellbeing of family carers
- Eating, drinking & mouthcare
- Sleep
- Constipation & incontinence
- Weakness & lack of energy
- Delirium
- Skin care
Maintaining emotional and psychological wellbeing

Dementia can be a scary experience for the person living with it, particularly if the person finds it difficult to voice these feelings. It is important that their emotional and psychological wellbeing is the centre of care provided.

1. Assess
- Ask the person if they feel sad
- Is the person more withdrawn?
- Are they communicating at their normal level?
  - Has appetite changed?
  - Is sleep disturbed?
- Do they look sad? Are they crying?
  - Has behaviour changed?

2. Causes
- Medications causing negative effects
  - Other illness
- History of mental health issues
- Other concerning symptoms highlighted from the IPOS-Dem
  - Environmental or routine changes
  - Significant date or time of year
    - ie anniversary of a loved ones death
  - Boredom
- Change in dementia stage
  - Bodily changes
  - Environment
  - Being alone
- Consider carer/family members wellbeing, someone with dementia can sense if others round them are upset

3. Manage
- Ask the person what would bring them joy.
  - Use individualised activities
  - Refer to *This is me* document or complete/ask family/advocate to complete
- Refer to activity flowchart for suggestions of wellbeing promoting activities (see next page)
  - Talk to the person
- Avoid automatic use of television or radio if this is not activity the person enjoys.
  - Establish routine
- Consider clinical review of mood if wellbeing activities do not help
  - Explore option for befriending service
Dementia and Covid-19

Rapid review
- Having a family carer, carer ability to cope, availability of multidisciplinary teams, and advanced care planning key factors
- Cultural appropriateness
- Need for continuous review of decisions

Interviews with support line staff
- Rapidly changing governmental guidelines caused confusion and lack of trust
- Uncertainty in engaging support and help – available?
- Concerns about care transitions
- Pandemic motivated care planning

Analysis of online forum
- Feeling guilt and anxiety because unable to visit the person living with dementia in a care home or unable to be with the person at the end of life
- Whether to admit person living with dementia to a care home

Decision aids

• Paper based communication tool
• Designed to help people make specific and deliberated choices
• Specify decision to be made
• Provide information on the options and outcomes

• May include:
  – Information on the disease/condition
  – Health risk factors
  – Information on others’ opinions
  – Guidance or coaching

Decisions

• How to manage care at home
• How to support your relative/friend in a care home
• Should they go to hospital?
Introduction

What is a decision aid?

A decision aid is a guide to support you when making decisions. It covers some of the common challenges and decisions you may face. It also gives you information about your options and how to make a decision. This includes seeking advice from health and social care professionals and other carers, like yourself.

Who is this decision aid for?

This decision aid is for you as a family member or friend caring for someone living with dementia who may not have the capacity or ability to make decisions alone.

WHAT IS THE DECISION AID?

- Your friend/relative may become unwell with coronavirus and need to make decisions quickly about their care.
- This decision aid is a guide to support you when making decisions about some of the common challenges and decisions you may face. It gives you information about your options and how to make a decision.

WHO IS IT FOR?

- This decision aid is for you as a family member or friend caring for someone living with dementia who may not have the capacity or ability to make decisions alone.

WHAT DECISIONS MIGHT YOU NEED TO MAKE?

- How to manage care at home?
- How to support your friend/relative in a care home?
- What to do if they became more ill?
- Should they go to hospital?
- How to keep in touch if you can’t visit?

WHAT DOES IT INCLUDE?

- Information on the common signs and symptoms of Coronavirus
- Important points about the legal aspects of decision making
- Information on what support is available at home or in the community
- Benefits and disadvantages of going into hospital
- Learning points about care homes during the Coronavirus
- Opportunity to consider the wishes and preferences – what is important to you? What is important to the person with dementia?
- Key tips on how to look after yourself as a carer

Coronavirus and beyond

How might coronavirus and government advice affect you and your family member/friend living with dementia?

- Your friend/relative may become unwell with coronavirus and you might need to make decisions quickly about their care.
- You may not be able to get the same support services because of changes to the availability of health and social care.
- Your friend/relative may not live with you and you may not be able to see them in person due to restrictions on travel and visiting.
- You may not be able to care for them – either because you become ill yourself, because you might be at increased risk or other consequences.

What decisions might you need to make?

- You may need to make some decisions if your friend/relative becomes unwell with coronavirus such as:
  - How could they be cared for at home?
  - How could I support them in a care home?
  - What should I do if they became more ill?
  - Should they go to hospital?
  - How would I keep in touch with them if I could not visit them?

What are some of the common symptoms of coronavirus?

The common symptoms of coronavirus include high fever, a new and continuous cough and loss of smell or taste. But some older people do not have these symptoms, instead they may have some of the following symptoms which may be mild and difficult to identify:

- Fatigue
- Delirium (sudden or worsening confusion)
- Dizziness
- Diarrhea
- Loss of appetite
- Feeling weak
- Vomiting/hicuarea
- Rash
- Falls
- Headache
- Stuffy or runny nose
- Congestion
- Abdominal pain
- Coughing blood
Thinking about any existing Advance Care Plans

Your friend/relative may already have a care plan. A care plan details their needs and the care they wish to receive to meet these needs. They may have also made an Advance Care Plan, sometimes called an Anticipatory Care Plan. This is a record of care the individual would like to receive in the future.

Does your relative have an Advance Care Plan? [ ] Yes [ ] No

If yes, consider this plan or discussions you may have had with them about their care wishes. Use this box to write down the important information to remember when making decisions about care and treatment (for example, going to hospital, treatment for infection, end of life care, and ventilation).

If they do not have an Advance Care Plan, you can consider their wishes and preferences on the next page.

Wishes and preferences

This section is to help you consider your own wishes and preferences as the person living with dementia’s wishes and preferences about their care and treatment if suspected or confirmed to have coronavirus. This is important if they do not have an advance care plan.

What is important to you?

For example:
My friend/relative is able to stay where they feel familiar/comfortable. Being able to be with them if they are seriously unwell or at the end of life. Knowing they are getting the care they need.

How might coronavirus affect their wishes and preferences?

What is important to the person living with dementia?

For example, staying in their own home or a particular care home, being pain free and comfortable, having family and loved ones around, seeing and talking to their pet.

Legal aspects of decision making

This section is to help you consider some of the legal aspects of making decisions on behalf of the person you are caring for when they lack capacity.

Mental Capacity Act

Under the Mental Capacity Act 2005 (England and Wales), when a person is unable to make decisions for themselves, decisions may need to be made about their care and treatment in their best interests.

Lasting Power of Attorney (LPA) for health and welfare

The person (or people) appointed under an LPA for health and welfare can make decisions about the person’s health and personal welfare. An LPA is made while the person living with dementia has the mental capacity to do so. The person appointed under the LPA can make decisions about medical treatment, where the person is cared for, and the type of care they receive.

Is there a Lasting Power of Attorney in place for your family member or friend?

[ ] Yes [ ] No

Cardiopulmonary resuscitation (CPR)

Cardiopulmonary resuscitation (CPR) is a way to help restart a person’s heart and breathing if they stop. Some people would like to have this treatment. Others would prefer not to. It is possible to make a decision about this in advance with the health care team and consider if this is suitable for them. If a decision has been made to not to give CPR, this will be recorded in a Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) form.

Does your relative have a DNACPR form or order?

[ ] Yes [ ] No

If your relative does not have a DNACPR, you can consider their wishes and preferences on the next page.

For more information: The Marie Curie website has information explaining reused DNA CPR during coronavirus: https://www.mariecurie.org.uk/cpr-during-coronavirus

Supporting you to make decisions while caring for someone living with dementia during Coronavirus (COVID19) and beyond

6

Supporting you to make decisions while caring for someone living with dementia during Coronavirus (COVID19) and beyond

Supporting you to make decisions while caring for someone living with dementia during Coronavirus (COVID19) and beyond

8
Who is supporting you?

We all need support from people to maintain our physical and mental wellbeing. If you are caring for someone you may benefit from extra practical, emotional and moral support from others. Draw your support network below by writing the names of people who support you in the circles. For example, spouse or partner, daughter, son, sister, GP, home care worker, neighbour, friend, social worker or volunteers.

Place yourself and the person with dementia in the centre two circles. Not everyone in your network will provide direct care, but they may support you in other ways. Add and delete circles as needed.

Further support and contact details

You may have found it difficult to complete some or all of the sections of this decision aid. Here are contact details for further information and support for yourself and the person you provide care for. Some of these organisations may have local branches. Check their websites for more information.

Alzheimer’s Society
0333 150 3456
www.alzheimers.org.uk

Admiral Nurse Dementia Helpline (Dementia UK)
0800 880 6678
www.dementiauk.org

Wales Dementia Helpline
0808 808 22 35
www.dementiahelpline.org.uk

Carers Trust
0300 772 9600
www.carers.org

Alzheimer Scotland
0808 808 3000
www.alzscot.org

Carers UK
0808 808 7777
www.carersuk.org

Marie Curie
0800 990 2309
www.mariecurie.org.uk

Independent Age
020 7605 4200
www.independentage.org

Young Dementia UK
www.youngdementiauk.org

Age UK
0800 055 6112
www.ageuk.org.uk

Rare Dementia Support
07388 220355 or 07441 776317
www.raredementiasupport.org

The Silver Line
0800 870 8700
www.thesilverline.org.uk
Resources

• Decision guide can be found here: https://www.ucl.ac.uk/psychiatry/decision-guide


Dementia wellbeing in the COVID-19 pandemic
Thank you

n.m.davies@ucl.ac.uk

@nathandavies50

Funding

Rules of thumb: This research was supported by funding from the Alzheimer’s Society grant number AS-PG-2013-026 and by the Marie Curie Research Programme, grant C52233/A18873.

EMBED: This project is funded by the Economic and Social Research Council (ESRC) and National Institute for Health Research (NIHR) dementia initiative 2018 (Ref Number ES/S010327/1). The views expressed are those of the author(s) and not necessarily those of the NIHR or the DHSC.

Covid: This work was supported by the Economic and Social Research Council (grant number: ES/V003720/1) and by the National Institute for Health Research (NIHR) School for Primary Care Research (project reference 489). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.
Shared decision making with people living and dying with dementia

Rachel Daly
Practice Development Admiral Nurse Consultant

www.dementiauk.org
info@dementiauk.org
@DementiaUK

Registered Charity Number 1039404
We know that...

Almost half a million people live in care homes in the United Kingdom (UK) – that’s more than the entire population of Luxembourg.

About 320,000 of those people are living with dementia and may need support with decisions about their life, care and death.

Only around 1% of people dying with dementia do so in hospice care.
Palliative care decisions

Maximise input

Pre-empt issues

MCA

SDM

ACP

LPA

ADRT
Decisions about end-of-life care

Making important advance care decisions, entails the need to envision a future self, in a future state, and this is particularly difficult for people with dementia.
Total Pain

- Social Pain
- Psychological Pain
- Spiritual Pain
- Physical Pain

TOTAL PAIN
Breakout rooms

1. Is end-of-life shared decision-making achievable in dementia care?
2. How can time best be used to facilitate shared decision-making?
3. What impact does the environment have on shared decision-making?
Next Session:

Topic: Use of Medication in Dementia at End of Life

Date: 19 January 2022
A National Conversation to inform a new Dementia Strategy for Scotland

The Scottish Government are seeking responses to a short discussion paper from anyone with an interest in the lives of people living with dementia. This discussion will inform the future of dementia policy in Scotland. For more information, visit the website.
Before you go...

https://www.surveymonkey.co.uk/r/PEOLCD-10-22