Supporting carers of people with dementia at the end of life: developing a decision aid

Dr Nathan Davies

Research Department of Primary Care and Population Health, UCL

Centre for Dementia Palliative Care Research, Marie Curie Palliative Care Research Department, UCL

@NathanDavies50

@Caps_UCL  @MCPCRD
Symptoms, dilemmas, complications and decisions towards the end of life

- Comorbidities
- Eating and drinking difficulties
- Breathing difficulties
- Agitation and restlessness
- Increased infections
- Pain
- Incontinence
- Pressure ulcers

Davies N, Iliffe S. End of life care—why those with dementia have different needs. BMJ. 2016;353(i2171).
Making decisions for others

• Many people with dementia reach the end of life without a care plan

• Often people with dementia, families and professionals are not ready to have conversations about the future

• Decisions are left to family (or friends) carers
• Carers are left with difficult decisions as proxy

“From my contact with other carers I think making decisions for someone you love is one of the hardest things to bear”
How can carers be supported more effectively?
Decision aid?

• Designed to help people make specific and deliberated choices among options (including the status quo), by making the decision explicit and by providing (at the minimum) information on the options and outcomes relevant to a person’s health status.
  
  • Information on the disease/condition
  • Costs associated with options
  • Probabilities of outcomes
  • Opinions of others
  • Guidance and coaching in steps to make decision and communicating this with others
What do we need to do first?

• What decisions need to be made by families and how these decisions should be made?

• What do people with dementia think families should consider when making such decisions?
Methods

• Semi-structured interviews
• People with mild dementia and family carers towards the end of life

Recruitment
1. Memory services
2. NIHR Join Dementia Research
3. Interested general practices

Participants (interviewed thus far)
• 7 interviews with people with dementia
• 18 interviews with family carers
Key considerations from people with dementia
Do we need to discuss this?

“Have you had those kind of discussions with them [family] in the past?”

I don’t think so, no. Me? I’m never going to die, I’m fit! No, I haven’t discussed it with them. I suppose that’s a form of cowardice, isn’t it?”
Do we need to discuss this?

“Do you think it’s helpful to have those kind of talks?”

“Once. Not to keep on. As long as, as long as they know that I wouldn’t object. That’s enough. There’s no need to keep going back and talking about it.”
Who should make decisions?

“Although, you see, I can’t ask them [family] to make a decision to let me go […]”

Who would you want to make that decision?

I think the doctor, yes, because you can’t ask your children to make that sort of decision. They might be haunted by the decision for the rest of their lives, deny you of the right, you know, thinking, “Should I have? Maybe I shouldn’t,” ”
How will this affect the family?

“But I must, if I could see that I was a damn nuisance at home, on the other hand, they would have to [think about a care home]. Or I’d blight their lives.”
Include me!

“Well I would like them to be consulted before any medical procedure was to go ahead. And I trust them to, not just brush me aside, “Oh do what you want,” you know. To give it a bit of thought and maybe discuss it with me if, if that was at all possible.”
What is my level of awareness and health?

“Well, if you don’t recognise anybody, anyone is as good as the next one. And if you’re incontinent, you don’t want to impose that on your family.”
Key decisions from carers

- Moving place of care
- Eating and drinking
- Balancing my life and their life
- Agitation and restlessness
- Washing and bathing
- Is something is wrong?
Eating and drinking

• How can I encourage Mum to eat?
  – Small amounts of food
  – Find the foods the person enjoys
  – Use a thickened liquid so easier to swallow
  – Create a connection with the person
    • Touch
    • Talking
    • Being close

• Mum is refusing to eat what do I?
  – What would they want?
  – Do they still get enjoyment?
  – What is their level of health?
Agitation/restlessness

Look for an underlying cause (don’t always attribute it to the dementia)

What has changed? (speak with and seek help from families/advocate)

Is there an environmental/social cause?

Is there a physical cause?

No identifiable cause
  - Is there a non-drug treatment? (i.e. music therapy, massage, aromatherapy)
  - Trial of pain relief
  - Seek specialist help
  - Trial of antipsychotic medication (after discussion with family/advocate)

Consider throughout is the individual a risk to themselves or others around them?

Check the health and wellbeing of the carer
What next?

• Workshops
  – People with mild dementia
  – Family carers
  – Practitioners

• Develop a paper based decision aid

• Evaluate the decision aid with family carers
Thank you!

N.m.davies@ucl.ac.uk

**Study team:** Dr Greta Rait, Dr Liz Sampson, Prof Steve Iliffe, Prof Jill Manthorpe, Dr Kate Walters

**Study Monitors:** Dick Abbott, Angela Baldock, Shirley Nurock

**Experts by experience:** Frank Arrojo and Jane Ward

Nathan Davies was supported by a Fellowship award from Alzheimer’s Society, UK (AS-JF-16b-012).