Dementia Community of Practice Webinar

26 October 2020
Welcome to the Dementia Community of Practice Webinar
Thank you for logging on early.

As you can see, we are still setting up. Please introduce yourselves in the chat box. Thank you.
Welcome and Introductions

- Karen Harrison-Dening, Head of Research & Publications, Dementia UK
- Cathriona (Cat) Sullivan, Senior Clinical Practice and QI Lead at Hospice UK
- Anita Hayes, Head of Learning and Workforce, Hospice UK
- Dr Julie Kinley, Research and Clinical Innovation Project Lead, Hospice UK
- Dr Tracy O’ Regan, Society & College of Radiographers
- Dr David-Peter Lynch, Specialty Doctor in Palliative Care, Ardgowan Hospice
- Lucy Donovan, Clinical Team Coordinator Hospice UK
Agenda

➢ Welcome and overview
➢ Presentations:
  ➢ Dr Julie Kinley: Supporting people who have dementia in planning for their future
  ➢ Dr Tracy O’ Regan, Radiography practice for the context of Anticipatory / advance care plans
  ➢ Dr David-Peter Lynch, Anticipatory Care Plans In Care and Nursing Homes in the Inverclyde Region
➢ Breakout session
➢ Feedback from Breakout session
➢ Summary and close
Supporting people who have dementia in planning for their future

Dr Julie Kinley, Research and Clinical Innovation Project Lead, Hospice UK
Supporting people who have dementia in planning for their future

Julie Kinley
Two Key Messages

1. We need to be proactive

2. “If one is truly to succeed in leading a person to a specific place, one must first and foremost take care to find him where he is and begin there. This is the secret in the entire art of helping” [Soern Kierkegaard 1859]
National Recommendations

1.42. With patients, families, local authorities and our voluntary sector partners at both a national and local level, including specialist hospices, the NHS will personalise care, to improve end of life care. By rolling out training to help staff identify and support relevant patients, we will introduce proactive and personalised care planning for everyone identified as being in their last year of life. A consequence of better quality care will be a reduction in avoidable emergency admissions and more people being able to die in a place they have chosen.

Quality statement 3: Advance care planning

Quality statement

People with dementia are given the opportunity to discuss advance care planning at diagnosis and at each health and social care review. [2010, updated 2019]

Rationale

As dementia is a progressive condition, it is important for people to be able to make decisions about their future care early on, before they find it difficult to communicate or they lack the capacity to do so. This is known as advance care planning. It is important that there are opportunities to review and change the plan as the dementia progresses and if the preferences or needs of the person change. Having an advance care plan ensures that the person with dementia can receive treatment and care according to their preferences, even when they can no longer express them.

[NHS 2019 p25]

[NICE 2019]
Ask yourself what is ‘Planning for the Future’ for this particular person?

It may or may not be Advance Care Planning [ACP]

‘Enabling individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals’ concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions.’ [Rietjens et al 2017 p.e546]
It is reported that in England 8% and in the United States, Japan, Germany, Canada and Australia 10-20% of the population have a written Advance Care Plan [ACP] document [Bollig et al 2015]

Most people [n=46] undertook practical, personal, financial, and legal planning. However participants did not make formal advance care plans with the exception of appointing someone to manage their financial affairs [Dickenson 2013]

Of n=85 people with advanced dementia 76% had a DNACPR statement, 5% a ADRT and 40% had PPD BUT ACPs did not record any other care preferences [Sampson et al 2018]

‘No high-quality guidelines are available for ACP in dementia care’ [Piers et al 2018]
What is my role in preparing people who have dementia for an ACP/FCP conversation?

Offer
‘No negative association with ACP’
‘HPC initiated’

Assess Knowledge/
Skills of all
‘Affairs in order’
‘Knowledge of Dementia’
‘Training for all involved’

Assess
‘Mental capacity’

Involve
‘Relationships’

Document
What is my role during ACP/FCP conversations with people who have dementia?

- **Assess**
  - ‘Mental capacity’
  - ‘ACP preference’

- **Involve**
  - Carer and PLWD similar choices in the ‘here and now’ but less agreement on future hypothetical health conditions

- **Set aside Time**

- **Initiate discussion**
  - linking past life experiences to current and future care
What is my role after an ACP/FCP conversation for people who have dementia?

Start/update Documents

Share

Outcomes
‘Decreased Hospitalisations, Increased concordance with care and prior wishes’

On-going conversation requiring review
Identify what ‘Person Centred Care’ means for this particular person

Its intent is to involve people in decisions about their own care throughout their life span, including at the end-of-life. Clinical decisions made will then be based on the values, preferences and needs of a specific person [NHS 2019]

[Wendrich-von Dael 2020]
Thank you

“If one is truly to succeed in leading a person to a specific place, one must first and foremost take care to find him where he is and begin there. This is the secret in the entire art of helping” [Soern Kierkegaard 1859]


Rietjens J. et al [2017] Definition and recommendations for advance care planning: an international consensus supported by the European Association for Palliative Care *Lancet Oncol* **18**(9):e543-e551. doi: 10.1016/S1470-2045(17)30582-X.


Anticipatory Care Plans In Care and Nursing Homes in the Inverclyde Region

Dr David-Peter Lynch, Specialty Doctor in Palliative Care, Ardgowan Hospice
Anticipatory Care Plans In Care and Nursing Homes in the Inverclyde Region

By Dr David–Peter Lynch MBChB, BMSc (Hons) Specialty Doctor in Palliative Care Ardgowan Hospice, Greenock
Contents

- Background
- Aims
- Methods
- Findings
- Limitations
- Recommendations
COVID Crisis

- At the end of week 32 46% deaths have been in care/ nursing homes\(^1\)
- Inverclyde has become known as the “COVID capital of Scotland\(^2\)” despite 1.5% populous
- Scottish Government committed to Pt autonomy and access to Pal Care\(^3,4\)
Aims

1. To identify patients who may benefit from Palliative Care input using the internationally recognised SPICT tool

2. Facilitate discussions around ACPs, specifically clinical escalation, in case of emergency with loss of decision making ability

3. To ensure compliance with autonomous patient wishes
Identify Patients

ACP: Create/Review

Develop Sticker

Update eKIS

Monthly Review
Findings

- 206/324 patients had ACPs (63.58%)
- 113 ACPs were created due to this project
- 6 admissions prevented, which recovered with conservative management
- 6 admissions prevented, which enabled end of life care at home
- 9 Patients sent to hospital against wishes expressed in their ACP – 2 of whom died in hospital
- 27 DNACPRs requested by patients/ POA
Capacity of Patients Reviewed

- Patients with Capacity: 83
- Patients without Capacity: 241
Cause for Lack of Capacity

- **Alzheimers**: 74
- **Vascular Dementia**: 40
- **ARBD**: 34
- **Psychosis NOS**: 22
- **Parkinson's Plus Syndromes**: 22
- **Cancer**: 10
- **Unspecified Dementia**: 7
- **No Cause Stated**: 1
As per Scottish Health Service Costs\textsuperscript{5}, of £1190 a night for emergency medical bed, we can estimate projected savings by these avoided admissions.

Of 12 avoided admissions:

• 48 bed days saved between 6 Pts who died at home
• 86 bed days saved between 6 Pts treated conservatively in community (using nationally accepted figures\textsuperscript{6})
12 avoided admissions saving an estimated 134 bed days

At £1190 per night, projected savings: £159,460 over 14 weeks

Not inclusive of inflation for 2020 or single/sessional use PPE in current crisis
Limitations

- Only 8/14 Homes participated
- Limited by staffing at present
- Average national figures must be used to project savings
- COVID crisis restricting face to face interaction
- The general limiters – Timing, capacity and human nature?
Recommendations

- Educational programme pre–wave 2
- Inclusion of all local homes
- A similar project in larger city populous: i.e. Glasgow: Inverclyde, 8.14 : 1
  - Projected savings of £1,341,211* if scaled

* Adjusted for inflation
1. Deaths involving coronavirus (COVID–19) in Scotland Week 32 (3 August to 9 August 2020) Published on 12 August 2020, National Records Scotland


5. National Health Service Scotland, Scottish Health Service Costs 2018, National Statistics for Scotland, Published November 2018

Radiography practice for the context of Anticipatory / advance care plans

Dr Tracy O’ Regan, Society & College of Radiographers
RADIOGRAPHY PRACTICE FOR THE CONTEXT OF ANTICIPATORY / ADVANCE CARE PLANS

DR TRACY O’REGAN
OFFICER FOR CLINICAL IMAGING AND RESEARCH, THE SOCIETY & COLLEGE OF RADIOGRAPHERS
OCTOBER 2020
SESSION AIM

A quick overview of Radiography practice – clinical imaging and radiotherapy.

Use that background information to consider practice with respect to care plans.
Care for and support a person, their family and any carers during:

- Screening
- Diagnosis
- Treatment / Therapy / Radiotherapy
- Monitoring of the progression of injury or disease.
Underpinning guidance:
Caring for People with Dementia: a clinical practice guideline for the radiography workforce (imaging and radiotherapy)

Identification of people with dementia

To help with clear communication when a person has a diagnosis of dementia, departments should have a question on imaging and radiotherapy referral forms or initial assessment forms to include a request for information about a person's type of dementia and cognition.

The staff who will be caring for a person with dementia should ideally be informed about the person's diagnosis, form and stage of dementia beforehand.

Departments should have mechanisms for referral on to the person's General Practitioner to follow up in cases of potential undiagnosed memory problems.
Radiographers and the NHS

70 years of innovation

What is the role of a radiographer?

Radiographers - high tech, high quality care
World Radiography Day
‘A balance of head and heart’
Mammography

Computerised Tomography (CT)
Magnetic Resonance Imaging (MRI)
Interventional Imaging / Radiology

Ultrasonography
Radical overhaul of imaging and diagnostic services recommended in landmark NHS England report

2 October, 2020

The NHS must radically overhaul the way that MRI, CT and other diagnostic services are delivered, according to a major review commissioned by NHS England.

Over the next five years the plan would see Community Diagnostic Hubs launched across the country, the imaging workforce expanded by 6,600 radiographers, a doubling of CT scanning capacity and a comprehensive equipment renewal programme.

NHS chief executive Sir Simon Stevens commissioned Professor Sir Mike Richards to undertake the independent review of diagnostic services in England as part of the NHS Long Term Plan.

Professor Sir Mike, who was the first NHS national cancer director and the CQC’s chief inspector of hospitals, said diagnostic services had already reached a ‘tipping point’ as a result of increasing demand but the need for radical change had been further amplified by the Covid-19 pandemic.

He said: ‘While these changes will take time and opportunities to assist recovery and renewal of the NHS diagnostic services, they must be implemented urgently. Not only will these changes make services more available and accessible to patients with cancer and other serious conditions, but also reduce waiting times for those questions.

The Community Diagnostic Hubs would be part of a drive to separate services for patients with suspected Covid-19, and should include as a minimum CT, MRI, ultrasound and X-ray services.

The report also calls for investment in reporting radiographers and the implementation of professional regulation for sonographers in line with the SCoR’s long-running campaign. Additional workforce requirements include:

- 2,000 Radiologists
- 560 Advanced practitioner/radiographer
- 3,500 Radiographers
- 2,500 Assistant practitioners
- 2,670 Admin and support staff
- 220 Physicists

Sir Mike said there would be major efficiency gains, including reductions in costs of CT and MRI scanners through bulk buying, increased use of same day emergency care through improved access to diagnostics in A&E departments, and shorter hospital stays through tests undertaken on the day of request.

Estimating the cost of growing the NHS cancer workforce in England by 2029

October 2020

Together we will beat cancer
Main points from the themes:

**Communication**
- Staff may not understand about the different types and stages of dementia. It may be helpful to explain.
- Staff should measure people that have time to listen questions.
- Staff should measure people that have difficulty understanding, explaining and using common information. Staff answers can help by using language and to help.
- Communicate with people at different times, e.g. good/“learning curve” or the person. When the person is added.

**Dementia-friendly environment**
- Dementia-friendly environments can help to create a calming atmosphere.
- There should be a calming atmosphere.
- Consistency, continuity, by staff, engagement in routine, and being able to offer the services. Tippeons or walking allows people to focus.

**Time and resource pressures**
- Staff need time to care.
- Staff need time to train.
- Departments do not allocate productive time to patients who want to help.

**Deficiencies in person-centred care**
- Staff can have difficulties recognizing and addressing the unmet needs of people with dementia.
- Staff can communicate effectively in non-discriminatory and non-discriminatory environments.
- Partnership between staff, the person with dementia, and their family members, and friends can result.
- People with dementia should be maintained in non-discriminatory environments.

**Optimization of dementia care experience**
- There needs to be collaboration and working.
- Staff should interact with patients and families.
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How Breakout Rooms Work

- For small group discussion we will divide into breakout rooms
- When the time comes you will see on your screen an invitation to join. Please accept
- When you get into your room, please take a few moments to introduce yourselves to one another
- If anything goes wrong and you find yourself on your own or unable to join your allocated room come back to the main room. If you lose connection at any point, re-join the meeting using the same Meeting ID and Password.
- When we return to the main meeting please put your three top points in the chat box and we will open a discussion to the whole webinar
Feedback from discussion groups
Resources

Dying Matters for people with dementia:

Social Care Wales support and resources for end of life care during the pandemic:

The Cicely Saunders Institute team October Open Seminar:
4:00-5.00pm on Wednesday 28 October 2020
1 CPD credit (Royal College of Physicians)

@ThePALLUPstudy anyone interested in palliative care and older people - do have a look at & contribute to this
https://surreyfahs.eu.qualtrics.com/jfe/form/SV_9HpNCTmTM1akN3n
pic.twitter.com/ktt76aqwT

www.hospiceuk.org
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Thank you for listening