The Palliative & End of Life Care & Dementia ECHO Network

Session 5: Early Advance Care Planning

Tuesday 26 April 2022
The Palliative & End of Life Care & Dementia ECHO Network

ECHO™ – Extension of Community Healthcare Outcomes

Project ECHO is a distance learning methodology that breaks down hierarchies of specialist knowledge by creating virtual knowledge sharing networks.

Project ECHO uses a 'learning loop' approach; specialist teams and local providers learn from each other by collaboratively problem solving real-time experiences and sharing best practice via video-conferencing.

- Participants register to join
- And then have access to a resource centre after each session held
- This includes recorded presentations and slides

Project ECHO therefore relies on presentations and case studies from participants:

clinical@hospiceuk.org
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.
<table>
<thead>
<tr>
<th>Time</th>
<th>Item</th>
<th>Presenters</th>
</tr>
</thead>
<tbody>
<tr>
<td>14:45</td>
<td>Welcome and Introductions</td>
<td>Cat Sullivan, Senior Clinical Practice and QI Lead, Hospice UK</td>
</tr>
<tr>
<td>14:50</td>
<td>Advance Care Planning with People with Dementia</td>
<td>Dr. Jon Martin, Consultant in Palliative Medicine, Central and North West London NHS Foundation Trust</td>
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<tr>
<td></td>
<td>Questions and Group Discussion</td>
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<tr>
<td>15:30</td>
<td>Supporting effective use of ReSPECT During COVID-19</td>
<td>Angela Moore, Consultant Admiral Nurse, Dementia UK</td>
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<td>Questions and Group Discussion</td>
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<tr>
<td>16:00</td>
<td>Planning Future Care</td>
<td>Dr. Steve Plenderleith, Consultant in Palliative Medicine, Southern Health NHS Foundation Trust</td>
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<td>Questions and Group Discussion</td>
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<tr>
<td>16:25</td>
<td>Palliative, End of Life Care and Dementia ECHO Going Forward</td>
<td>Cat Sullivan, Senior Clinical Practice and QI Lead, Hospice UK</td>
</tr>
<tr>
<td>16:40 – 16:45</td>
<td>Session Close</td>
<td>Cat Sullivan, Senior Clinical Practice and QI Lead, Hospice UK</td>
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Advance Care Planning with People with Dementia

Jonathan Martin
Consultant in Palliative Medicine
UCLH Symptom Control & Palliative Care Team
National Hospital for Neurology & Neurosurgery
April 2022

www.hospiceuk.org
Advance Care Planning with People with Dementia

Jonathan Martin
Consultant in Palliative Medicine
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National Hospital for Neurology & Neurosurgery
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Outline

• Context
  – Dementia and disability
  – The “good death”

• Advance care planning
  – Potential benefits
  – Potential problems
“An excellent physician must also be a philosopher.”

(Becker 2015 citing Galen)
Dementia

• Dementia can be considered both a chronic disease and a terminal condition (van der Steen 2014).
• Life expectancy is unpredictable
  – Median survival after diagnosis 3-12 years (Todd 2013)
  – Most of that time in the severest stage (Arrighi 2010).
• Changes in different systems happen at different times
  – In Alzheimer’s disease the changes in memory and behaviour occur much earlier than a deterioration of physical functions, including oral feeding, respiratory function and mobility (RCP 2010, Maddocks 2006).
Disability in the last years of life

• In advanced dementia patients typically have profound cognitive deficits (no longer recognise family), limited verbal abilities (<5 words), functional impairment (bedbound), inability to perform ADLs, urinary and faecal incontinence, and high mortality rates (Mitchell 2015).

• Gill (2010) identified five distinct trajectories of disability in the last year of life in community-dwelling people over 70 years.
  – The condition showing the least variability of disability is dementia, which showed high levels of disability throughout the final year.
Figure 1. Trajectories of Disability in the Last Year of Life among 383 Decedents (Gill 2010)
End stage symptoms and cause of death

Another study of common symptoms in the end stage included (Hoben 2016):

• Urinary incontinence (79.9%)
• Faecal incontinence (66.7%)
• Challenging behaviours (29.2%)

Death is most often due to (Koopmans 2007):

• Cachexia with dehydration (35%)
• Infection (pneumonia) (20%)
• Complications of cardiovascular disease (20%)

Relatives’ impressions of dying peacefully (De Roo 2015):

• Less likely to occur in the context of physical or psychological distress.
This world is above all a practical and moral one in which patients have life projects and everyday concerns, things “at stake”

(Mattingly 1998)
The “Good Death”

• For many people a good death is commonly thought about in terms of awareness of dying, choice, communication, and control (Seymour 2005).

• But the typical journey of advancing frailty is ‘prolonged dwindling’ (Lunney 2003).
  – This fits poorly with the popular idea of a ‘good death’.

• Rather ‘living as well as possible until you die’ seems actually to be most realistic and relevant.
Aging and dying

The idea of dying in old age as an *event* is less useful than thinking of dying as a process, where ageing and dying coalesce (Nicholson 2012).

- This way of seeing life and death in the everyday allows us to recapture McCue's (1995) truth of an old age moving towards closure.
- We need to de-emphasise dying as being different to living in this context – the two are closely linked i.e. whatever is valued, the preoccupations of what makes a life meaningful and rich, are no different in the dying phase (Goodman 2013).
- Dying as a normal process rather than a problem to be fixed (Fairfield 2014), to be engaged holistically, and not resisted biologically without careful thought.
The “Good Death” in Dementia

• Dementia combines loss of intellectual capacity and cognitive function, but also brings profound social and relational impairment (Stoddart 1998)

• In those with cognitive impairment a good death is better conceptualised as being treated with compassion and respect; being kept clean, comfortable and free from distressing symptoms; and being in a familiar place surrounded by those close to them (Alzheimer’s Society 2013).

• Psychological, social and spiritual needs should be met, and family/carers should be supported.
The “Good Death” in Dementia

Person centred care is made up of:
• Valuing the person and those who care for them
• Treating the person as an individual
• Looking at the world through the perspective of the person with dementia
• Developing a positive social environment for the person (Brooker 2003)
What should I know about you as a person to help me take the best care of you that I can?

(Chochinov 2007)
What is the evidence for palliative care in dementia?

• Not much
• A recent Cochrane review found:
  – Changes to the organisation and delivery of care may lead to improvements in comfort in dying
  – Advance care planning interventions increase the documentation of advance directives and the number of discussions of goals of care, and may increase concordance with those goals
    • Uncertainty in the published evidence for both of these areas (Walsh S et al, 2021)
• ACP benefits for the family in reduced uncertainty (Brazil 2018) and better bereavement
Definition

“a process of discussing and/or recording the wishes, values and preferences for future care and treatment held between an individual, family members and their care provider(s)” (Sudore 2017)
What you bring

What drives us? Often it is a moral concern for others (Dewing 2008).

But you may:

• Lack time
• Be reluctance to have ‘difficult’ conversations
  – Not knowing how to start such a conversation
  – Not knowing if an ACP conversation would be welcomed or would cause distress
  – Worry about opening a ‘can of worms’
  – Worry about causing offence e.g. appearing to ignore cultural values
  – Worry about taking away hope
• Uncertainty of prognosis
• Uncertainty of likely future decision nodes
  – Made all the more difficult by the need to portray decisions as binary
Personal attributes

The following are helpful and may be innate or learned:

• A non-judgmental approach.
• Empathy.
• The capacity for curiosity.
• Self-awareness on the part of the professional and the capacity for self-critique.
For people with dementia

• May be difficult to talk about illness and progression towards death (Bosisio 2018).
  – When we do talk about it, the emotional disconnect necessary may mean that the decisions we make are not fully grounded in ourselves, but only reflect (the rational) part of ourselves

• May not conceptualise of dementia as a terminal condition

• Capacity and communication deteriorate at different rates – may believe there is more time, leads to difficulties in applying ACP
An approach to ACP in dementia

• Address ACP before cognitive impairment
• Conversations should be values-based, rather than treatment-based
  – Advance statements of wishes are arguably more useful than advance decisions to refuse treatments
• Assess capacity for any decisions made and record this
• Encourage the use of an attorney or named person for the unforeseen decisions
• Consider using a structured tool (deLima 2018)
Common ACP topics

• Cardiopulmonary resuscitation
• Dysphagia and the role of clinically assisted nutrition and hydration
• Management of infections, typically chest and urine
Death and dying are not to be seen as bodily processes alone, but as personal and social experiences

(Kellehear 2008)
What ACP cannot do

• Cannot predict all possible eventualities as an illness progresses
• Cannot deliver full autonomy for future decisions
• Cannot encapsulate all the nuances of a person’s wishes
  – Tends to work best for ‘simple’ binary decisions
  – Other decisions often require interpretation and judgement
Practical challenges

Biases:
• Affective forecasting error
  – Impact bias: overestimating the emotional impact of a future event
• Optimism bias
  – Things will be okay, so I don’t need to think about the future
• Present-biased preferences
  – My current concerns will also be my future concerns
• Default bias
  – Whatever is the default is the right decision for me e.g. CPR, CANH – leads to overly aggressive treatment
Philosophical challenges

Change of mind:

• On one reading, ACP is ideal for those with dementia because they face possibly many years with no capacity and lost autonomy – ACP facilitates adherence to the person’s wishes.

• But on another reading this same context is a problem because we know that people may change their minds over time, whereas the dementia patient may find themselves locked into a past view of their wishes and feelings.
  – This may lead to conflict between the person’s advance care plan (especially an ADRT) and their apparent current wishes (Auckland)

• So, which views should we prioritise?
  – Those of the person when they made the plan, or those of the person now.
  – Sometimes these views may be so radically different as to seem to be of two separate people
Personhood

The quality or condition of being a person.
Can be viewed as arising from:
• The innate quality of being human (which may have a religious aspect)
• Individual consciousness (values, beliefs, memory, self-awareness)
• Relationship (close family and other ties)
• Societal values (the protection of rights and privileges)
Personhood

Depending on your view, personhood may be taken away by dementia, or simply concealed by it.

• Personhood is enhanced by:
  – Close emotional bonds with family and close professional relationships with caregivers.

• Personhood is diminished by:
  – Task-orientated care and relationships and reluctant helping relationships (Smebye 2013).
Conclusion

• Advance care planning has much to offer the person with dementia
• But it requires careful thought with regard to timing and recognition of multiple other influences on autonomous choice
• There remain some tricky concerns about application, particularly of the more ‘set in stone’ aspects of prior decision making
• In the context, care should be values-based, dignified and dignifying


• Dewing J. Personhood and dementia: revisiting Tom Kitwood’s ideas. *International Journal of Older People Nursing* 2008;3:3-13
Supporting effective use of ReSPECT During COVID-19

Angela Moore
Service Development Consultant Admiral Nurse
Supporting effective use of ReSPECT During COVID-19

Angela Moore
Service Development
Consultant Admiral Nurse
Impact COVID-19

- The number of excess deaths in England in people with dementia, between 27 March 2020 and 8 January 2021, was 20,100 (Burns and Howard, 2021)

- Reported 31% excess deaths

- People with dementia disproportionately affected

- Tragic decisions about who lives or dies will be necessary. (Cipriani, Fiorino and Cammisuli, 2021)
KEY POINTS

- Lack of confidence and consistency in implementing ReSPECT forms
- Worry from people living with dementia regarding goals of care
- Increased referral rate
Interventions

- All patients on GP dementia register without ACP were referred to Admiral Nurse Service

- Training delivered to health and social care colleagues

- People living with dementia were grateful for the opportunity to discuss ACP

- Implemented online support for professionals
Development

- All patients on GP
- Training
- Online support
- Increased engagement and empowerment of people living with dementia
OUTCOMES

- Collaboration between health and social care professionals
- Sharing information
- Change to documentation on social care records
- Social care professionals felt more confident when discussing Advance Care Planning and priorities of care.
- Greater awareness of wider MDT who could support.
- People living with dementia felt empowered and had a voice
QUESTIONS
References


- [ReSPECT for healthcare professionals | Resuscitation Council UK](#)
Planning Future Care
Chipping away at a really hard thing. . . .

Dr Steve Plenderleith
Consultant in Palliative Medicine
Medical Director, Physical Health Services, SE Division, SHFT
Planning Future Care

Chipping away at a really hard thing.

Dr Steve Plenderleith
Consultant in Palliative Medicine
Medical Director, Physical Health Services, SE Division, SHFT

(Has been “going on” about ACP for 12 years)
The Story So Far . . .

• Future Planning in Hampshire

• Identical coded Future Planning template in EMIS and SystmONE that sends info to the Summary Care Record

• Available to ALL General Practices for 6 years

• But, only actively supported in 4 CCGs
  • Mentioned in LES contract
  • Daffodil Standards (RCGP) encouraged
  • Reports reviewed
Autumn 2017 to just before COVID hit. Quarterly figures per CCG
Two brief case histories
Future planning and patient wishes

This leaflet has been designed to help you to collect your thoughts and wishes for your care in the future. It has been produced at the request of ambulance service paramedics who attend patients at times of crisis. They often have to do so with no up to date clinical information.

With your consent it is now possible for your GP to share your wishes, recorded in your General Practice record, instantly & securely to the National Summary Care Record.

This information and your past medical history can then be seen by emergency clinical staff when providing your care anywhere in England.

Once you have added the information you want to share, please hand the form to your General Practice reception. From there your "My Wishes" information will be added to the Future Planning section of your GP record.

If your writing worse than your doctor? Then you might want to use an online My Wishes form which is available at www.futureplanning.org.uk/dodgy_handwriting

CONSENT & INFORMATION
You will need to provide your consent before any information can be added to your GP record.

You can withdraw your consent at any time by speaking to your GP however this could potentially reduce the speed and safety of the care that you receive. And may leave the clinicians caring for you unsure of your wishes if you are unconscious or confused.

IS THE INFORMATION SHARED SECURELY?
As with all healthcare information there are strict guidelines about how information can be used. Only staff involved in your care will access your information through an NHS smartcard and password protected system.

SUMMARY CARE RECORD
In an emergency please call 111. Your ambulance crew & Emergency Department staff know that you have "My Wishes" information, which they can view in the Summary Care Record.

If you need to update your "My Wishes" information or discuss any Future Planning concerns, please ask your GP, community nurse or specialist team.

www.FuturePlanning.org.uk/MyWishes

Click on the file opposite to download the middle pages of the leaflet...

Dodgy_Handwriting - FUTURE PLANNING
If you are signing this form on behalf of someone else then you will need to provide evidence that you are authorised to do so. E.g. Lasting Power of Attorney (Health and Welfare), child’s age, court order, etc.

I consent to Additional Information being shared to my national Summary Care Record for use in Emergencies. Including:

- The information in this form.
- Diagnoses & significant events from my past medical history.
- Information about teams looking after me.

Please remember to sign

My Signature ..............................................

My Name  Click here to enter text.

Date  Click here to enter text.

Relationship (if relevant)  Click here to enter text.

| I would like to discuss tissue donation further with my clinical team. | YES ☐ | NO ☐ |
| I would like to discuss Cardio-Pulmonary Resuscitation CPR further | YES ☐ | NO ☐ |
| I would like a copy of My Wishes: Future Care Plan. | NO ☐ | On PAPER ☐ |

Email ................................................................. Or via EMAIL ☐

Practice Admin Use: Date of Receipt: ..................Initials: ............... Please enter the information into the patients Future Planning Template in your clinical system. Date added .................Initials ..................

Keep this paper copy as proof of receipt for no more than 3 months

My wishes

Name  Click here to enter text.

D.O.B.  Click here to enter text.

NHS number (if known)  Click here to enter text.

Address  Click here to enter text.

Postcode  Click here to enter text.

My regular GP is  Click here to enter text.

General Practice name  Click here to enter text.

The My Wishes leaflets can be ordered from Harlow Printing.

Jade Sinclair
Contracts Department
Company registration number 435445.
7-21 Maxwell Street, South Shields, Tyne and Wear, NE33 4PU.
www.harlowprinting.co.uk

Using the details.

SH009 FUTURE PLANNING: My Wishes Leaflet.

UOM: pack 100 @ £33.00 per pack.
This includes delivery.
I have health conditions that sometimes require urgent medical care. E.g. infection, diabetic collapse, fit, breathlessness.

<table>
<thead>
<tr>
<th>PROBLEM OR CONDITION</th>
<th>How I would like this to be managed. E.g. Meds to use &amp; where they are kept, what has worked in the past, etc...</th>
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Perhaps think about how far you would want treatment to go. You may need to discuss this & the management of these problems with your GP or Specialist.

My wishes for my care. Should include your preferences. Might, include cultural, religious/spiritual needs, beliefs, etc.

| Click here to enter text. | |

Please be aware of, or consider where possible, the following opinions of my family/friends/carers regarding my care:

| Click here to enter text. | |

Information about my home. E.g. keycode – which I consent to share, who can care for my pets, access problems, etc.

| Click here to enter text. | |

Emergency Contacts: friends, family, neighbours or clinical team

<table>
<thead>
<tr>
<th>Name:</th>
<th>Contact numbers &amp; address:</th>
<th>Are they aware of your wishes? Add other relevant details:</th>
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Advice to a friend over G&T

- Mrs Brown. 82
- Nursing Home resident in Warrington with late stage dementia
- Unable to recognise her family. Care is lovely.
- Not independently mobile but able to sit out in a recliner chair.
- COPD. Had been expecting mum to die for months/year from a LRTI
- Not a quality of life she would ever have wanted

- Family feel dying in the NH with staff she knew would be ideal
• Fell earlier in the day and had just been identified in ED as having a small subdural haemorrhage. Awake and disorientated, as per normal.
• Friends brother/other son in attendance. Referral to Neuro had been mentioned earlier in the day, but nothing was happening on this. Friend and brother advocating for mum were pushing for this referral
• WHY? What are you trying to achieve?

• Burr hole, decompression and then risk of seizures
  • Assuming anyone considered this to be in her best interests?
• Longer hospital stay, hence higher chance of dying in hospital
• Guaranteed delirium
What was happening.

- Sons
  - Advocating for best care for mum, as per usual
  - They assumed this meant, “investigate and treat as for anyone”

- ED staff
  - Were reacting to the brother’s advocacy. Mentioned Neuro but didn’t have the time, language or confidence to say “why this was not appropriate”.
  - May be frightened of being criticised for not doing something?
  - Just because we can, doesn’t mean we should!

- NH staff
  - Are they allowed to not seek a CT scan?
The Outcome

• Friend and brother advocated for mums return to NH the next day
• The doctors expressed relief

• Mrs Brown died of a LRTI a few months later in her NH without any further admissions
• The friend recognised his whole way of viewing his mums care and the aims of her remaining days changed in an instant.

Or certainly before I had to refill my glass
Case 2 – even briefer
This is Margaret and Jim. They live up North. They are both getting older 79 and 84. In late April 2021, immediately post lockdown, they got in their car and had a nice week in the Cotswolds. Following that they stayed in a caravan on the edge of the Solent to see their family.

That week they talked about moving from a house to a bungalow. Which . . . . . Is probably one of the single biggest reducers of acute hospital frailty admissions that there is. They also talked about Future Planning because they had a My Wishes leaflet.

Margaret was a nurse. A Nancy Roper trained SRN. She knew stuff. So when , after returning up North, doing the washing and getting the shopping, she completely unexpectedly (no hypertension, no PMH) had a ruptured AAA. She knew her chances were not good when going to theatre a couple of hours later.

Two days later in ITU her family knew her wishes, very clearly, when the ventilator was withdrawn.
What was significant about this case. As it worked!

- Margaret was my mum.

- We had a conversation over a cup of tea which lasted no more than 10 minutes. And involved quite a bit of dark humour.

- And, as it happened, it made a world of difference a week later . .
Be prepared. Do ACP...

End of Life Wishes

Treatment Escalation Planning

Emergency Access Details

Anticipatory Medication
So why present on a Dementia and EoL ECHO?
Future planning and patient wishes

10 thousand My Wishes leaflets ready to go
• Mostly about Emergency Care Planning
  • Practice Receptions
  • Community Clinics
  • Care Home receptions

4 thousand posters
But all about encouraging conversations
So, what is......
Future Planning Video

https://vimeo.com/377595465/4669a39b12
Your advice would be appreciated.
The Future Planning Template is present in >80% of EMIS practices across England.
Treatment Escalation Planning (TEPs)

Structured...

<table>
<thead>
<tr>
<th>Problem</th>
<th>Treatment level (Comfort, Home, Hospital or Intensive)</th>
<th>Management Plan</th>
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**E.g.**

**COPD exacerbation**  **Home**  **Plan** - Rescue antibiotics kept in kitchen cupboard with steroids. If not responding I do not want to go back to hospital and would like to be kept comfortable at home.

**Oesophageal bleed**  **Hospital**  **Plan** - Previously managed with balloon compression in PHT hepatic ward. Please contact Dr Ellis/team on A3 ward.

**Hypoglycaemia**  **Intensive**  **Plan** - Tends to take insulin at set times even if not immediately due to eat. Refuses food when hypo and has been known to get punchy. Generally responds rapidly to any source of oral glucose.

**Most patients only need 2-3 problems planned for..**

They are not legally binding ADRTs (Advance Decisions to Refuse Treatment), as often recommend treatment. But, may be more clinically relevant to the problem in front of you and give a good idea of how to manage it.
Potentially !!!!! reversible causes..... We need to know if the patient wants these reversed or to what extent. And this view may change over time as they become more poorly or fed up going into hospital

- Infection
- Dehydration
- Hypercalcaemia
- Accidents
- Toxicity of medications
This is **NOT** about End of Life

• Because COPD, MND, MS, CCF, PD, renal failure and frailty (+/- dementia) are all really difficult to judge even the last year!

• And as all can have sudden deteriorations. They all need **TEP & Future Planning**.

• As can many long term conditions – epilepsy, diabetes.

• And some of the treatments we give are really dangerous! (Who knew?)

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<tr>
<th>Chemotherapy – neutropenic sepsis</th>
<th>Immunotherapies – endocrine collapse</th>
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<tr>
<td>Operations – clots, bleeds, infection</td>
<td>Insulin - hypos</td>
</tr>
<tr>
<td>Anticoagulants - bleeds</td>
<td>Opioids – addiction &amp; overdose</td>
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Maybe we should be doing this at birth or soon after!!
The long read

Letting go: my battle to help my parents die a good death

https://email.rcplondon.ac.uk/1V12-7CECC-DMKIYG-4F6U0C-1/c.aspx

My parents were determined to avoid heroic medical interventions in their dying days, even before the pandemic. Why wasn't anybody listening?

by Kate Clancy
Next Session:

Topic: Curriculum Setting Session

Date: 12 July 2022
Call for papers now open!
Conference date: 22 November 2022, Glasgow

Contribute to our conference by displaying a poster or giving an oral presentation.

Closing date: 23:59 on 16 May

No extensions to the closing date.
Mentorship scheme & getting in touch

New mentorship scheme introduced this year to support people who are new to the business of writing abstracts

Mentorship applications deadline is 9 May.

If you have any questions about the call for papers or mentorship scheme, contact Stuart Duncan at: s.duncan@hospiceuk.org
Find out more

To submit an abstract, find out more about the process, access FAQs and learn about the mentorship scheme, visit:

https://www.hospiceuk.org/professionals/courses-conferences/national-conference/call-for-papers