Leeds Palliative Care Network

Future Wishes: Advance Care Planning for people with dementia

Leeds Locality Workshop Report

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Introduction

Dementia has become a leading cause of death in England and Wales (Office for National Statistics, 2015). With many older people living with dementia alongside other comorbidities; it is estimated that approximately one in three people over the age of 65 will die with or from dementia (Alzheimer's Association 2017).

The Dementia & End of Life Care group, part of the Leeds Palliative Care Network (LPCN), is dedicated to optimising end of life care for people with dementia in Leeds. Advance Care Planning (ACP) for people with dementia has been identified by the group as a potential area for improvement that could lead to better end of life outcomes.

Regionally the West Yorkshire and Harrogate Health and Care Partnership (WYH HCP) is one of three Sustainability and Transformation Partnership (STP) national dementia pilot sites aiming to deliver a reduction in non-essential acute hospital admissions and a reduction in average length of stay in acute hospital for people living with dementia. Increasing the quality and quantity of ACP for people with dementia is an identified key area to achieving this. This workshop adds to the series being held by localities within the WYH HCP area to collect qualitative data.

Workshop aims:

- to understand the extent to which people living with dementia in Leeds are being given the opportunity to discuss their wishes about their future care and to share them with those involved in their care at a time when they are able to have these conversations

- to understand the extent to which family/ advocates are involved in timely conversations about the future care needs of the person with dementia who has lost capacity to make these decisions.

- to consider how we can work collaboratively across Leeds to improve opportunities and ensure these conversations are recorded and shared effectively with all involved in a person's care

- to support the delivery of the STP national dementia pilot commitments

Background

In the UK it is estimated that at least 25% of older people in an acute hospital bed have dementia and the average length of stay is twice as long as those without; in some hospitals this has been found to be 5-7 times as long (Alzheimer's Society 2016). With the distress caused by a lack of understanding of invasive procedures and new environments, studies show a high risk of delirium and decompensation for people with dementia who are hospitalised, as well as shorter survival rates compared to hospitalised patients without dementia (European Association of Palliative Care, 2013). WYH HPC is chosen as one of the STP's for the dementia national pilot as it has above the national average rate of admissions to acute hospital for people with dementia (Alzheimer's Research UK).

ACP is a process of discussions between an individual and their health/social care providers to identify personal goals and preferences for future treatment and care. ACP can lead to a palliative approach which supports the weighing up of the burden and benefits of care and treatment; limiting unwarranted aggressive medical treatments. It can also relieve family carer stress by helping them understand their family member's wishes. In this way it can reduce the number of non-essential hospital admissions or lengths of stay and allow a person to express their choice for where they wish to die. There are many barriers that exist to the effective use of ACP these include: difficulties in starting the conversations which may sit with the confidence and skill of the professional or the willingness and understanding of the person and/or their carers; non-standardised processes for recording and sharing information; professionals from various different teams and specialities being involved with an individual but no one person taking overall responsibility for ACP (Kononovas and McGee, 2017).

It is acknowledged that dementia adds complexity to the process. People with dementia will need to engage with ACP early in their disease trajectory while they can still hold meaningful conversations and have capacity to make informed decisions. For some, this would mean they are being asked to consider their wishes for future care at a time when they are coming to terms with a diagnosis of dementia. For others this 'window of opportunity' may be missed due to a delay in diagnosis. It is generally found that in people with Long Term Conditions, preferences for care often change as people adapt to their illness and gain an understanding of its progression. Similarly in mild dementia, individuals can find it difficult to think about how the future will be for them and are likely to establish their views based on their current situation (Harrison Dening, 2012). This highlights the need for an ongoing process of review, which can be difficult for people with dementia as they likely lose decision-making capacity at an early stage of their disease. Lack of capacity over an extended period while the person is still able to feel emotion and connection to the world around them creates particular challenges to balancing their current apparent wishes or best interests with their previously expressed preferences. There is also evidence that people with dementia may be reluctant to record their wishes at an early stage in case it constrains the discretion of their carers and health care providers later on (Dixon et al, 2018).

It is found that in the absence of ACP the ability of family carers of a person with dementia to accurately predict end of life care and treatment preferences is no better than chance. This reaffirms the importance of starting ACP conversations early and involving, with consent, family carers who can then continue to participate in the review process. There is evidence to suggest that a case management approach for people living with dementia reduces hospital admissions and length of stay as well as reducing admissions to care homes. This continuity spanning the trajectory of dementia from the time of diagnosis helps to build therapeutic relationships with the person and their family and to offer a flexible and cohesive approach to ACP (Harrison Dening et al, 2019).

The Mental Capacity Act (2005) states that an individual must be given all practicable support to make their own decisions and should be involved in conversations concerning their care for as long as possible; even when they lack decision-making capacity, their feelings and emotions are to be taken into account. The ACP process for people with dementia further benefits from healthcare professionals who have the skills to support people with dementia to communicate.

ACP definition

Definitions for ACP and its various components can vary nationally and internationally. WYH HCP and LPCN dementia and EOLC group have agreed on the use of the following definition:

ACP is a discussion between an individual and their care provider(s), irrespective of discipline. If the individual wishes, their family and friends may be included. The process of ACP is to make clear a person’s wishes and will usually take place in the context of an anticipated deterioration in the individual’s condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others.

With the individual’s agreement, discussions should be:

- Documented
- Regularly reviewed
- Communicated to key people involved in their care

(National Council for Palliative Care, 2008)

An advance care planning discussion may result in one or more outcomes. In England and Wales, these would be classified as: a Statement of Preferences and

Wishes; Advance Decision to Refuse Treatment; appointment of a legal advocate-Lasting Power of Attorney for ‘health and welfare’ and/or ‘property and affairs.’ Under the Mental Capacity Act (2005) the latter two are legally binding, if valid and applicable, and although the former is not legally binding, it is obligatory that it is taken into account when a best interest decision is being made.

Dixon et al (2018) adds that in the case of dementia, ACP conversations may also be conducted with a carer within a ‘‘best interests’’ framework.

ACP and other sources of information for supporting and planning care and treatment.

	Type of documents	**Examples**	**Notes**
1	Providing information for a person’s current care and support	‘This is me’ – Alzheimer’s Society ‘All about me’ –Yorkshire Ambulance Service ‘ Hospital Passport’-Learning Disabilities	Paper based patient held records to provide information about a person at the time that the document is completed. It can help health and social care staff to build a picture of that person.
2	ACP Statement of Preferences and Wishes	Preferred Priorities for Care Advance Care Plan: Personal preferences and wishes for future care	These are paper based patient held records completed by the patient usually through a discussion with their health and social care provider at a time when the person has capacity. Only comes into fruition when a person loses capacity.
2	ACP Legal documents	Lasting Power of Attorney Advance Decision to Refuse treatment	Legal documents-made when a person has capacity usually in consultation with health/social care professional, witnessed and signed and relate to specifically identified circumstances. Only comes into fruition when a person loses capacity
3	Emergency Care Plan	DNACPR ReSPECT	These are made through a discussion with the patient and clinician to provide concise, relevant, rapidly accessible clinical recommendations for use in an emergency. Should be tailored to consider the most likely individual situations, such as a sudden acute illness, deterioration in a long-term condition or sudden cardiac or respiratory arrest.

All these plans are complementary. They may be developed together or the completion of one may prompt consideration of the other (Pitcher et al, 2017)

The workshop

Thirty four delegates representative of health and social care; primary, secondary and voluntary sectors across the city attended the workshop.

They included:

Leeds Teaching Hospitals Trust- LTHT Consultant/ Geriatricians Consultant in Palliative Medicine Head of Mental Health Legislation Adult Safe Guarding Hospital Liaison Workers Deputy Ward Manager – Intermediate Care Unit (ACP champion) Clinical Nurse Educator (ACP champion) Speech and Language therapist Patient/carer representative	Leeds and York Partnership Foundation Trust-LYPFT Health Facilitation Team/ nursing /support staff - Learning disabilities Memory Nurses Memory Support Workers
Leeds Community Healthcare Trust-LCHT Palliative Care Lead End of Life Care Home Facilitator	Hospices Speciality doctor CNS Social Workers (ACP champion)
Yorkshire Ambulance Service-YAS Planning and development manager Paramedic	Other GP/ Clinical Lead for EOLC- LPCN IMCA manager – Advonet Care Home managers/nurses

The workshop was divided between three components:

A. Update on the regional work of the national dementia pilot

B. Table discussions facilitated by members of the LPCN Dementia & EOLC group to gain an understanding of delegates' current experiences and their considerations for the future.

C. Raising awareness and information giving about local initiatives being developed/piloted

A. Update on the National Dementia Pilot regional work-

Penny Kirk, Quality Improvement Manager, Dementia and Older People's Mental Health Clinical Network

Defining Target Populations

Categories of patients admitted to hospital where the project will be expected to have a beneficial impact:

1) Short Hospital Stays (less than 72 hours)
2) Those who died within 72 hours of Hospital admission
3) Hospital admissions for longer than 21 days (referred to as ‘super-stranded’)

Primary Care Data

Based on the premise that people with an ACP in place have fewer visits to Emergency Departments and admissions to hospital, key measures for ACP have been developed:

- % of people on GP dementia registers who have an ACP recorded, including:
  - LPA
  - Carer details
  - Preference for CPR
  - Emergency Care Plan

- % of people on GP dementia registers who are also on the End of Life Register (to enable sharing of info across care partners)

Baseline data for Leeds (S1 practices only)

Patients on dementia register who died during 2018	Patients on dementia register as at 31/1/19
1106 patients (~23% of dementia register) 11% with an ACP recorded (1% declined ACP discussion) 8% with ECP ACP or care plan review (76%) 9.7% record of ACP discussion; 21% no indication at all 35% had specified preferred place of death; 11% declined to discuss 6% with an LPA 51% with resuscitation status recorded 12% on EoL register; 10% no indication of ANY related conversations 3% consent to record sharing	4815 patients on 7.6% with an ACP recorded (1% declined ACP discussion) 2.6% with ECP ACP or care plan review (84%) 6.8% record of ACP discussion; 14% no indication at all 11% have specified preferred place of death; 4% declined to discuss 3.7% with an LPA 23.8% with resuscitation status recorded 3.3% on EoL register

Minimum content for ACP

Proposed minimum content for ACP that is required by Yorkshire Ambulance Service (YAS) to support their decisions around whether to convey a person to hospital is:

- Resuscitation status
- Lasting Power of Attorney (Health & Welfare)
- Advance Decision to Refuse Treatment (ADRT)
- Preferred Place of Death /Care

DeAR-GP (**De**mentia **A**ssessment and **R**eferral Tool), is a paper based tool used by care workers to identify people who are showing signs of dementia. There is consideration in using a similar model to pass ACP minimum content information onto the GP to enable them to upload it onto their 'System one' electronic records. This will be helpful to those who currently do not have access 'System one' to allow for the information to be stored and shared more widely.

The regional work is closely aligned with NHS England Electronic Palliative Care Coordination System (EPaCCS) Demonstrator site working on interoperability of systems to ensure ACP information is recorded consistently and can be shared with YAS, out of hours GPs as well as between the other health and social care services.

ACP leaflet

In collaboration with the Alzheimer's society there are plans to work with people with dementia and carers to co-produce an ACP information leaflet

Advance Care Planning and Communication Skills -Facilitator Training

This is based on the successful programme of training developed and rolled out in the North West by the North-West End of Life Partnership, supported by Health Education England and evaluated by Edge Hill University. Although this is a generic programme it has been commissioned to be rolled out through the WYH national dementia pilot with the aim of targeting training to staff working predominantly with people with dementia and/or frailty

St. Gemma's Hospice and Wakefield Hospice have been commissioned as the two education hubs to deliver this train the trainer ACP/communication skills programme. Each hub delivers a standardised package of resources to 20 ACP champions and support the champions in delivery of cascade training to 40 frontline staff per champion. The following criteria is used to select suitable candidates to attend the two day training to become ACP champions:

Essential	***Desirable***
Completed Communication Skills Training at Intermediate Level	*Completion of Communication Skills Training at Advanced Level*
Education / training skills	*Completion of Train the Trainer for Communication Skills*
Education/training or facilitator role within own employing organisation	*Completion of Educator Development Programme or equivalent*
Knowledge of ACP, MCA, 'Best Interests' decision-making, legal and ethical implications	
Clinical and / or practical experience within current role relevant to frontline staff who will be trained and supported to Advance Care Plan	

There will be two cohorts of 10 facilitators per hub; Leeds has been allocated 4 places per cohort.

The first cohort of ACP champions completed their training in June. The four for Leeds locality included:

- Hospice palliative care social worker
- Matron-Intermediate Care Ward LTHT
- Clinical Nurse Educator- Emergency and Speciality Medicine- LTHT
- Regional Clinical Development Nurse- Springfield Healthcare

Three were present and introduced to the workshop delegates.

A further four will be trained at the next cohort in September.

Evaluation/feedback from the first cohort of ACP champions following their training

Very informative and made me more condiment to talk about the ACP and future plans.

Giving the staff confidence to take talking about ACP forward. Giving the staff the ideas/ clues to take forward.

There are lots of issues to consider around the issue of ACP generally and particularly in relation to supporting people with dementia. The important focus of training is to try and get the ACP discussion moving.

B. Table Discussions

Delegates were sat at tables with around 6 people per table. Each table had a member of the LPCN Dementia & EOLC group to facilitate the discussion.

Summary of discussions

Who would be appropriate to have ACP conversations?

The list was comprehensive to include a range of health and social care staff who have contact with the person with dementia at different points on their trajectory. It was widely recognised that starting these conversations early particularly for people living with dementia was beneficial with some suggesting that family/friends/informal carers were also in a good position to help people to start thinking about the future.

The list included:

Advanced care nurse practitioner's in GP setting Consultant Geriatricians in hospital Palliative care teams in hospital Community Matrons GP'S Care Home staff	Memory clinic Staff Memory Support workers Social prescribers Dementia cafes Voluntary services Outpatient appointments that are not dementia related.

What are the opportunities in current practice?

NHS information leaflet 'planning for your future care: a guide' is good to have available for people with dementia and families to 'plant seeds' supporting further conversations. Memory services offer post diagnostic support appointments where a range of information is given. There is potential opportunity to discuss what the dementia journey entails and in some cases this may include discussing Lasting Power of Attorney and resuscitation wishes. If GPs are proactive they can use the annual reviews to offer opportunity to discuss ACP and look to anticipate the end stages. When there are other comorbidities, opportunities for ACP may arise through non-dementia specific outpatient appointments. 'Pink Folders' are used in the community for keeping important health and social care information in one place so they can be easy identified by professionals entering the home and taken with patients to appointments/admission to hospital. The roll out of Recommended Summary Plan for Emergency Care and Treatment (ReSpect) offers a consistent approach for Leeds. Financial incentives (QOF) are given to GPs and Care Homes to complete ACP with patients/residents.

Concerns and challenges from current practice

Health and social care professionals do not always take responsibility and grasp opportunities to have ACP conversations when they arise. They may assume someone else has done it or that they need permission. They may not feel confident and have the right skills, with training and time to undergo training not always available. Nurses from the acute hospitals generally do not raise these discussions while doctors tend to focus on discussing resuscitation wishes. Having resuscitation discussions in the first instance can hamper a wider approach to ACP. The ReSPECT form is rolled to promote a wider approach to emergency care planning but they are not always completed comprehensively and may still be used just to record the resuscitation status. There is space for recording other aspects of ACP including statements of preferences and wishes on the ReSPECT form but this is not initiated until there is contact with healthcare services. YAS have contact at a critical time for triggering ACP conversation but this tends not to happen due to the adhoc nature of contact and lack of continuity.

Memory nurses attempt to have ACP conversations in the early stages but there is a pressure to discharge and the person with dementia and their families may not be ready to discuss this at this stage. MSWs felt that they are in need of training and would like more support and guidance. At this stage they felt that they lacked the confidence to have ACP discussions. The memory nurses also highlighted problems with recording and sharing any discussions that do take place.

The confidence and skill and time to have the conversations are still needed. There are financial incentives for GPs and Care Homes to complete ACP for patients/residents but these may become tick box exercises and there is no guarantee of the quality of the information and how it is shared. These conversations may be occurring within families or any member of the healthcare team but they might not be recognised as such and the importance of recording and sharing them with others may not be realised.

Although palliative care teams are seen as the experts in this field, the point at which someone with dementia requires palliative care they are likely to have lost their decision making capacity and may have missed out on many choices they could have made earlier. While the opportunity for these conversations should be made available from the time of diagnosis of dementia through the memory clinic and/or GP, people generally require time to come to terms with their diagnosis and it is not always made clear to them that dementia is a terminal condition. Furthermore post diagnosis follow up often involves a lot of information giving with the emphasis on living well in the present. Anyone on the GP dementia register should have an annual review which gives good opportunity to discuss ACP; however a person’s cognition could change significantly within a year. People diagnosed with dementia who are physically well may not need to access health and social care services at an early stage leaving a gap in support at a significant time for starting ACP conversations. Family dynamics and their attitudes towards ACP may have positive or negative influence, with family members having their own support needs. Family carers are not always there to support or to hear the conversations. They may also affect how the person with dementia responds or they may talk for the person. People with dementia may be assumed to lack capacity when perhaps more could be done to support them to communicate their feelings. It is not always made clear if the ACP is made by the person with dementia or through the family carers.

There is a need for a multidisciplinary/service approach so opportunity to initiate and to review ACP is available whenever the person is ready which can vary depending on their circumstances and the way they cope (right time, right place). There is however a lack of consistency and coordination made more difficult by the involvement of different health and social care teams over an extended period of time. Health and social care workers, not knowing what services exist including voluntary services and who else may be supporting the person and their family, may run the risk of duplication or assumption that someone else is taking the lead. There lacks a case management approach to ACP.

Different systems are in place for recording and sharing ACP information. IT systems between health and social care and within healthcare do not ‘talk to each other’. This means relying on paper documents kept with the patient. These may be lost or not kept where they are easily found in a crisis or not carried by the patient at all times and between transfers to different services. Changes following a review may be missed if there are several copies and they are not all updated. YAS is often the first contact when there needs to be a decision made to convey someone to hospital but do not have access to IT systems for up to date information and paper ACPs may not be easily available at this crucial time. Even when ACP documents are in place staff may not have the confidence to follow them and be concerned of the consequence (Care Quality Commission; complaints from family). Transfer to hospital in a crisis can be seen as the safest and easiest option especially when time and resources are limited. If ACP are completed but not taken into account , those who were involved in their development can feel let down. ACP documents are patient held records rather than clinical records. If they are to become electronical templates who will have ownership?

Recommendations

- Conversations triggered through appropriate coding on the GP Dementia register
- All healthcare staff who come into contact with the person living with dementia to ask if conversations have already taken place about their future wishes
- Encourage therapists to be more involved
- LPA at minimum discussed at the Memory Clinic
- Consideration about how and who will fill the gap between diagnosis and more regular contact with health and/or social care services
- Link with diverse communities through cultural/spiritual groups
- Link with raising awareness campaigns within the city
- Information pack/leaflet on ACP in generic settings (GPs, One Stop Centres, Health centres)
- More Admiral Nurses for the city to allow for a case management approach
- Continue to support ACP with CQUINS to include a wider range of services.

Tina Wormley (former carer) of tide- together in dementia everyday, also member of the LPCN Dementia & EOLC group -Unable to attend workshop but sent following statement:

‘’ ACP’s need to be offered to people with dementia early in the disease. This requires an honest and frank approach. Dementia is a terminal disease; patients don’t recover from it. If we are not honest or if we are evasive about their future, it puts them at a serious disadvantage. It deprives them of their right to make choices about their care.

Conversations need to take place before loss of capacity occurs. Two years into the disease and my mum could not have truly understood the implications of an ACP. At the beginning she could have. This is perhaps the most difficult aspect of delivering ACP’s for dementia patients. A judgement about capacity is never easy to make. That said, I certainly knew when my mum still had capacity. I think those closest to them are in a good position to judge when the time is right for a conversation about ACP’s. I would have wanted to have that conversation with her and would have appreciated support from practitioners about the best way to do that.

Not at any time during the early stages of mum’s disease did anyone say that it was a life limiting disease and that we should discuss this. By the time her GP informed me that her life was limited, she was at the end stage of the disease and had lost all capacity.

In summary, it seems disrespectful not to have the conversation about future wishes as we do with patients suffering from other life limiting diseases. Conversations about ACP’s need to take place as early in the disease as possible. Knowledge is power and having a plan in place can be reassuring for all concerned’

C. Local initiatives

YAS Volunteer Advocate Training- Leeds

Alistair Gunn, YAS Planning and development manager

This pilot project is to train YAS volunteers to act as advocates for people with complex needs which may include supporting people to consider their future care wishes. Thirty volunteer staff have received training with the aim of starting to develop Health Care Plans with people identified by two GP surgeries in Leeds (Rutland Lodge Medical Practice (LS7) and Hillfoot Surgery (LS29). Following completion of a Health Care Plan, the volunteers print these off and leave them with the individual

Planning Ahead: Digital ACP for Leeds

Dr Adam Hurlow, Consultant in Palliative Medicine, LTHT, LPCN

The project aim is to develop one digital advance care plan per patient at point of care across all electronic records in Leeds

To do this there needs to be ways for all electronic record systems to speak to each other. These include PPM+, System1, EMIS, EDAN, Leeds Care Record. While currently EPaCCS is the key place for recording details of ACP, this needs to be extended to include patients who may not be identified as palliative/end of life to cover people with long term conditions, dementia and frailty and allow recording of ACP developed early in a person's illness trajectory.

It is proposed that ReSPECT template on EPaCCS can become an integrated citywide digital solution. This work is ongoing and there will be links to the regional and national work in this area

MCA Leeds ACP animation

Kulvant Sandhu, Named Nurse for MCA & Dementia, LTHT

There are plans to produce a short animated public information video for public on ACP to be played in public areas such as GP surgeries, One Stop Centres, Health Centres. The Workshop delegates were asked for their thoughts on the key messages to be put across in such a video to be shared at the design workshop.

Key messages identified

What is ACP	Where to record and share
Why do an ACP	Examples of ACP
Applies to all	Benefits of ACP
Types of decisions in ACP	How to do it
Not just for elderly or palliative	Who to share ACP with
Myths- don’t need a solicitor	Everyone to consider it
Not just about DNACPR	Link to MCA, important when lack capacity
Involve/tell family	Not just health decisions

Conclusion

Based on the information presented at the workshop along with the table discussions it is clear that there is a realisation of the potential benefits of ACP but that much more work is to be done to overcome the challenges particularly in relation to people with dementia. The challenges identified through the table discussion reflected those presented nationally in literature.

There is currently a whole system review regionally and locally aimed at providing a consistent coordinated approach to recording and sharing ACP information across services particularly in relation to digital records. This development will not be immediate and in the interim it is important to consider the best available ways of working with different IT systems and paper documents to share the information effectively.

Regardless of how the information is recorded and shared the opportunities for these conversations need to be created in the first instance, at the right time and in the right place. Training of health and social care staff across services including the voluntary sector and raising public awareness can be seen as important first steps.

Knowledge and understanding of dementia and how to support people with dementia to communicate their needs as well as a case management approach are further considerations for optimising ACP quality and uptake for people with dementia.

Limitations

Apart from hearing the statement from Tina Wormley (member of tide and LPCN), there was only one other bereaved carer who attended the workshop at the Hospice. The discussions predominantly reflected the experiences of health and social care staff. Further work is needed to get a more comprehensive understanding of the experiences and views of the people living with dementia and their careers in Leeds.

Action Points for the LPCN Dementia & EOLC ACP group

1	Link in with local and regional work to support and implement future developments: • Minimum content for ACP – for sharing with YAS • Co-produced ACP leaflet – Alzheimer's Society • Work progressing to enable electronic sharing of data across services, including YAS
2	Consider a way of promoting the sharing of key ACP information across health and social care setting in the interim until all electronic systems (including care homes) talk to each other- Adopt Bradford model tear off sheet at back of ACP document with information for GP to put of System one (or in the form of a DeAR-GP letter for ACP), ReSPECT document.
3	Promote the use of the ACP awareness animation being developed by LCHT
4	Consider formats – easy read ACP documents and information – what is available, are they appropriate for people with dementia, how do we promote their use?
5	Link with support groups and Dementia Cafes to talk to people with dementia and their carers about ACP – raise awareness, gain their thoughts.
6	Promote the roll out of the one day ACP training to frontline staff who work with people living with dementia, focusing particularly on staff who will have the opportunity to have these conversation early on. This can be done by linking in with the ACP facilitators for Leeds
7	Ensure the ACP facilitators for Leeds have a clear and consistent message about ReSPECT to deliver within their training
8	Continue to look for funding for End of Life Care- Admiral Nurses for Leeds

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