End-of-Life Care in Community Nursing

Hints and Tips!

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Session Aim

- To consider the various aspects of end-of-life care provision in the community setting

Topics

ACP	Have an understanding of what Advance Care Planning (ACP) is and what it might mean to the people that we are supporting. Think about 'what matters to you' Talk about documentation, including TEP forms
End-of-Life care	Revisit the 5 Priorities. Recognise the symptoms that may be present at end-of-life, think about symptom management Talk about Just In Case (JIC) and syringe pumps
Community	Understand the context of community care. Talk about Social Prescribing, compassionate community, support for caregivers. RDUH context and updates.

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What is Advance Care Planning?

- What's important to me:

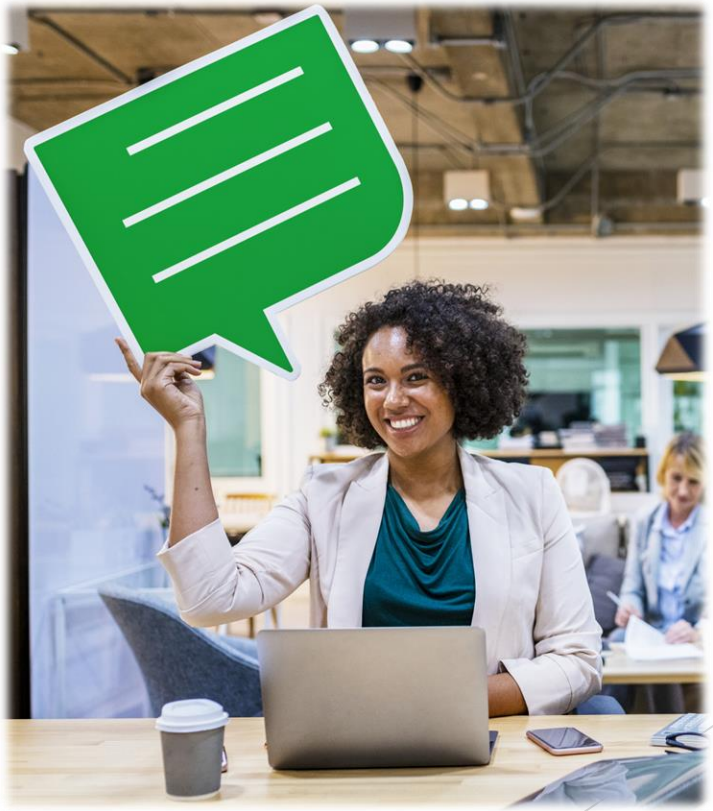
A review of choice in end of life care (2015)

- Ambitions for Palliative and End of Life Care:

A national framework for local action (2021)

- Universal Principles for Advance Care

Planning (2022)



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Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with [them].”
- International Consensus Definition of Advance Care Planning, 2017

‘Advance care planning can make the difference between a future where a person makes their own decisions and a future where others do’(NICE, 2019)

“Advance care planning and good, early care planning in general, play a crucial role in conveying these wishes and ensuring individual care choices and preferences are recorded and delivered. These wishes might take the form of refusing a specific treatment, making an advance statement setting out their wishes and preferences, or appointing people under a Lasting Power of Attorney to make decisions on their behalf.” (The Choice in End of Life Care Programme Board, 2015)

“ACP is a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care, while they have the mental capacity for meaningful conversation about these. The process, which is likely to involve a number of conversations over time, must have due consideration and respect for the person’s wishes and emotions at all times. As a result, the person should experience a greater sense of involvement and the opportunity to reflect and share what matters most to them”. (Universal Principles for Advance Care Planning, 2022)

“A goal without a plan is just a wish.”- Antoine de Saint-Exupéry.

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Frailty context

- 10.5 million people aged over 65 in England
- 3% of the population aged 65+ in England live with severe frailty, 12% with moderate frailty and 35% with mild frailty
- 74% of people aged 65-74 live with at least one long term health condition
- 86% of people over 85 live with at least one long term health condition
- 14% of people over 85 live with 4+ long term health conditions
- 1 in 6 emergency admissions of people over 75 occur within 30 days of last being discharged from hospital (AGE UK, 2023)
- Around 1 in 5 people over 70 die within a year of an emergency admission
- Identification of frailty nearing end of life:
  - Two or more unplanned hospital admissions in the past 6-12 months
  - Persistent and recurrent infections
  - Weight loss of 5-10% in the past 6 months
  - Multiple morbidity in addition to frailty
  - Combined frailty and dementia
  - Delirium
  - Exacerbation of falling
  - Rapidly rising frailty score
  - Escalating patient, family or service provider distress
  - Older person asking for palliative care support and/or withdrawal of active treatment (BGS, 2020)

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Barriers and challenges to ACP

- Professional confidence, knowledge and experience
- Insufficient time
- Prognostic uncertainty
- Limited patient participation
- Competing demands
- Information sharing, integrated systems, silo working

"Everyone has a plan: until they get punched in the face" – Mike Tyson.

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What Matters To You

Remember, you don't have to be an expert and have all the answers

There may be something you can sort or maybe something you can't, but that's okay.

Often just the listening and connection is enough.

No time to have a conversation?

Think about how much time you'd waste doing what's not important if you don't

Make the time to find out 'what matters' and 'what's important'

Check our website for more information and resources

www.whatmatterstoyou.scot

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Handy guide

www.whatmatterstoyou.scot

Conversations can take 40 seconds or 40 minutes

For a quality conversation the length of time is not as important as the compassion, and human connection it makes

Sometimes it's easy to start a conversation but when it's not what can you do?

Be observant, look for openers to help you start the conversation, or just ask

"would you like to have a chat?"

You could ask:

"What's important to you?"

"What makes a good day for you?"

"Is there anything you would like to talk to me about?"

or whatever works best for you

Don't feel the need to force a conversation

Don't be afraid of silences or pauses, they can be as important as words

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Treatment Escalation Plan (TEP)

- A TEP form records the persons views about whether they would want to be admitted to hospital or not, should they become unwell.
- An overall plan of care – the TEP allows clinicians to document a plan of care for patients and whether they are FOR or NOT FOR Cardiopulmonary Resuscitation.
- Should be more about the process & discussions with patients/families/carers than the form.
- Should be reviewed if there are changes
- …'It is vital that all health and care professionals are open with people using services, patients, their families and carers about the clinical and other factors being taken into account in any decision about CPR/DNACPR. They should provide reassurance that if a DNACPR decision is made it does not mean that other appropriate treatments will cease - other options of care will still be available and should be discussed and agreed.' (NMC, 2020)

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End-of-Life care – the 5 Priorities

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Priority 1 - Recognise

- **Recognising** that someone is deteriorating and may be approaching the last few days/hours of life.
- Discussing this within the multidisciplinary team, ensuring that this recognition of dying is communicated clearly
- Discussing this with the person, with clear decisions being made regarding their care and actions taken in accordance with the person's wishes
- These decisions should be reviewed regularly

Recognising End of life

- Reduced eating and drinking
- Spending more time in bed
- Fatigue and weakness
- Noticeable deterioration and change in their condition
- Becoming more withdrawn and less able to engage
- Symptom management e.g agitation, respiratory secretions
- Restlessness/Terminal agitation

Priority 2 - Communication

- Open and honest **communication** between health care professionals and person who has been identified as being in the last days/hours of life, alongside whoever is important to them
- Staff should listen and respond sensitively to the persons/relatives issues and concerns. Providing information that meets their communication needs, checking with them that the information and explanations are understood
- Staff should actively seek to **communicate** and not wait for the person or their relatives to ask questions or raise concerns

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Priority 3 - Involve

- The dying person and those important to them should be **involved** in decisions surrounding their care and treatment.
- e.g eating and drinking, personal care, symptom control and clinical decisions
- The person and those important should know which teams or healthcare professionals are **involved** in their care
- The person and those important should know how to contact any teams **involved** in their care

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Priority 4 - Support

- The **support** needs of the person, their family and those identified as important should be met and discussed.

-e.g spiritual, psychological, physical

- Although it is not always possible to **support** these needs, they should be listened to and acknowledged, explored and met as far as possible.
- CHC Fast Track?

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Priority 5 – Plan & Do

- The 5 priorities of **care** formulates an individualised **care** plan which includes conversations and actions of the following:

-Symptom management

-Psychological support

-Food/drink

-Social

-Spiritual needs

The 5 priorities **care** plan should be agreed, co-ordinated, reviewed daily and delivered with compassion and empathy.

Caring for someone approaching the end of their life

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Good practice around End of Life care

- Regular mouth care needs to be provided

-Can use any drink, establish from those important what the persons preferred drink would be

- Repositioning
- Managing bladder/bowels

-If the person is showing signs of distress is it because they are in retention, consider if a catheter be more comfortable

- Creating an environment they would like

- Enjoyed certain music
- Pictures of loved one
- Dimmed lights
- Hot or cold, did they usually have a fan or like their feet to be uncovered in bed

- Spiritual needs

- Is faith very important to them, is this causing them distress

End-of-Life care – symptom management

- TIP sheets (handout)
- Conservative Measures
- JICB - troubleshooting
- Syringe Pumps

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JICB – TOP 10 TIPS

- Educate patient's to know what has been delivered.
- To Know on your caseload who has a JICB + to have links with your GP surgery to patients who have JICB not known to the team.
- Not to be task oriented with the JICB – this is a great opportunity to complete a full holistic assessment.
- Checking exactly what medications have been delivered to the patient.
- Checking storage; expiry dates; signatures, prescriptions chart.
- Provided needles and syringes + sharps box.
- Provide contact details for the patient – who to contact in a time of need.

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Syringe Pumps - TOP 10 TIPS

- Ensure teams maintain their syringe pump competencies.
- Have a syringe pump box – ready to go!
- Prepared folders containing any information and documentation.
- Stock levels are checked at every visit- taking into account PRN + weekends.
- Do not remove analgesic patches before setting up a pump.
- 1 Prescription chart per pump.
- Ensure that PRN medications are prescribed on the authority to administer chart and not JICB + ensure as the medications increase to meet the needs of the patient that the PRN's increase to reflect this change.

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Compassionate Communities

- In this context, describes communities that are compassionate in their support of people through the difficult times associated with care, deteriorating health, dying and bereavement.
- Compassionate communities do not assume the formal service responsibilities of health and social care services - their role is different and complimentary. A compassionate community:
- Recognises that care for one another at times of crisis and loss is not simply a task solely for health and social services but is everyone's responsibility
- Encourages, facilitates, supports and celebrates care for one another during life's most testing moments and experiences, especially those pertaining to life-threatening and life-limiting illness, chronic disability, frail ageing and dementia, grief and bereavement, and the trials and burdens of long term care.

Social Prescribing

What is social prescribing?

- Social prescribing is a key component of Universal Personalised Care. It is an approach that connects people to activities, groups, and services in their community to meet the practical, social and emotional needs that affect their health and wellbeing (NHS England)
- Brainstorm, look at what is in the locality, find links to community support – REFER, SIGNPOST, COLLABORATE
- **The JOY app** https://services.thejoyapp.com/
- **Devon Carers** https://devoncarers.org.uk/

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RDUH context

- End of Life *discharge* support
- JIC meds to trigger ACP
- Nurse-led TEP and ACP Training: community
- Palliative Care Facilitators for Care Homes
- FLAG: Last Year of Life, End of Life
- Devon and Cornwall Shared Care Record: Treatment Escalation Plan
- Care Homes education and training
- Care Coordination HUB
- Front door frailty and palliative care team

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Some suggestions - ANY MORE?

- Carry a Blank TEP/draft TEP with your PIN included
- PIN on back of badge
- VOED checklist
- TIP sheets for medication – could be a photo on phone?
- Blank ACP document
- Contact numbers in phone
- Use contacts for advice e.g. local Hospice
- Conversion chart for oral to injectable

Reading list

RECOMMENDED READING

- With the End in Mind – Kathryn Mannix
- The Book About Getting Older – Lucy Pollock
- Thomas, K, Lobo, B. and Detering, K. (eds) (2018) *Advance Care Planning in End of Life Care* 2nd edition Oxford University Press

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Thank you

Q&A

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