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Edinburgh Health and Social Care Partnership

Evaluation of care planning with family members of residents in care homes using the '7-Steps to ACP' in Care Homes approach

Background

Anticipatory care planning (ACP) is a core aspect of quality care for residents living in care homes across Scotland. Covid-19 highlighted the importance of ACP further. The Edinburgh Health and Social Care Partnership's (EHSCP) Long Term Conditions Programme ACP team has been working with care homes and GP practices to embed an ACP process in routine care. The '7-Steps approach to ACP' provides training and resources for care home staff to support implementation of person-centred ACP with residents and their families.[1] It was developed from an initial quality improvement study of ACP in a small number of care homes in North Edinburgh that included the view of primary care professionals, care home staff, residents and relatives. Since then the 7-Steps to ACP has been developed, improved and extended to involve over 30 care homes across Edinburgh. The *ACP Improvement Programme Learning Report* [2] of Phases 1-3 captured service use data and perspectives of care home staff and GPs. A qualitative evaluation was designed to explore the experiences of relatives of residents living in care homes where the 7-Steps approach is implemented.

Methods

The ACP team identified a sample of 5 care homes involved in Phase 3 of the ACP in care homes programme to participate in the qualitative evaluation. A researcher from the Primary Palliative Care Research Group at the University of Edinburgh conducted the evaluation and worked with the ACP team in setting up the study. The study was approved as part of a wider quality improvement project so formal research ethics committee review was not required. The manager of each care home consented to take part in the evaluation. A study flowchart was used to guide recruitment (Appendix 1). Care home staff approached relatives of residents meeting the eligibility criteria:

- Resident is currently living in the care home.

[1] Health Care Improvement Scotland. April 2019. Dr Andrew Mackay. *ACP in Care Homes. Living Well in Communities.* Accessed on 08/10/2021. Accessed at: https://livingwellincommunities.com/2019/04/09/acp-in-care-homes/

[2] Edinburgh Health and Social Care Partnership. 2019. *ACP Improvement Programme Learning Report – Phase 3 2018-2019*. Accessed on: 08/10/2021. Accessed at: https://services.nhslothian.scot/CareHomes/SupportingResidentsNeeds/Services/Documents/ACP%20Improvement%20Programme%20Learning%20Report%20Phase%203%202018-19%20revised%2015.11.19.pdf

- Resident has been living at the care home for at least 6 months.
- Care home staff have discussed the ACP Questions sheet (from the 7-Steps toolkit) with the resident and/or family members.
- The ACP question responses were recorded in the resident's Key Information Summary (KIS) as part of their care plan and are kept in their record at the care home.
- The resident's condition is reasonably stable at present (*they are not very ill or dying at this time*).

Relatives were told that the care home has been working with Edinburgh Health and Social Care Partnership to improve conversations with residents and families about planning ahead for care and treatment. They were asked about sharing their experiences of having care planning conversations with an independent evaluator in a brief, confidential telephone interview. Contact details for relatives who wished to consider taking part were passed to the ACP team and an administrator provided further information verbally and in a short information leaflet which included a copy of the ACP Questions sheet. (Appendix 2). Relatives then returned a written consent form and the interview was arranged at a time convenient for them. The researcher conducted each interview by telephone having re-confirmed consent. A semi-structured interview schedule was used but participants were also encouraged to talk freely about their experiences, thoughts and feelings. Anonymised field notes were written during and immediately after each interview.

Results

The evaluation was delayed due to the pandemic and the interviews took place over a longer period than anticipated (December 2020–May 2021). All five residents were female, over 80 years old and living with advanced dementia and general frailty. The relatives were two daughters, one son, a niece and a husband. All of them were keen to take part and share their stories. They described the care received by their relative in the care home as high quality, and felt that it was the right place of care for them.

Four themes were explored during the interviews:

1. What does 'anticipatory care planning' for your relative/friend mean to you?
2. What can you tell us about your own experiences of care planning with the care home staff and your relative?
3. What do you think about people being given a document like the Anticipatory Care Planning Questions (ACQ) to help care home staff talk with them about care planning?
4. How do you think care planning with residents and their families can be improved?

Theme 1: None of the interviewees were familiar with the term 'anticipatory care planning'. Those with prior knowledge of aspects of future care planning due to personal or professional experience had much greater knowledge and understanding of the process and its value to their relative even when the resident lacked capacity for ACP decisions by the time of admission to the

care home. Two thought their relative had signed a previously completed DNACPR form and were unclear about the process for those decisions.

'You make decisions as the next of kin when she is no longer able and use what you know about her and what she said before.'

'Anticipatory' care planning is not something I've heard of, future care planning might be better.'

Theme 2: Experiences of ACP varied with some asking questions about avoiding 'heroics' up front and others wanting time and support to consider future scenarios. Two of the relatives wanted more detailed plans for actions to be taken and explanations about the rationale for decisions. Both wanted reassurance that completing the questions did not exclude them from decision-making when something happened to their relative. One relative was quite happy to leave the decisions to staff, confident that they were already caring so well for his relative that they would do the right thing. The final two relatives were only able to have phone conversations with care home staff and received the ACQ by email due to Covid-19. Both navigated this additional challenge by asking more questions of care home staff.

'We had Power of Attorney long ago so the rest of the family leave it to us. We are open about these things and we expected to be asked about resuscitation and so on. Other people like my mother-in-law are different and her family wouldn't discuss dying so it was very difficult…'

'Well, I balked a bit at first but it was ok when we talked about the options.'

'Having a structure would make it easier for the staff but put right at the top that they have a duty to contact you if things change.'

'You feel more confident about doing your best for her. It makes it feel safer if it is well-planned. You feel at peace… less worried.''

Theme 3: Using a set of questions and options for common scenarios that can happen when a care home resident's health deteriorates was met with different responses, largely positive.

'It enables you to focus on specific scenarios.'
'Nobody likes to think about if x happens, but having these options helps.'

'I know from the questions that it is not just, well we let ill people get on with it but people could go to hospital' (This resident had a short hospital admission and surgery for a hip fracture before returning to the care home.)

'You need to keep the language simple and not so medical. I didn't like 'clinically assessed' for example – what does that mean?'

'What was missing in her plan was calling a priest if she got very ill, so I had to ask for that when she had Covid. Everything else was in place, the drugs and so on… And she got better anyway.'

'How does this relate to her problems and specific needs on an ongoing basis…You need a list of her problems first and a plan for each…'

'Some of the questions are impossible to answer as you don't have a context or know what the outcome would be. I was just told to read it and sign it and give it back so I had to question that.'

Theme 4: All the relatives thought making plans in advance for future care of their relative was important and should be offered to everyone even those who were more reluctant to engage with the process. Most felt they had to undertake the responsibility of making these important decisions for their relative. Having built up a good relationship with the care home staff member before or around the time of the admission, made it easier when care planning was raised by staff. The ACP questions should be part of a conversation with someone who knows the resident and their family. Three relatives spoke about the recent organ donation campaign in Scotland and wondered if something similar would help with care planning.

'It could phase some people, so you need to go gently.'

'It is my responsibility to make good decisions, I can't ask her now.'

'A public campaign from an organisation you can trust might help like the NHS. You could have an independent advisor on a helpline to talk to.'

'We need a process like this. We should be having these conversations. Looking at this for Mum helped me talk to Dad …We found the MyACP document online and went through that together.'

Conclusions

All the relatives thought that care planning was important and should be part of routine care for residents of care homes. Good relationships with care home staff having these conversations mattered, as did a flexible approach to the process that took account of people's different knowledge and priorities. The questions and options were helpful but need to be as simple and free of medical terminology as possible and start with focusing on plans for the health problems and holistic care (e.g. spiritual care) of an individual resident. More clarity about the DNACPR decision-making process is needed, and what it means when a relative signs the ACP questions sheet. There is a need for better public information about care planning and how it helps residents get the right care including having treatment and going to hospital when that is the best option for them.

ACP Team's response to the evaluation findings
Edinburgh Health and Social Care Partnership's (EHSCP) Long Term Conditions Programme ACP team would like to thank all participants in this evaluation. The feedback has enabled improvements to be made to the 7-Steps to ACP in Care Homes toolkit, with the following changes being made/planned:

Theme 1

- The 7-steps toolkit has been improved to re-iterate the reasons why the ACP questions sheet (documents 3 and 4) should not be sent in the post or completed in isolation. The documents are intended to be a guide for care home teams to facilitate ACP conversations. Starting with the ACP information leaflet and the RED-MAP conversation guide followed by the ACP questions, as set out in the guidance, is the best way to ensure the resulting plan will be appropriate and reflect the circumstances and wishes of the resident and their family.
- Documents 3 and 4 have been updated to clarify the CPR/DNACPR process for residents and families.

Theme 3:

- Documents 3 and 4: amended to replace 'clinically assess' with 'Keep them comfortable, treat any pain or other symptoms, and continue to care for them and review them regularly in their care home.'

Theme 4:

- Documents 3 and 4: amended to move the 'what matters most to you/your relative or close friend' free text box to the top of the ACP questions. This puts a greater emphasis at the start of the document on considerations of the resident's wishes (and or family members), what they know about their health now, and how they would like to be cared for in the future, before discussing the three scenarios.

Feedback from Participants
The ACP Team followed best practice and shared the report and our response to the themes identified in the evaluation with participating relatives and care home staff. Participating relatives that fed back all said they were happy that the content reflected their interview and did not have any additional comments on the report's findings.

'Thank you for the opportunity to review this report. I think it accurately reflects the various issues I recall being interviewed about, and I have little more comment to add. I hope my contribution to the exercise has been helpful.'
Relative of resident

'I did pass on your report to the relative which had been involved but neither [they] nor I wish to add anything before you publish the findings.'

In addition, staff members contributed further reflections that are important to consider going forward.

'I know I find it more difficult having this conversation with families whose relatives are fairly fit and well as know sometimes they don't like to think that far ahead. Usually engaging and building up a relationship with the relatives and families is always good before diving straight into this chat.'

Deputy Manager

'I find that relatives get confused when you use the term anticipatory care, simplifying the language is a good change. It is always better to have ACP conversations with relatives in person once the resident has been in the home for a while, when they and family are more familiar with staff....I like the idea of starting by focusing on what is important for the resident and their families - that is good person-centred practice. It sometimes helps when we are discussing the scenarios and questions to let relatives know that they can take their time completing the forms and that (the plan) can be reviewed and changed depending on circumstances. We usually advise that our GP would discuss DNACPR but having more information (about that) might be helpful.'

Team Leader

Acknowledgments

The Long Term Conditions Programme Anticipatory Care Planning Team would like to extend their thanks to the Edinburgh care homes who helped identify participants for the interviews during a challenging time for care home staff, residents and their families and friends. A thank you also is extended to the relatives of care home residents for sharing their experiences of future care planning conversations in care home settings.

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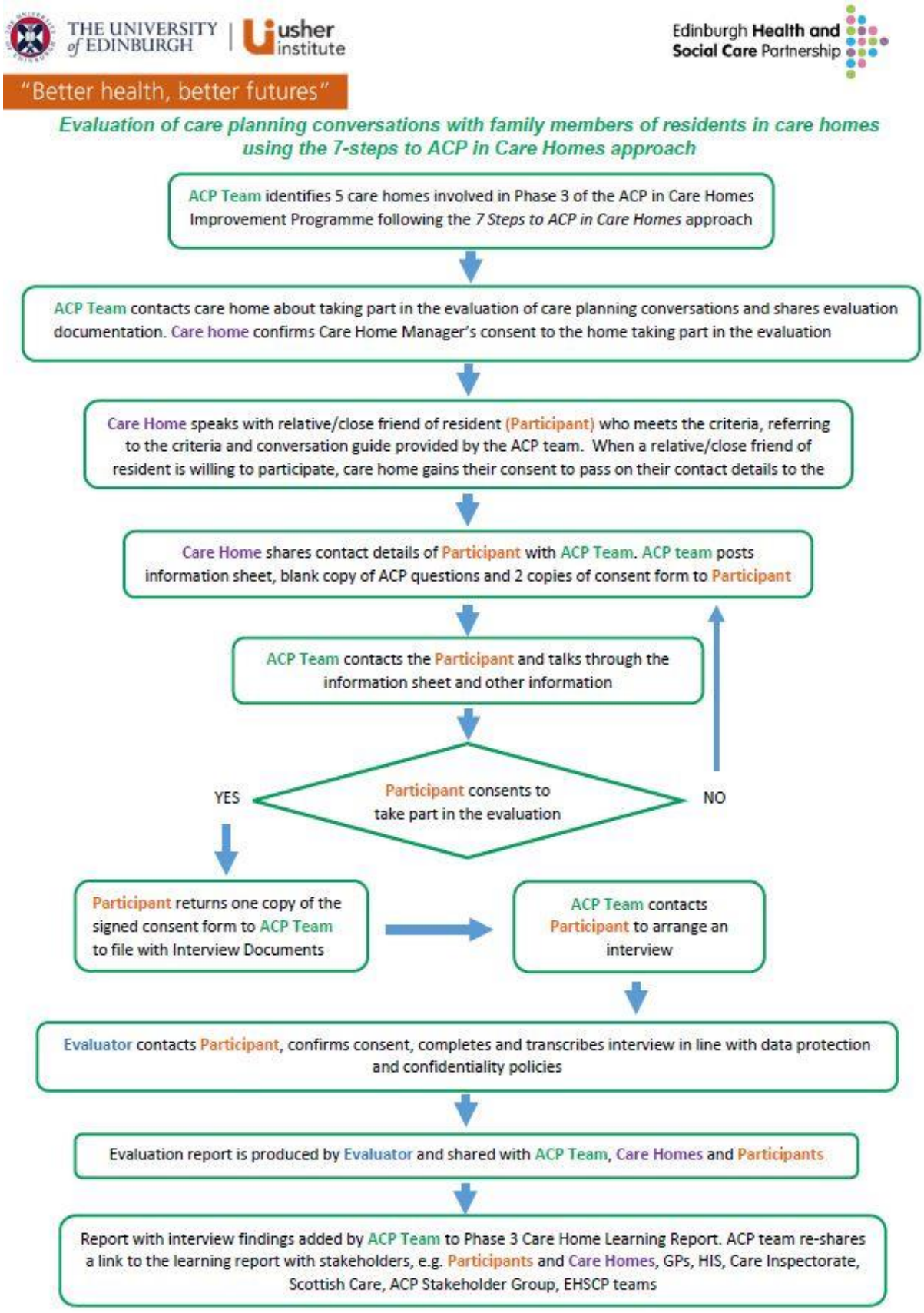
Appendix 1: Project flowchart



Appendix 2: Participant information sheet

Evaluating Care Planning Conversations with Care Home Residents and their Families

Family/Relatives Information Sheet

We need your help!
We are conducting an independent evaluation of care planning conversations that take place in care homes in Edinburgh. This sheet tells you why we are doing this evaluation, and how you might be involved. Please take time to read it carefully. Please ask if anything is not clear or if you would like more information.

Before you decide if you want to take part, we would like to give you some information about Anticipatory Care Planning conversations and a programme for care home staff to improve this. Care planning aims to support better decision-making around care and treatment if your relative or friend becomes less well.

What is Anticipatory Care Planning?

Anticipatory Care Planning (ACP) means thinking and planning ahead and understanding what is happening with a person's health and care.

When someone lives in a care home, the care home team wants to find out as much as possible about what matters to them. Care home teams involve residents in planning their care and treatment as much as they are able and want to. Residents often choose to include family members or a close friend in these conversations. If a resident is not able to make decisions about their health and care, care home staff will involve family or close friends in care planning conversations.

It is important for care home staff to talk about:
- What is happening with each resident's care and treatment.
- What might happen if a resident's condition changes and they are less well.

These discussions are used to make a care plan for each resident.

The GP practice keeps a copy of the care plan in the resident's records at the practice and uses it to create a secure summary for professionals to use if the resident needs urgent care, called a Key Information Summary (KIS).

Background
For the last three years Edinburgh Health and Social Care Partnership's (EHSCP) Long Term Conditions Programme has been working with care homes and GP practices to make sure Anticipatory Care Planning is offered to all residents.

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Care home staff in some Edinburgh care homes have been using a set of Anticipatory Care Planning Questions with residents and families. These are given to the GP practice to help write a care plan for each resident. Care home staff have had training to help them use the Anticipatory Care Planning Questions in conversations about care planning with residents and families.

We are doing this study as part of a project to find out how well Anticipatory Care Planning is working using this approach. It is important to hear from families and close friends of residents who have been involved in care planning using the Anticipatory Care Planning Questions.

What are the Anticipatory Care Planning Questions?

The Anticipatory Care Planning Questions are on a one-page sheet given to people to read and then used by care home staff in care planning conversations. Residents and their families are offered support from the care home staff and/or an appointment with the GP to help them think about planning ahead using this information.

The Anticipatory Care Planning Questions describe situations we know can happen when a care home resident gets less well and available options for care and treatment at those times. It also includes questions about what matters to each resident, and specific information about their health problems that might be important to plan for.

Why is this independent evaluation being done?

We want to find out what you think about any care planning conversations you were involved in, and how the care plan was used if your relative has been less well.

Why have I been approached?

We would like to talk to people like you who have a close relative or friend living in one of the care homes taking part in the Anticipatory Care Planning training and improvement programme. We want to hear from people with a wide range of experiences. This may mean we are not able to include everyone who is willing to take part.

What will happen if I take part?

You will be offered a phone call with an independent project evaluator who is a health professional to talk through some questions about care planning. These are questions like:

- What does 'care planning' for your relative/friend mean to you?
- What do you think about people being given a document like the Anticipatory Care Planning Questions to help us talk with them about care planning?
- What can you tell us about your own experiences of care home staff talking about care planning with you and your relative/friend?

- What are your views about the benefits or disadvantages of using questions like these?
- How do you think anticipatory care planning with residents and their families can be improved in general?

See Appendix 1 for Relatives Interview Question Guide.

Personal information in your relative's care plan will not be discussed.

The independent evaluator will be happy to answer any questions that you may have about the evaluation. If you agree to take part, Tracey Rogers will arrange a date and time that suits you for the phone call with the evaluator which will last about 30 minutes.

With your permission, we would like to record these discussions to help us keep an accurate record of what people say. If you wish to take a break during the discussion, just tell the evaluator who will stop the recording and give you as long as you need.

Do I have to take part?
No. It is up to you whether or not to take part. What you decide will not affect the care of your relative or friend in any way.

What are the possible benefits and disadvantages?
Agreeing to take part will not help you personally, but the information we collect will help improve care planning for care home residents in the future. We do not think there are any disadvantages to taking part.

Will my taking part in the study be kept confidential?
The recording of your interview will not include any of your personal details. It will not be heard by anyone other than the team who are doing the evaluation, and will be kept in a secure place. You may listen to the recording, or read the summary of it, if you wish. All of the information collected for the evaluation will be kept confidential. Data will be kept in a locked filing cabinet and backed-up on a secure computer. No names will be attached to the stored data.

Who do I contact for further information about the study?

Tracey Rogers
Project Support Manager
Long Term Conditions Programme
Edinburgh Health & Social Care Partnership
Tracey.Rogers@nhslothian.scot.nhs.uk
07976 582298

Thank you for reading this information sheet

Relatives' Interview Question Guide

Talking about ACP

What does 'care planning' for your relative/friend mean to you?

Language used – ACP, thinking ahead, KIS (+/- CPR)

Purpose/aims of planning – media, personal experiences

Experiences of care home planning for resident – initial, later, COVID

Anticipatory Care Planning Questions

Do you remember care home staff giving you the Anticipatory Care Planning Questions?

If not, can we talk about the Anticipatory Care Planning Questions sent to you with the study information?

- What do you think about people being given a document like this to help us talk with them about care planning?
- What do you think and feel about the questions (content, language)?
- Specific comments on any questions, and on Anticipatory Care Planning Questions as a whole?
- Views and experiences of talking about ACP and/or completing the Anticipatory Care Planning Questions
  - How broached, and by whom?
  - How explained and supported when using it, and by whom?
  - How was the resident involved in the care planning process?
  - Updated since?
  - Used for managing a specific episode of care; outcome?
  - What went well, or could have been done differently?

Anticipatory Care Planning Questions in general:

- What are your views about the benefits and disadvantages of using the Anticipatory Care Planning Questions?
  - Clarify barriers and facilitators to process of completing and returning Anticipatory Care Planning Questions?
- How do you think anticipatory care planning with residents and their families can be improved in general?

Any other comments