

Planning Ahead

Care Home Residents' Experiences of Advance Care Planning



Healthwatch Surrey
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This project was undertaken by Healthwatch Surrey to help more people achieve a good death, by giving care home residents a voice to share their experiences of advance care planning.

Project Purpose

The Surrey Health and Wellbeing Board (SHWB) has identified 'helping people die well' as a key focus for Surrey's 10-year Strategy. A Surrey-wide end-of-life care partnership is working to understand the current picture and identify opportunities to work collaboratively across the county.

Clinical Commissioning Groups (CCGs) across Surrey are undertaking a range of different end-of-life initiatives:

- Identification of end of life
- Enabling people to discuss and record their plans and wishes
- Providing resources to support those providing end of life care
- Information and advice
- Utilisation of GPs to lead advance care planning processes
- Systems and protocols (such as ReSPECT*, DNACPR†, PACE‡)

To ensure people's views are represented in the development of these initiatives, Healthwatch Surrey spoke to care home residents and those who care for them about their experience of making advance care plans.

What we did

In summer 2019 we visited 15 care homes in Surrey:

- 2-3 per CCG selected at random
- All have residents funded by Surrey County Council
- 5 nursing and residential care, 10 residential care only, 15-63 beds
- Independent homes, small chains, national chains and direct SCC management

We spoke to 21 care home residents or their families:

- Residents or their families known by the home to have made plans
- 21 people (residents, families) interviewed for 10-45 minutes each
- Wide range of life expectation, frailty and plans in place
- Specific plans only discussed if interviewees initiated the discussion

We also spoke to care home staff:

- 45 min discussion with the care home manager, clinical leads, senior team leaders
- Discussed their approach to advance care planning (ACP), experiences with people and families, and experience of putting the plans into practice

* <https://www.resus.org.uk/respect/>

† <https://www.resus.org.uk/dnacpr/>

‡ Proactive Anticipatory Care Plan Documentation

Executive Summary

1. People we spoke to who had put advance care plans in place - whether for themselves or for a loved one - were all happy that they had done so

- Plans give people confidence that things won't happen that they don't want to happen, and there is comfort in relieving loved ones of the burden of difficult decisions
- However, care home staff told us that few new residents arrive with any plans in place, and many people avoid making plans

2. There are three key barriers to people initiating their own advance care planning

- **No perceived need** - Until people accept that a decision point is likely to arise in the near future they feel there is no need to put plans in place
- **Don't know what decisions to make** - People have very little understanding of modern death. They do not understand the kinds of decisions they might have to make or how these should be recorded
- **Don't want to think about the issue** - people are reluctant to think about and discuss their own death, or the

death of a loved one. Discussing death in the abstract is easy: discussing 'my' death is distressing

3. Most plans need a trigger such as a medical event, or are initiated by care staff or healthcare professionals

- Most people had not spontaneously decided that having an advance care plan would be beneficial, and had been guided in what to record by care staff, GPs or hospital doctors
- The most meaningful and person-centred plans had been made in response to an event or change in health status and enabled by care staff or HCPs with experience and knowledge
- Timeliness, knowledgeable guidance and an opportunity to record the decisions had removed the barriers to planning

"They've come here to live, not to die"

Care home staff

"I know I don't want to be brought back after I've died - what do they call it? Resuscitation? What else do you mean? What else would I need to think about?"

4. Plans may be recorded in several different ways for a single resident, and we saw inconsistency across plans for some individuals

- There may be several written records - assessment forms, care plans, medical records, ReSPECT forms
- People also trust loved ones or care staff to “know what I want” and act accordingly, with or without POA
- In particular there can be a gap between clinical/GP-led documents and residential home documentation

5. Most people want to die ‘at home’: happy residents of residential care homes want to die in that home

- While many care home staff want this to happen too, it does place additional demands on the home and on community health care services that some homes struggle to meet

*Jenni’s Story**

After mum came here she was much better, then she had a bit of a wobble and a trip to hospital.

When she was home and settled Nancy (the manager) explained what was happening. She said that over time antibiotics would stop working as well and that the time between mum’s infections would get shorter.*

We talked about it, mum definitely doesn’t want to go to hospital any more, so we agreed with Nancy that mum would be on end-of-life care and would stay here with no more hospital trips.

She’s enjoying her time now and that’s great, I don’t want to see her ill and suffering.”

**Names changed*

Recommendations

1. Commissioners should support providers with systems that help those providers initiate timely conversations and create effective, actionable advance care plans for people

- Providers need to initiate and guide advance care planning: most people do not have the awareness or knowledge to create their own plans
- While larger homes and nursing homes have staff who are experienced and confident, residential homes and smaller homes need training and support
- Commissioners can support providers in two valuable ways
 - By providing training and support in people-centred skills such as when and how to initiate conversations, how to support people and families making difficult decisions
 - By adopting robust and consistent systems (paperwork, recordkeeping) that deliver actionable advance care plans

2. Homes and clinicians should ensure all plans and wishes relating to an individual are consistent across all records

- An unintended consequence of the desire to improve end of life care planning is that records are proliferating, and ownership of those records is fragmented. Conflicting plans are not actionable.
- Care home staff are in the best position to take responsibility for consistency, but residential homes may need staff training and support to action this with confidence

3. Commissioners should investigate the value of enabling higher-needs residents at end of life to remain in their residential home until death

- A late transfer from a long-term residential home to a nursing home for short-term end of life care is contrary to many people's wishes
- Depending on the detriment (numbers involved, needs, length of time in nursing care) we recommend commissioners consider approaches that will help people fulfil their wish to die in their own residential home

“John and Mary have been married for over 60 years. When he couldn't be cared for at home any more they both moved in here so they could be together. He's deteriorating now, and we're struggling to meet his needs, but if he went to a nursing home Mary would have to stay here and they'd be split up and we just can't bear to let that happen, we all want him to pass away here with Mary at his side”

Key Insights

We saw many excellent examples of advance care planning in both residential and nursing homes

The staff we spoke to were strongly motivated to help residents understand their options, express their wishes and achieve a 'good death'. All but one home⁵ had established approaches to advance care planning and many had taken advantage of external training opportunities.

People who have plans in place are happy these are in place

Having plans reassures people they are going to get what they want and not get what they don't want. They prevent loved ones having to make decisions in a distressing emergency; they reduce the lottery of strangers making decisions on their behalf. The planning process gives families time to discuss and come to an agreement.

"I don't want them to panic, they can look at the form and decide for me"

"It was a conversation that needed to happen [among the family], not to keep being buried"

"You want to talk about my death? I don't want to, I don't need to, and I don't know how"

Residents at care homes don't want to think about their death, but this is just one of several barriers to advance care planning.

1. Unless they are entering a home for end-of-life care they are **not planning on dying anytime soon**. They have come to a new home for better care which will sustain their health and quality of life. They can plan for death later.
2. Most people have **no close experience of death, so they do not understand the clinical trajectory**. Many assume they will remain well then suffer a short period of decline followed by death. They don't know there is a strong possibility of a slow decline, maybe punctuated by serious episodes of illness; that the health detriment of hospital admission may come to outweigh the benefits; that they may be asked to choose between life-sustaining treatment and comfort.
3. **People do not like thinking about or talking about their own death or the death of a loved one**: They may be happy to talk about what happens after their death - funeral plans, resuscitation attempts, disposal of personal items -

⁵ One small independent home under very new ownership were still reviewing and revising all the home's processes.

but they shy away from talking about their death. Even those in end-of-life pathways may prefer not to think about their death.

Care home staff - residential home staff in particular - estimated that four out of five new residents had made no advance care plans of any sort before moving into their care home.

What is important to people is not always important to commissioners, and vice versa

People and commissioners are in tune when it comes to preferred place of death

- Broadly speaking, the people we spoke to were consistent in what they want for the circumstances of their death.
- People told us they want to die pain free, in calm comfort. They want privacy and dignity. They want to die in familiar, comfortable surroundings and this may involve very personal preferences such as flowers or music.
- Some have specific spiritual requests, some want particular companions with them.
- For most people this means dying 'at home', not in a hospital.**
- These wishes are mirrored by The System - there are clear objectives to

increase the proportion of people dying in the location of their choice, primarily at home, and clear objectives to reduce deaths in hospital.

What happens after death is often very important to people, but is not important to commissioners

- Many of the people we spoke to had strong wishes for after their death. These start with resuscitation and include funeral management, where their ashes will be scattered, wills and disposal of personal possessions.
- Obviously these are not of value to The System, but they are often the first plans people make for their death and as such a valuable 'front door' to advance care planning.

Hospital avoidance is a non-issue for most people, but of great importance to the system

- For the majority of people we spoke to hospital avoidance is not something they think about at all.
- Nobody wants to go to hospital, but
 - they don't expect to have to†† and
 - they will go to hospital if it will make them better
- Firm plans for future hospital admission only become meaningful when people reach the stage where the possible detriment of a stay in hospital outweighs

** Our sample reflects the National Survey of Bereaved People 2015 where 81% of the sample believed the deceased had wished to die at home.

†† and the figures would bear this out - emergency hospital admissions are under 1 per resident per year

in care homes.

<https://www.health.org.uk/sites/default/files/uploads/publications/2019/Emergency-admissions-from-care-homes-IAU-Q02.pdf>

the possible benefit of hospital treatment or investigations. Many people have no idea that they might have to make this decision in the future.

- Conversely, the System has clear objectives around reduction of non-elective hospital admissions. This is partly for compassionate reasons - better to prevent an illness than try to cure it, hospital can be distressing and detrimental - but there is also a financial aspect. Emergency admission to hospital is the most expensive form of healthcare: it is to everyone's benefit to spend more effectively elsewhere.

Timing needs to be person-centred, not system-driven

- Most care homes and most advance care planning systems have a structured timetable for discussions: questions about future plans are asked at initial assessment, on or immediately after arrival in the home, at regular care reviews or when there has been a change in health or care needs.
- However, people's decisions about their future care evolve over a period of time in response to random events and experiences.
- Care home staff witness those triggers and are on hand to listen to people's wishes as they develop, offer guidance, and ensure wishes are recorded appropriately.
- Staff told us that the most receptive time for people to think about future plans is during a period of good health

and stability, not during or immediately after a crisis.

- Timetabled discussions may pick up firm decisions that have already been made such as DNACPR or funeral plans. However, if the person is not in the right emotional place to have a meaningful discussion no new plans will be made.
- We found people had recorded decisions they no longer remembered making, were equivocal about, didn't fully understand or were based on circumstances that were no longer relevant.

"I do remember there was loads of paperwork when mum arrived, it was all such a whirl, I probably did sign something, but it was a couple of years ago now"

Records are proliferating, and are not always consistent

A single resident may have several different documents recording different aspects of their future care plans.

- Typically the care home will have a record of personal and spiritual wishes ('were there any particular wishes your relative wanted to try to achieve while still able?')
- There will be separate documents recording clinical instructions ('clinical guidance on specific interventions...').
- In areas where ReSPECT is replacing DNACPR the ReSPECT form can contain yet another record of clinical guidance ('prioritise sustaining life vs prioritise comfort').

Different records should be reviewed together to ensure consistency and a holistic understanding of people's wishes. This is especially important in residential homes, where the care staff are not involved with clinical decision making.

"blimey looking at this [ReSPECT] now, they've ticked the box saying dad has capacity! No way!"

Care home staff also told us that while ReSPECT is a much more rounded approach than DNACPR, forms are being completed and clinical decisions made by hospital staff who do not know the patients and who are seeing them out of context. Residential home staff were often simply adding the ReSPECT form to the resident's care folder without reviewing it, and we spoke to one family member who suddenly recalled she

Several people we spoke to decided to check their recorded decisions during our interview. The content came as a surprise to some - for example we found care planning documents that relatives were unaware of. Their relative had been at the care home for several years, the document was completed on arrival in a flurry of activity and paperwork, and as the plan was 'medical' and fell under the GPs jurisdiction it had been updated by the GP based purely on the residents' condition without discussion with relatives.

had her mother's ReSPECT form at home and that it ought to be at the care home with her mother.

"Angela knows what I want, don't you dear?" (resident to residential care staff)

Many plans are held in people's minds, not on paper

People trust other people more than they trust paperwork. Care home residents trust those around them to know what they want, and to respond to emergencies in a way that reflects their wishes. People assume that if someone knows their wishes these wishes will be respected.

We did hear stories of staff trying to contact family in an emergency, and of staff knowing a resident had received treatment contrary to their general wishes but being unable to prevent this without specific paperwork.

There is an imbalance of power between people, care staff and clinicians

When a resident is unwell the first port of call is their GP. For most a GP will know the patient and take this understanding into account when recommending treatment. However, the 111 service, out of hours doctors and ambulance crews do not have this insight. There may be tension between a resident's known wishes and medical advice from a clinician who is a stranger. In these circumstances residential home staff told us they felt they had no authority to advocate for their resident or were not listened to.

"It was awful. The GP wanted her to go to hospital, she didn't want to and she had capacity and we argued too but they sent an ambulance. We all talked to the ambulance crew too but they laid it on and said 'we will get into trouble if you don't come to hospital' so she sighed and gave in. It was the GPs doing, we're just carers, we didn't have a leg to stand on".

Everyone wants to die at home: for long term residents of care homes, that means they want to die at that home, not move to an unfamiliar home

Despite the many and varied attitudes to planning for death, the majority of people want to die at home, and The System wants to enable this. For the people we spoke to this meant dying in their care home.

Residential homes wish to enable this too, but staff we spoke to told us this can be a challenge. As people near the end of their life their needs increase. External nursing support can help - *"the district nurses have been brilliant"* - but this does not cover the additional hours of care that are needed. There may also be delays in accessing the next level of care (eg lifting equipment). Asking for a needs reassessment may force a resident to move home into nursing care to die, therefore preventing them from dying 'at home'; delaying the needs reassessment puts stress on the home and may disadvantage other residents.

We also heard of an unintended consequence of reduced hospital admissions. Residents who are admitted to hospital as an emergency are likely to trigger a needs reassessment resulting in a greater package of care or a move to a nursing environment. If they become unwell but don't go to hospital there will be no needs reassessment to match their increased frailty and growing care requirement.

Thanks

We would like to thank all the people who shared their experiences with us. Advance care plans can be a difficult subject and we are most appreciative of their help.

We would also like to thank all the care homes we visited for their welcoming approach, open responses and for sharing their systems and paperwork with us. We are especially grateful to those homes who introduced us to residents and families willing to discuss their advance care planning experience.

Appendix

Summary of Initiatives in Surrey, Autumn 2019

Surrey CCGs are undertaking a range of initiatives around end of life care. Broadly speaking, these can be categorised as follows (with some initiatives encompassing more than one category)

Identification of end of life

- Such as initiatives designed to identify and register people moving towards the end of their life to ensure they received targeted care

Encouraging people to discuss and record their plans and wishes

- Initiatives designed to encourage discussion and reduce stigma (such as Death Cafes)
- Funding health care professionals to support those who talk to people about their advance care planning, such as care home staff
- Funding community matrons to support end of life care in care homes

Providing additional resources to support those providing end of life care

- Health hubs to assist local nursing and care homes
- Psychological debriefing support for community nursing team

Information and advice

- Directories of services or access to specialists for symptom control for healthcare professionals
- Helplines for people to get advice and support

Utilisation of GPs

- Targetted GP support focussing on medication reviews and end of life care
- GP-led advance care planning processes such as PACe in Guildford & Waverley

Systems and protocols

- Introduction of ReSPECT process
- PACe end-of-life discussion and documentation
- Patient Passports