Wessex Care Records
Leading the way to sharing information

User journey for End of Life (EoL)
(summary take from the LHCRE assurance document)

This user story describes the breadth of end of life care and covers interactions with primary, secondary, and social care. It also involves private care in the form of domiciliary support services.

The context

Every year, approximately half a million people die in England. For three quarters of people, death is not sudden but is expected, and many individuals may benefit from end of life or palliative care. There is potential to improve the experience of care in the last year and months of life for approximately 355,000 people.[1]

End of life care has been a key issue for the NHS for some time. Death and dying are inevitable. The quality and accessibility of this care will affect all of us. The needs of people of all ages who are living with dying, death and bereavement, their families, carers and communities, must be addressed, considering their priorities, preferences and wishes. Personalised care at end of life will result in a better experience, tailored around what really matters to the person, and more sustainable NHS services.[2]

The NHS Long Term Plan tells us that people in England can now expect to live for far longer than ever before – but these extra years of life are not always spent in good health, with many people developing conditions that reduce their independence and quality of life.

The NHS has a key role to play in helping older people manage these long-term conditions, making sure they receive the right kind of support to help them live as well as possible.[3]

The End of Life Care Strategy (fourth annual report) stated that, wherever possible, people should be able to spend their last days in the place of their choosing. Most people say that they would prefer to get this support in their own home.[4]

Now read Betty's story.

Betty is an 87-year-old widow and retired teacher living in Lymington, Hampshire. She has two children that live close by. She has always been supported where possible by

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[1] Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman
[2] NHS End of Life Care: https://www.england.nhs.uk/eolc/
[3] NHS Long Term Plan
[4] Department of Health and Social Care End of Life Care Strategy: fourth annual report

her children. Betty is aging and her health is declining naturally. She has generally been in good health during her life apart from some high blood pressure which has been managed with medication.

She sees her **GP** for blood pressure and routine blood sample checks and takes a range of medication to control her blood pressure. She has in the past suffered side effects from her medication and been given dosage changes over time.

During several months, Betty's close network notice a sharper decline in her health. She is becoming increasingly frailer and more dependent upon support from others. She becomes less socially active and worries more about falling. She starts to forget to take her medications and is increasingly confused which dose she is taking.

Betty's GP observes a significant change in her attendance patterns. From yearly appointments, these become more regular, are increasingly attended by her daughter, and then appointments slow and start to be managed at a distance; by telephone or some cases home visits.

Social Services are engaged. Betty is assisted by **Social Services**, initially with enabling socialisation and community equipment for her home. A **domiciliary care agency** is also engaged to provide some personal care to support her washing and dressing needs and medication support.

As Betty's health further declines, a referral is made to the **community nurse** due to her now being unable to manage her condition. She is less mobile and begins to have continence issues. Self-medication management has also stopped.

Betty has an episode of feeling unwell. The **111 service** is contacted and an **out of hours GP** is called. An **ambulance** is called out and Betty is transferred to her local **community hospital.** In hospital Betty undergoes tests and is diagnosed with an urinary tract infection She is given antibiotics and fluids and remains briefly in hospital. She is then discharged with a further course of antibiotics.

After a short period of time Betty's condition worsens. She has a further episode of feeling unwell where she is short of breath, agitated, and highly confused. A member of the family, panicking, calls **999** and an ambulance is dispatched. Paramedics on scene determine she is best kept at home and are eventually able to hand over to the **community nursing team.** Betty is supported with medications to keep her stable and comfortable.

Over time, Betty passes away at home with family present.

Betty's story is relatively medically un-complex, yet despite this, her interactions and movements through the system raise several complexities that can be better supported through joined up information sharing.

What is the current situation across Wessex?

The individual has not always been supported by professionals to express their wishes, or if they have, not been supported to share this with relevant parties.

Barriers in technology or information sharing around an individual's wishes often means information is not known to all professionals, and more importantly the right professionals at the right time. Wishes regarding end of life care, specifically at or near to the very end, are not shared with family / carers and an agreement / consensus on a way forward documented. This results in conflicting perspectives, which don't always reflect the patient's wishes at the crucial time.

Legal basis such as power of attorney and ownership of this are not documented or not shared. In the case of urgent care needs, health care professionals don't know who has the power of attorney and what it covers.

There is currently no centralised coordination platform, in which professionals of all roles can collectively plan or contribute to care delivery. Plans are not available, or more crucially, are not able to be accessed by the services when they are most needed leading to duplication. Family / carers often do not know where to turn for help, do not have the plan to hand, do not know how to deal with it and do not know who to contact.

During the declining period, poor health increases the chance of various 'events' occurring such as falls, which can lead to avoidable admissions and calls to emergency services, despite a network of professionals already being actively involved, and perhaps against the wishes of the patient. Health and social care systems work against each other due to budget constraints. Issuing of equipment or determination of support becomes more about the process and funding, and less about the patient. The patient and family spend a lot of time repeating information, with this being captured and current information sharing arrangements are fragmented and still entrenched in information governance concerns.

Increasingly technology is being used to support maintaining independence, this is often not joined up with other services and opportunities are lost by not sharing data collected.

What is the target situation that Wessex Care Records wants to achieve?

An older person, in the later years of their life, can discuss death with those they feel most comfortable with, which may include friends, family and professionals who are involved in their existing care. These details can be both formal and informal but are collected and recorded and made available to others at the appropriate time via a single source.

For the individual, they feel comfortable and confident that they can provide details regarding their wishes towards end of life care, and that these are captured and accessible to those that will need to use them. There is also confidence that should these views or wishes change that the information can be updated.

All professionals involved in the individual’s care have access to a single, electronically held social and medical record. This data should include, but not be limited to: demographics and wishes, medical history, current and historical medications and allergies, appointments, activities and investigations, Pathology and radiology including results and imagery, assessments and care plans, current and historic clinical involvements and role, social care involvement and activities.

“As an elderly person who is increasingly requiring health and social care support in the later stages of my life, I want information relating to my care and conditions (including diagnosis), assessments, medications and support preferences to be shared and available to all professionals, so that appropriate care decisions are made, at the right time, in the place/s I feel most comfortable.”