NHS
Mansfield and Ashfield
Clinical Commissioning Group

NHS
Newark and Sherwood
Clinical Commissioning Group

# Care for People at the End of Life


Executive Summary:

Improving end of life care is a priority for both mid-Nottinghamshire Clinical Commissioning Groups. We aspire to more people being able to choose their preferred place of care and place to die. Presently, for too many the default is hospital care. Moreover, the quality of end of life care people receive should be timely and coordinated.

This paper summarises the work being undertaken to address the national findings from the *More Care Less Pathway* review of the Liverpool Care Pathway, as well as our local initiatives to build capacity and capability.


## 1. Preferred place of death

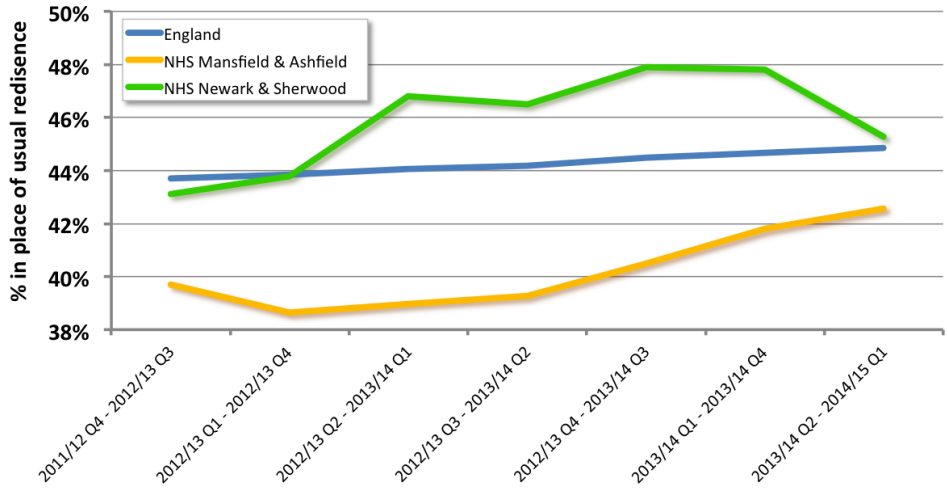
There is good evidence that many people prefer to die in the community. The most recent national Voices survey reports that the majority preferred to die at home (79%), with the minority in hospital (3%) (*www.ons.gov.uk/ons/dcp171778_370472.pdf*). These results are supported by systematic reviews of studies that report that at least two-thirds of people would prefer to die at home (*www.endoflifecare-intelligence.org.uk/view?rid=771*). The aspiration to increase the number of people that achieve their preferred place of care and death is part of the Nottinghamshire End of Life Care Pathway (*www.nottslandd.nhs.uk/attachments/article/75/1.%20Nottinghamshire%20EOLC%20Pathway%20for%20all%20Diagnoses.pdf*).

Across mid-Nottinghamshire there are about 3,000 deaths per annum, of which approximately 50% are in hospital.

| | Mansfield & Ashfield Number | Mansfield & Ashfield % | Newark & Sherwood Number | Newark & Sherwood % | England Average | England Lowest | England Highest |
|---|---|---|---|---|---|---|---|
| 1. Deaths in Hospital (Persons, All ages) | 997 | 52.9 | 575 | 50.2 | 50.7 | 38.7 | 66.8 |
| 2. Deaths in Home (Persons, All ages) | 391 | 20.7 | 254 | 22.2 | 21.5 | 16.4 | 28 |
| 3. Deaths in Care home (nursing or residential) (Persons, All ages) | 356 | 18.9 | 234 | 20.4 | 19.6 | 4.5 | 31.2 |
| 4. Deaths in Hospice (Persons, All ages) | 96 | 5.1 | 54 | 4.7 | 5.6 | 0.1 | 11.8 |
| 5. Deaths in Other Places (Persons, All ages) | 42 | 2.2 | 26 | 2.2 | 2.1 | 1.3 | 4.1 |


www.endoflifecare-intelligence.org.uk/profiles/CCGs/Place_of_Death/atlas.html
Annual average 2010-2012, Source: Office for National Statistics processed by Public Health England

The trend in deaths occurring in the usual place of residence across mid-Nottinghamshire is increasing:




www.endoflifecare-intelligence.org.uk/view?rid=203
Source: Office for National Statistics processed by Public Health England

Evidence suggests that older people who have had three or more admissions to secondary care are more likely to be in the last year of their life. Secondary care providers should be an integral part of identification of patients in their last year of life. From local data, about 70% of patients who died in hospital had 3 or more admissions in the previous 18-months, 40% of those admissions were elective. The average length of stay in the final admission is 11½ days, and adding in the previous admissions gives a cumulative total of 45 bed days. The total tariff costs of admissions ending in death is c.£3m per annum.

We know that more deaths at home where preferred cannot be achieved by secondary care alone. Hospitals will need to increase their early identification of patients who are having repeat admissions and are likely to be in their last year of life. The hospital will need to work in partnership with community services to gain and record patients' preferences, then to determine advance care plans that can be communicated using EPaCCS (electronic end of life palliative care coordination system).

To be able to offer patients the choice of their preferred place of care, we need to have sufficient capacity to provide the right level of support outside of hospital. Services will need to be consistent and dependable. Currently, we do not routinely and systematically develop care plans in advance, allowing people to state their preferences. We also do not have sufficient capacity to ensure those preferences can be reliably enacted in every case. This means people at the end of their life are sometimes admitted to hospital as an emergency. Our strategy is to increase community alternatives to hospital and to increase the degree of choice through advance care planning.

## 2. End of Life Summit

In November 2013, Mansfield & Ashfield and Newark & Sherwood Clinical Commissioning Groups jointly published a *Review of Mortality* covering 2007–2012. Overall, it found mortality had reduced by 6% for our population between these years. This included a 36% reduction in deaths from Acute Coronary Syndrome. However, it also found that there had been an increase in patients dying in hospital with a length of stay greater than 28 days across all causes of death, and that patients who died in hospital had more ward moves on average than patients who survived. In response to this, we hosted a summit in January 2014 with over 60 participants representing hospitals, primary care, hospices, social care, community providers, care homes, children's providers, clinicians & managers, as well as patients. The Summit asked participants to think about their own preferred care when they die, or that of their loved ones. It distilled the essential qualities of excellent, personalised end-of-life care that we should all expect. There was a commitment from each person to implement that vision within their own organisation. It concluded:

- the necessity for advance care planning, so clinicians and relatives were not responding in the heat of the moment to predictable crises;
- the need for electronic communication of those advance care plans (including Do Not Attempt CPR orders), so that any care staff who comes into contact with that person knows what has been agreed;
- the need to ensure that realistic expectations about prognosis and care are set with patients and relatives. This may be done by hospital, hospice or primary care clinicians, but patients must not fall through the gaps between services;
- that community capacity is expanded to ensure it is dependable and a viable alternative to death in hospital;
- to increase the consistency of end-of-life care for different diagnoses through the integrated care teams.

Following the Summit, Newark & Sherwood Clinical Commissioning Group hosted an afternoon workshop and fourteen of the Newark & Sherwood practices have commenced a year-long programme of Gold Standards Framework (GSF) 'Going for Gold' accreditation. Some of the local care homes and hospices are also undertaking their version of this training.

## 3. Liverpool Care Pathway (LCP)

Baroness Neuberger said in the More Care Less Pathway review of the Liverpool Care Pathway "*Approaches like the LCP have made a valuable contribution to improve the timeliness and quality of clinical decisions in the care of dying patients, and plenty of evidence received by the Review shows that, when the LCP is used properly, patients die a peaceful and dignified death. But implementation of the LCP is sometimes associated with poor care…(and) the review panel heard many instances of both good and bad decision-making*."

The Report says "*Integral to success in implementing approaches of this kind are the key elements of end of life care: planning at all stages of the dying process, rapid discharge models to enable patients who wish to die in the community to be discharged from hospital in good time; and electronic co-ordination systems, which enable clinicians to access and contribute to the patient's record online at any time and from any setting*."

Our End of Life Strategy reflects this well by fostering individualised, planned, coordinated care close to home delivered sustainably by a network of local, trusted providers. Furthermore, we are developing a consistent form of anticipatory medication prescribing.

## 4. Electronic Palliative Care Coordination System (EPaCCS)

Individualised, planned, coordinated care is aided by well-structured advance care planning. Clinical practice is being developed through the GSF Going for Gold programme. Alongside this, there needs to be a mechanism to communicate those care plans with other services that patients turn to in an emergency, such as the out-of-hours service, ambulance service and Emergency Departments. This is hindered by services using different computer systems that are not interoperable.

At the End of Life Summit, there were patient stories of people dying on Emergency Department trolleys because ambulance and hospital staff did not know their patient's preferences.

Nottingham CityCare, on behalf of the Nottinghamshire Clinical Commissioning Groups, have developed a secure and safe way of sharing the care plans from the clinical system that General Practice and the Integrated Care Teams use (SystmOne) with those of the other services. It involves the lead community health professional using a GSF template on SystmOne that can be electronically shared and updated with specified other services. This has been

rolled out across Newark & Sherwood practices in autumn 2014, and is being spread to Mansfield & Ashfield in spring 2015. Already there are over 100 mid-Nottinghamshire patients with advance care plans and do not resuscitate orders shared through EPaCCS, with some very positive stories of patient's wishes being supported.

## 5. Care Quality Commission

The mid-Nottinghamshire Clinical Commissioning Groups have funded a senior nurse to work in Sherwood Forest Hospitals (covering King's Mill and Newark Hospitals) over two years. This has focussed on working with the hospital discharge team to expedite dying patients' discharge home, and implementing the Amber Care Bundle across four wards.

The Amber Care Bundle involves four elements:

- talking to the person and their family to let them know that the healthcare team has concerns about their condition, and to establish their preferences and wishes;
- deciding together how the person will be cared for should their condition get worse;
- documenting a medical plan;
- agreeing these plans with all of the clinical team looking after the person.

Sherwood Forest Hospitals was inspected by the Care Quality Commission, and their report published in July 2014. There were positive comments about compassionate care. However it was critical of a number of aspects of end-of-life care:

- The trust had not implemented guidelines, protocols or documentation to all wards that provided end of life care;
- There was no trust-wide, coordinated multidisciplinary training in end of life care;
- Medical staff did not have clear guidance about providing end of life care;
- Throughout our inspection we witnessed patients being treated with compassion, dignity and respect. We saw that call bells were answered promptly, and patients and their families we spoke with told us "staff are very kind". Care and comfort rounds were carried out regularly to ensure patients were well cared for. We found that most of the patients we reviewed had chosen to stay at King's Mill Hospital for their care;
- We looked at patient records and found they were not always completed sensitively. The reasons for allowing a natural death were not always clear, and at times inappropriate;
- There were no formal arrangements in place with all the services to ensure that all stages of the discharge process were available for patients requiring a fast track discharge. There had been no audit to demonstrate how many patients were discharged to their preferred place of care, or the time it took to discharge patients;
- Staff relied on end of life experience within their own teams, and occasionally from other wards. Staff saw the provision of good end of life care as a priority; however, there was little in the way of guidance, protocols or documentation available from the trust;
- There had been very little engagement with the staff about end of life care until March 2014, whereby the staff on the four end of life pilot wards had an opportunity to help develop the guidance for patient care in the last days of life.

It is interesting to note that "*most of the patients we reviewed had chosen to stay at King's Mill Hospital for their care*". Following the report, the Trust has initiated an organisation-wide programme of work.

United Lincolnshire Hospitals (that includes Lincoln County and Grantham Hospitals) and Nottinghamshire Healthcare Trust (that includes John Eastwood Hospice) have also had recent CQC inspections including their end of life care.

| Safe | Effective | Caring | Responsive | Well-led | Overall |
|---|---|---|---|---|---|
| **King's Mill Hospital** | | | | | |
| Requires improvement | Requires improvement | Good | Requires improvement | Requires improvement | Requires improvement |
| **Newark Hospital** | | | | | |
| Requires improvement | Requires improvement | Good | Requires improvement | Requires improvement | Requires improvement |
| **Lincoln County Hospital** | | | | | |
| Requires improvement | Requires improvement | Good | Requires improvement | Requires improvement | Requires improvement |
| **Grantham Hospital** | | | | | |
| Good | Good | Good | Good | Good | Good |
| **Nottinghamshire Healthcare NHS Trust** (including John Eastwood Hospice) | | | | | |
| Good | Good | Good | Good | Good | Good |

| Sherwood Forest Hospitals NHS Foundation Trust | United Lincolnshire Hospitals NHS Trust | Nottinghamshire Healthcare NHS Trust |
|---|---|---|
| www.cqc.org.uk/sites/default/files/new_reports/AAAA1772.pdf | www.cqc.org.uk/sites/default/files/new_reports/AAAA1707.pdf | www.cqc.org.uk/sites/default/files/rha_coreservice_end_of_life_care_nottinghamshire_healthcare_nhs_trust_scheduled_20140724.pdf |
| Date of publication: 22 July 2014 | Date of publication: 10 July 2014 | Date of publication: 31 July 2014 |

## 6. Commissioning plans

Mansfield & Ashfield and Newark & Sherwood Clinical Commissioning Groups intend to expand community capacity to provide more reliable, personal alternatives to hospital.

Our patients receive services through a Nottinghamshire-wide contract for Specialist Palliative day-care and hospice at home, and bereavement services. The term was due to end in March 2015, but has recently been extended until March 2016 to fit with the Better Together recommissioning process. We are working with end of life providers to explore the benefits of integration to improve outcomes and equity.

Nottinghamshire County Council commissions an end-of-life carer's support service, Pathfinders, on behalf of Nottinghamshire CCGs. This is presently provided by CNCS.

As well as providing our PRISM integrated care teams, County Health Partnerships (CHP) supply community specialist palliative care nurses that have recently become part of the integrated care teams together with specialist palliative care provided at John Eastwood Hospice. To reduce the artificial divide between the end-of-life care in cancer and other long term conditions, in partnership with Macmillan we are soon to launch a year-long programme of action learning whereby each locality can co-create their own solution to care coordination.

We buy three services from Beaumond House Community Hospice in Newark: inpatient respite care, day-care, and hospice at home. Their funding has increased in 2014/15; it should be noted that this still involves a substantial contribution from their voluntary giving but is in line with other hospice funding.

Mansfield & Ashfield Clinical Commissioning Group has been piloting a specialist nurse service to coordinate care.

No one provider can deliver all the skills or all the community capacity required. In order to create a responsive and dependable service it will require a network of providers to collaborate to fulfil our patients' needs. Our clear direction is to build community capacity through a network of providers. To facilitate this, Newark & Sherwood Clinical Commissioning Group hosts a dedicated partnership forum, comprising of acute, community, and third & voluntary sector participants. It is chaired by Dr Julie Barker, GP from Barnby Gate Surgery, who provides strong clinical leadership and champions end of life care across General Practice.

Our work programme over the coming year:

| | |
|---|---|
| February 2015 | Developmental workshop for end of life providers (including third sector) to develop the benefits of integration |
| March | Complete year long programme of Gold Standards Framework training and accreditation in Practices, care homes & hospices |
| | Spread EPaCCS across Mansfield & Ashfield Practices |
| April | Commence end of life CQUIN (Commissioning for Quality and Innovation) to improve the quality of end of life care and incentivise links between hospital and the community |
| May | Public events to encourage advance care planning for Dying Matters week |
| June | Commence care coordination pilot in Newark & Sherwood (already started in Mansfield & Ashfield) |
| Spring/Summer | Develop the outcomes, service specifications and model capacity requirements for recommissioned integrated service |
| | Work with Practices to increase palliative and end of life registers |
| April 2016 | Recommissioned services commence |

We forecast that this programme should result in approximately ten percent more people able to die in the community, where this their preference.

Mansfield & Ashfield and Newark & Sherwood Clinical Commissioning Groups are committed to improving care at the end of life, and increasing the opportunities for care to be provided at home or in the community.

Simon Parkes
Head of Engagement & Service Improvement
February 2015

Notes:

(1) It is important to note that 'End of life' can mean any period between the last year of life of a person with a chronic and progressive disease to the last hours or days of life. The More Care, Less Pathway report recommends the term 'Liverpool Care Pathway' is unhelpful and should be abandoned. Within the field of end of life care, the term "pathway" should also be avoided, the simple term 'end of life care plan' being the suggested alternative