

Patient Story

Subject:	End of Life Services
Presented by:	Nichola Bramhall
Report prepared by:	Mariea Kennedy
Summary:	A relative's perspective of services associated with end of life care

1. Introduction

Bringing patients or their carers into the Board to tell their stories is welcomed by the Governing Bodies as a mechanism for understanding the impact of the service we commission, positive and negative, on service users. Patient Stories are advocated as a powerful catalyst for change by the Institute for Healthcare Improvement (www.ihl.org).

Patient stories are a key feature of our ambition to revolutionise patient experience. They provide a focus on how, through listening and learning from the patient voice, we can continually improve the quality of services and transform patient and carer experience.

2. Background

The story is told from the perspective of the niece of M, a 75 year old lady diagnosed with chronic heart failure. The patient also had scoliosis and oedematous (swollen and leaking) legs and could not lie in a bed. The story highlights the frustrations and anxiety family members encountered over a four week period when trying to navigate numerous processes and services in an attempt to ensure their family member's end of life wishes were met.

M knew she was dying and had clearly expressed her wish to die with dignity at home.

3. The Patient's Story

On 18 September 2015 my Auntie was diagnosed with terminal chronic heart failure. On 25 September 2015, I contacted her GP for advice and to discuss end of life/palliative care. The GP advised that he was trying to get my Auntie into Ling's Bar Hospital to enable assessment and control of the leaking from her legs so that she may have a better quality of life. He also chased up an outstanding dermatology appointment which was then scheduled for 29 September 2015. My Auntie really struggled to get to this appointment and we were left wondering whether it was actually necessary for someone at the end of their life to go through this? Following the dermatology appointment a new care plan was put in place by the hospital, but the community nurses were not happy with this and we struggled to get them to follow the hospital instructions.

Throughout this time my Auntie was suffering excruciating pain and was trying to control this through alternately taking Codeine Phosphate and Di-hydrocodeine every 4 hours. On 1 October 2015 following a call to NEMS, the doctor advised that he would send an ambulance to take her into hospital. M called her next of kin, my mother, in a panic and she and the carers made their way to the house. A NEMS ambulance driver arrived and would not take her; quite rightly, our family felt, because she was in so much pain and did not want to go into hospital. Thankfully, the district nurse arrived later in the evening and gave M pain relief.

On 2 October 2015 a call had been scheduled between me and the community matron however, when I chased the call, the matron was on leave. Another member of staff advised that we could request an MDT (multi-disciplinary team meeting) to discuss my Auntie's care. Prior to this we didn't know that such a meeting was available to us and indeed felt the professionals should have called this.

On 5 October 2015 I called the GP again to inform him of my Auntie's on-going pain and to request that she be assessed for continuing healthcare. I felt that she needed urgent end of life support, she and the family were aware she was dying and she was struggling to cope with the pain and other symptoms she was experiencing. The GP agreed to come and visit my Auntie and although acknowledging that she didn't want to go to hospital, he was still looking into respite care at Ling's Bar Hospital. My Auntie categorically said no to a bed, due to her scoliosis and wish to die at home. The GP reluctantly agreed that it may be best if she was 'fast-tracked' in order to receive the care she needed at home and advised this may take a couple of days to arrange.

By 6 October 2015 my Auntie was struggling to even take her pain relief tablets out of the packet so morphine patches and injections to control the pain were instituted. These worked for an hour or two but then the pain returned.

On 7 October my Mum and I arrived to find that my Auntie had been on her own for an hour, she had been sick and was covered in black bile. After that she had a family member with her 24/7. The next day she experienced 2½ hours of excruciating pain and it took 2 hours for the nurse to come and give her some additional medication to control the pain. My Auntie was peaceful through the rest of that night and the next morning.

However, on the afternoon of 9 October, my Auntie started to get agitated. I called the district nurses' daytime number at 4.59 pm to be told that I would have to wait to call the night time staff, who came on duty at 5.30 pm. After our experience the day before we were frightened to wait so I called the GP practice who rang back to say the GP had called the nurse. The nurse called us back at 6.00pm and we put the phone to my Auntie so the nurse could hear her pain. She said she would come but no one came until 7.00 pm. My Auntie was given more morphine which allowed her to settle but at 10.00 pm she started to experience pain again. The hospice carer and our family were with her and my family called me at 11.00 pm to collect a prescription from NEMS which would be ready. By 11.30 pm it was still not ready. I called home and I could hear my Auntie screaming in pain. The prescription was eventually ready and I got the morphine to my Auntie by 12.30 am. I remember that the nurses who had just come on duty were annoyed that the family had to go driving round Nottingham to get medication. The nurses were also concerned that there was a wet patch on the clothing around the access point to the syringe driver and possibly a kinked pipe, but could not be sure due to the four layers of clothing my Auntie was wearing. They cut through her clothing to get better access and more morphine was administered at 4.30 am.

The next day the nurse called again. The sleeve of my Auntie's night shirt was wet. The nurse felt this might explain the pain she had been in due to her not receiving the correct dosage. At this stage the access point was changed. This seemed to help and my Auntie was peaceful.

On 11 October 2015 my Auntie started to grimace again and began to feel pain around 1.30 - 2.00 pm. The syringe driver was due to be changed at 2.30 pm so we called for an earlier visit. The community nurse arrived and changed the driver and gave my Auntie an additional 5 ml dose.

On 12 October 2015, I went to see the Practice Manager to complain and when I got to the house I found my mum in tears. The community nurse had been and insisted that my Auntie was turned due to her bed sores. The family had previously requested that the carers did not do this due to the excruciating pain my Auntie was in every time she was moved. My mum had asked the nurse to give an additional dose of pain relief before my Auntie was moved but she refused. My mum had to go to the bottom of the garden so she couldn't hear my Auntie's screams. The nurse administered pain relief after she turned her and caused her distress. The syringe driver dosage was doubled by the doctor that afternoon and Auntie was finally free from pain before she passed away on the morning of 13 October 2015.

My observations:

- I understand community nurses are located in surgeries and not directly under GP control however, we see the NHS as one service – we do not care about who's budget is who's.
- Why was my Auntie not placed on the palliative care register with a palliative care co-ordinator? No one person took responsibility for her care as a whole and I think this is where she was let down.
- Since my Auntie's death, I have found out that the carers from the Carers Trust who were initially looking after my Auntie are a different organisation to fast track services. This is not continuing care – the patient and carers have got to know one another so when they are 6 weeks from death why should the patient have to have strangers looking after them?
- The nursing staff are brilliant BUT one nurse on nights for the whole of Nottinghamshire is insufficient and unacceptable. There are often long waits to get the nurse back if required.
- When trying to get medication I was told that I would have to wait to call night-time staff. Also, family members shouldn't be expected to drive around Nottinghamshire to obtain medication. Staff should be ensuring there is enough medication to cover the night/weekend.
- Sadly my Mum is struggling to deal with the pain my Auntie suffered on the Monday before she died (12 October 2015). We feel the pain she went through on that day was completely unnecessary and whilst nothing can undo this I think an acknowledgement that my Auntie was moved unnecessarily and suffered additional pain as a result would help my Mum with closure of her sister's death.
- I am certain that once the syringe driver dosage was increased on the afternoon of 12 October 2015 she was pain free and that is why she passed away the next

day. We do not treat animals this way and it has been the worst experience of my life to see someone you love be in pain and be totally helpless. You rely on the professionals and I feel that we were let down.

- It was apparent that my Auntie wanted to die at home and we as a family supported this. My Auntie's death should have been dignified and peaceful - she should not have had to endure the pain she did and we should not have had to be involved in the traumatic chasing around we had to do.

4. Key issues raised from story

- Lack of cohesive working between organisations and services, with no team taking the lead for care
- Poor communication between organisations, resulting in poor information being provided to the patient and her family
- No clearly defined End of Life pathway established or followed, allowing the patient's and the family's wishes to be considered
- Poor patient and family experience

5. Contextual Information and Triangulation with Other Data Sources

Every year, around half a million people die in England, and two thirds of them are people over 75. Most of these deaths come after a period of long term illness such as heart disease, cancer or dementia.

Although everybody has their own idea of what a 'good death' is, for most people it would involve being without pain, in a familiar place with close family or friends and being treated with respect. 75% of people say they would prefer to die at home. Recently, the number of people dying at home has increased (42% in 2011 National End of Life Care Intelligence Network 2012 report), but over half of deaths still occur in hospitals.

In a 2011 survey (End of Life Care Strategy Fourth Annual Report 2012) 43% of bereaved people said they thought that care for their loved one in the last 3 months of life was excellent or outstanding. However, 24% said it was fair or poor.

The Liverpool Care Pathway for the Dying Patient (LCP) developed from a model of care successfully used in hospices, was a generic approach to care for the dying, intended to ensure that uniformly good care was given to everyone thought to be dying within hours or within two or three days, whether they were in hospitals, nursing homes, or in their own homes.

Due to substantial criticism of the LCP, the Government appointed an independent panel in January 2013 to review the use and experience of the LCP in England. The panel published its report '*More Care Less Pathway*' on 15 July 2013. The majority of the panel's recommendations focussed on creating strategic frameworks to deliver better care and highlighted failings in the implementation of the LCP. It was recommended that the Government replace the LCP with individual care plans by 14 July 2014.

One Chance to Get it Right - Improving people's experience of care in the last few days and hours of life.

Following publication of the LCP report, the Leadership Alliance for the Care of Dying People (LACDP), to whom the review panel addressed recommendations, was formed by statutory and regulatory organisations such as the Care Quality Commission (CQC), the National Institute for Health Research and Health Education England.

The approach to addressing the recommendations is outlined in “*One Chance to Get it Right*”, and is based on five Priorities for Care which replaces the LCP as the new basis for caring for someone at the end of their life.

The five Priorities for Care are:

When it is thought that a person may die within the next few days or hours...

1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

In July 2015, the “*Nottinghamshire Guideline for Care in the Last Year of Life A Guide for Professionals*” was produced between Nottinghamshire Healthcare NHS Foundation Trust, Nottingham CityCare Partnership, Nottingham University Hospitals NHS Trust, NHS Bassetlaw CCG and Sherwood Forest Hospitals NHS Foundation Trust. This directs professionals to develop individual plans for End of Life Care and to ensure this is in collaboration with patients and carers.

6. Providers Responses

A complaint in relation to the patient's experience was sent to both the GP practice and community health provider. Both services investigated and provided a detailed final response to the complainant. It was acknowledged that there were gaps/delays in M's care, which clearly and understandably left the family feeling let down. An apology was made to the family and assurance was given that learning from their complaint would be shared and actions taken to prevent a similar occurrence in the future.

The lessons learnt and actions to be taken, identified by each organisation, are summarised below:

GP practice

Lessons learnt:

- Improved communication and a coordinated approach to end of life care is required between GPs, Clinicians, family/carers, across all services and partner organisations.
- There are some gaps in community nursing provision and hand over processes between day and evening nursing services

Actions:

- Review MDT Process to ensure better coordinated approach
- Practice has introduced a new procedure (managed by the Administrative Team)
- All clinical information is made available to clinicians prior to MDTMs
- Pro-form 'Patient Information' sheet developed to ensure all attendees can communicate with the group (when unable to attend in person) and will be scanned onto the patient record once completed
- Community colleagues will use the same method of communication (via their Managers)
- Patient records will be read-coded to reflect inclusion in MDTM discussions
- Minutes will be circulated via secure NHS net email to all attendees (managed by the Administrative Team)
- These changes come into immediate effect

County Health Partnership (CHP)

Lessons learnt:

- The need for better communication and a coordinated approach to end of life care is needed between GP's, clinicians and families/carers

Actions:

- Ensure all senior clinicians/community matrons are confident and competent to initiate/undertake timely CHC and Fast track assessments
- Ensure a care coordinator is identified to co-ordinate end of life care across all services and partner organisations and to ensure patients, family and carers are fully informed and involved in decisions throughout the pathway
- Implement seam free handover between day and evening nursing services to avoid any delay in providing treatment and nursing care
- Ensure anticipatory medication is prescribed in a timely manner and be readily available for use day or night
- Remind clinicians to clearly document all conversations had with patients, family and carers

7. Commissioners Response

In November 2015 Nottinghamshire Healthcare NHS Foundation Trust and Nottinghamshire Hospice were selected as the preferred bidders for a range of five year contracts to deliver community adult and child health services in Nottinghamshire (excluding Bassetlaw). The new contracts began in April 2016 and for the first time the providers will be monitored using Quality Outcomes Frameworks. This includes a specific community outcomes framework for End of Life care as part of the contract with Nottinghamshire Hospice.

The provider will be monitored against a set of indicators, which were developed in consultation with patients and will be assessed via patient surveys. The indicators include:

- Proportion of patients and their carers who are in contact with services and report that they are treated with respect and dignity by all staff involved in their care.
- Proportion of patients and carers who report that they know who the first point of contact or lead professional was for all aspects of their care
- Proportion of patients and carers who report that their history and patient and carer experience care plan was known and used by all involved in their care
- Proportion of patients and carers who report that carers/family had their needs considered and were given support.
- Proportion of patients and carers who report that they felt those involved with their care worked as a team (including communicating well together, sharing information and co-ordinating care)
- Proportion of patients and carers who agree that: they have been involved in the planning of their care and are aware of the treatment options available; they understand all the elements of their care, including the medicines they have been prescribed; their choices and preferences are reflected in their care plan.
- Proportion of patients and carers who report that they have access to their own care plans and records
- Proportion of patients who have been asked whether they consent to sharing their information, for whom a response has been recorded
- Proportion of patients and carers who report feeling supported with appropriate access to information when required
- Proportion of patients who report that they feel informed and involved in decisions about their medicines
- Proportion of patients and carers who report that they are able to access services locally

This procurement will allow further integration of services and provide more opportunities for providers to work with health and social care partners in delivering transformation projects.

The Commissioning for Quality and Innovation (CQUIN) scheme is intended to deliver clinical quality improvements and drive transformational change.

During 2015/16 CHP had an End of Life CQUIN aimed at developing both the capacity and capability of community nursing teams and specialist palliative care services to utilise a standardised approach to palliative/end of life care, reducing variations in the quality of care.

Key outcomes that have been identified:

- CHP End of Life facilitators are currently working with and supporting GPs and community nursing teams across all Nottinghamshire localities to work together and identify patients who require end of life care in the community setting
- CHP palliative and end of life care programme of education and training has been developed in line with 'Ambitions for Palliative and End of Life care (2015)' and has now been rolled out across community and primary care

The Continuing Healthcare (CHC) Team at CityCare have confirmed that where individuals already have a package in place that can meet the needs and the patient and the family are familiar with carers, this would not necessitate a change of provider. This is only necessary when additional or more complex care needs are identified that the current care team cannot provide. The fast-track process should not change this,

fast track looks at the funding stream as all fast track packages are fully funded as opposed to joint or solely funded by social care.

The team has confirmed that a fast-track referral request was made by the GP on 6 October 2015, however there was no supporting information and an assessment was required. The fast-track care package was put in place on 13 October, unfortunately this was the day that the patient passed away. The CCG Quality Teams from South and Mid Nottinghamshire are currently working with the CityCare CHC Team to improve the timeliness and quality of fast track referrals. This includes undertaking weekly audits of the referrals and using findings to feed back to individual referrers and inform training and awareness raising sessions developed for groups of referrers e.g. GPs, District Nurses, Specialist Nurses and Hospital Doctors.

8 Recommendations

The following recommendations are made:

- Promote the patient story within all Patient Experience forums, to ensure that patient experience is embedded at the heart of all services we commission
- Promote The Nottinghamshire Guideline for Care in the Last Year of Life 2015 to all staff to ensure patients and carers have the information they require to make informed choices and decisions
- Ensure that End of Life care information is available to staff and patients within NHS settings
- The Quality Team will continue to increase awareness in primary care regarding the use of fast track and improve the quality and timeliness of referrals
- The Quality and Contracting Teams will monitor the providers' achievement of the Quality Outcomes Frameworks and continue to develop these during the life of the contracts

These recommendations have been added to the service improvement log and will be monitored until completion by the Patient Experience Team.

We would like to take the opportunity to thank the family for taking the time and having the courage to share their experiences during the last few days of M's life.

9. Update on Actions Taken Following Previous Patient Stories

- I. Story presented at March 2016 Governing Bodies: Positive Experience of the Fetal Care Unit, City Hospital Campus, Nottingham University Hospitals.**
- II. Story presented at January 2016 Governing Bodies: Discrimination experienced by a same sex couple during the birth of their second child.**

The Quality and Patient Safety Team in conjunction with colleagues from NHS Nottingham City CCG, the Mid Notts CCGs and NHS Improvement carried out a planned quality visit to Maternity services at City Campus in April 2016.

The Family and Friends scores reviewed for March identified the response rate for the 3 City wards combined was only 7% however all would recommend the service 100% with no passive scores. At QMC they achieved 25% in all areas for FFT, except for Labour suite which was below 25% in Quarter 2. Poor response rates in maternity is

recognised as an issue nationally. A site visit by NUH staff to Leicester revealed that they use iPads and have reminders on the labour suite to encourage FFT to be offered and completed. Staff at NUH now have iPads in all areas and are hoping that this improves the response. This will continue to be monitored via the Quality Scrutiny Panel.

Effective communication is often an issue highlighted in many complaints. NUH has attempted a different approach to ensuring that the patient voice is heard in that they share patients' stories from the perspective of the women/families. This seems to have a hard hitting impact. They ask all staff to reflect on the story and ask them to consider the complaint in relation to their own practice.

Good assurance was received during the visit of the effective leadership and awareness and monitoring within the service of the safety and quality of care delivered to pregnant women. A number of initiatives indicating that service improvement is encouraged (e.g. shared governance, multi-professional working for complex conditions) were evident during the visit. All staff encountered during the visit were welcoming, open and friendly and the experience of patients who were asked during the visit was good.

The Maternity teams are working towards modeling all new working practices, as identified within [Better Births](#) developed by the National Maternity Review and benchmarking will be identified within quality reporting on a 6 monthly basis. This will be monitored via the Quality Scrutiny Panel.

iii. Story presented at November 2015 Governing Bodies: Carer's Story

Following presentation at the Governing Bodies in November 2015 this patient story has been widely disseminated to various groups, across all 3 Clinical Commissioning Groups. Updates include:

- Public Health England in collaboration with Age UK, Carers UK and The Carers Trust have produced a patient booklet entitled [A Practice Guide to Healthy Caring](#). The booklet will help carers if they look after a friend or family member or have any form of caring responsibilities, but it is written to be particularly relevant for those who are about 65 years or older and are new to caring.
- Clarity has been provided around Carers Breaks funding in that a sitting service at home can be provided and that a carer's break does not have to be taken in one go e.g. a sitting service for a few hours a week for a few weeks can be taken rather than one full week. What would be exceptional is the timeframe i.e. for the support to extend over a period of months. Although this has been supported in the past, this provision is outside the remit of the NHS-funded service which, prior to July 2015, was not directly managed by the Clinical Commissioning Groups (CCG). A review led by Rushcliffe CCG, on behalf of the five Nottinghamshire County CCGs, in consultation with the County Council and representatives from these organisations is being undertaken. The purpose of the review is to clarify the remit of the service and how it relates to the Council's provision for planned short breaks.