

End of Life Care Services

March 2023



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Disclaimer

Please note: This report is based upon feedback provided to Healthwatch North and North East Lincolnshire from members of the public. The findings are based upon individuals' perceptions, which are not verified for factual accuracy.

Quotes in the report are written as received, to ensure opinions are kept in context, as such there may be grammatical errors within quotes.

The report contains people's experiences of end of life care. Some readers may, therefore, find the content upsetting.

What is Healthwatch?

We are the independent champion for people who use health and social care services. We exist to make sure that people are at the heart of care. We listen to what people like about services and what could be improved. We share their views with those with the power to make change happen. We also help people find the information they need about services in their area.

We have the power to make sure that people's voices are heard by the government and those running services. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them. Our sole purpose is to help make care better for people.

In summary Healthwatch is here to:

- Help people find out about local care
- Listen to what people think of services
- Help improve the quality of services by letting those running services and the government know what people want from care
- Encourage people running services to involve people in changes to care

Executive Summary

Since the introduction of the new end of life strategy, services have been slow embedding the new systems and processes. This has led to an inconsistent approach to end of life care across Northern Lincolnshire, and our findings have indicated a mixed experience of end of life care across both areas.

Communication seems to be a major stumbling block for service users and their families. When communication is effective and everyone who is involved in the process knows what is happening and the wishes of the service user are taken into account then the process runs smoothly. When communication is not effective service users feel they have been abandoned and pressure is put on the family, sometimes leaving them feeling unsupported and 'lost' in the system.

For those service users and their families where the documents were completed in a timely manner and ReSPECT documentation was used, the End of Life process was easier than for those that had not had this documentation in place.

Our report found that some unpaid carers/family members felt alone, isolated and unsure of what to do when their loved one had died. The End of Life Pathway and strategy need to encompass a package of support for unpaid carers/family members during the end of life and beyond.

Our findings have shown that overall, the agencies involved in end of life care have treated the service user, family and unpaid carers with sensitivity, care and dignity. However, some patient experiences suggest this has not always been the case if a patient has had to access a hospital service that is not caring directly for their terminal illness. Clinical and care staff should be made aware that the service user is nearing end

of life and care should be taken to treat the patient with sensitivity and ensure that extra measures are taken to keep them comfortable.

The following findings reflect the voice of service users and their families. It shows their own personal experiences of the End of Life Pathway and includes both good practice and where changes could be made to improve patients' journeys.

Recommendations

Recommendation 1

All relevant documents in relation to a patient's wishes at end of life, including the ReSPECT document and care plans should be shared with all agencies involved in the individuals care to allow for seamless communication between care givers.

Recommendation 2

A single point of contact/ helpline number for service users and families should be made available 7 days a week to ensure that service users and unpaid carers are able to get all the information they need in one place. The details of the single point of contact/ helpline should be provided to the service user and their carers as soon as they enter the end of life pathway.

Recommendation 3

All agencies should ensure that the service user has access to their own care plans to keep all the information in one place allowing it to be updated at every point in their care journey.

Recommendation 4

The commissioning an end of life advocacy service should be considered to ensure that service users have the opportunity to discuss end of life preferences with someone who is independent, and will speak on their behalf. Where this isn't possible, service users should be signposted to a national end of life support line. Mechanisms should be put in place to ensure that this is offered to every person on the pathway.

Recommendation 5

Hospital processes should be reviewed to make sure that patients who are receiving end of life care are identified and treated with sensitivity and kept comfortable in all departments not just those caring for the patient's terminal illness. This includes being provided with a place to rest and something to eat/drink if needed.

Recommendation 6

Information on how to access carer's assessments should be offered to all unpaid carers in order to support them to carry on their caring roles should they wish to.

Why this subject?

In September 2019 the Care Quality Commission (CQC) conducted an inspection of the Northern Lincolnshire and Goole NHS Foundation Trust. When the report was published in February 2020, it was noted that end of life care services had been rated as 'Inadequate'. The report raised some issues of particular concern, such as:

- Respecting patients' wishes / individuality in end of life care
- Record Keeping
- Communication from the trust to patients / relatives
- Staff attitude
- Patient comfort

The report highlighted that a system approach was necessary. With the support of NHS England a system approach was adopted, which included reviewing end of life care to understand how care could be more seamless and how resources could be effectively utilised. The Northern Lincolnshire End of Life Care Steering Group gives key partners an opportunity to come together to discuss important issues relating to end of life care, the group also developed the new End of Life Care Strategy for North and North East Lincolnshire.

Alongside this was the national roll out of ReSPECT (Recorded Summary Plan for Emergency Care Treatment), which aims to ensure people nearing the end of their life are able to die with dignity and at a place of their choosing. In addition, the Electronic Palliative Care Co-ordination System (EPaCCs) was introduced. The EPACC record is a way of sharing a person's wishes and includes ReSPECT.

Limitations of the Study

Many of those wishing to participate in the project, through interview, were approached by other organisations who were looking after the individual/family either whilst on the end of life care pathway or after someone had passed away. Healthwatch was, therefore, largely dependent on the cooperation of other organisations and on receiving these referrals.

Some people attending the interviews or focus groups had experienced a loss more than 12 months ago, which was outside the original, one year, scope of this project. However, it was felt that these experiences should be captured as some information and learning may still be relevant. When writing up the project Healthwatch staff have used their discretion as to what information would still be relevant for inclusion.

In total 14 interviews were carried out. Due to the topic being end of life care Healthwatch North and North East Lincolnshire focused on gathering in-depth opinions through qualitative research rather than aiming for a larger representative sample.

Finally, it should be noted that some of the experiences highlighted in the report happened during Covid lockdown restrictions. During these periods additional temporary measures / processes were put into place to help protect patients, staff and other members of the public. This included restrictions on visitors at the local hospitals.

Some of the experiences, therefore, may not be typical of the service received under pre and post lockdown conditions.

Introduction

The National Picture

The first National Strategy for End of Life and Palliative Care was developed in 2008 and had 3 key insights:

- That people didn't die in their place of choice
- That we needed to prepare for larger numbers of dying people
- That not everybody received high-quality care. 'Some people experience excellent care in hospitals; hospices; care homes and in their own homes. But the reality is that many do not'

This strategy was refreshed and added to in 2015 and today the following strategy applies.

The Ambitions for Palliative and End of Life Care: A national framework for local action 2021-26 document was published, this national framework sets out how health and social partners are equal partners in the care of those who are entering the final stages of their lives.

This document sets out 6 ambitions for those who are receiving palliative or end of life care. The 6 ambitions are as follows:

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help

The strategy states

“When the end of life is in sight everybody should have the care and support to enable them to live to the end in the best way that they can”.

The full document can be found at <https://www.england.nhs.uk/publication/ambitions-for-palliative-and-end-of-life-care-a-national-framework-for-local-action-2021-2026/>

The Legislation (law)

The Care Act 2014 sets the legal framework for councils with social care responsibilities to support individuals nearing the end of their lives along with their families and carers.

The first national end of life care programme was established in 2004 and the first National Strategy in 2008.

This legislation, in simple terms has been developed to ensure that people nearing the end of their lives are supported to die with dignity and care. It also means that their families and unpaid carers are supported through the process and after their loved one is no longer with them. The framework sets out good practice and what people should expect when they are part of the end of life pathway.

An integrated care board (or ICB) is a statutory NHS organisation which is responsible for developing a plan for meeting the health needs of the population, managing the NHS budget and arranging for the provision of health services in a geographical area. The Humber and North Yorkshire integrated care board is responsible for the areas within North Lincolnshire, North East Lincolnshire, Hull, East Riding of Yorkshire, York and North Yorkshire.

The Health and Care Act 2022 states a legal duty on ICBs to commission palliative care services

The duty is intended to ensure that the palliative and end of life care needs of people of all ages, with progressive illness or those nearing the end of their lives, and their loved ones and carers, receive the care and support they need to live and to die well.

The Local Picture

Partners in the Northern Lincolnshire end of life strategy group have worked together to develop a joint end of life strategy in North and North East Lincolnshire.

The strategy covers the period of 2021 to 2026 and sets out how the partnership will improve the patient experience of those nearing the end of life and the experiences of those caring for them. The full strategy can be found at

<https://northlincolshireccg.nhs.uk/wp-content/uploads/2021/09/EOL-strategy-Final.pdf>

One major element of the strategy includes the introduction of the ReSPECT document.

The ReSPECT document is the Recommended Summary Plan for Emergency Care and Treatment and it creates a personalised recommendation for a person's clinical care in emergency situations, where a person is not able to make decisions or express their wishes. This is a National initiative but was introduced in September 2020 within Northern Lincolnshire. One element of the ReSpect document includes the patient's decision about whether or not they would like to be resuscitated. This was previously known as Do Not Attempt Cardiopulmonary Resuscitation (DNACPR).

As a result of the end of life strategy there was more focus on Electronic Palliative Care Co-ordination Systems (EPaCCS), which is a record of people's care and important details about a person's care at the end of life. This record is available 24 hours a day

and it is available to all professionals who are involved in the care of a person who is at the end of their life.

Locally within Northern Lincolnshire all agencies have adopted a standards competency framework for end of life skills and competencies. As part of the education and training for professionals, 3 initial priorities are being developed; these are Clinical Practice/Direct Patient Care, Communication Skills and Symptom Management including Last Days of Life. This framework is for all staff within the end of life pathway to undertake so they all have the training/skills that are needed and the training/skills are the same across the board, this is not dependent upon which agency a member of staff is employed by.

Approach

Methodology

During conversations with a member of the Northern Lincolnshire End of Life Steering Group, questions were devised to cover all aspects of the end of life strategy and pathway. These questions were discussed at the End of life steering group, the questions were then finalised and it was agreed that referrals from services would be coordinated by this group to ensure both service users and carers could be identified across primary, secondary and community care.

Interviews were initially identified as being the most appropriate method of collecting the information of the strategy and pathway and how it works in practice. This would enable service users, carers and their friends to share as much or as little of their own experiences with Healthwatch North and North East Lincolnshire as they wished. Individual responses would be written up in the form of case studies and kept anonymous.

It was also felt that the 'Way Forward Groups' in both North and North East Lincolnshire would be a valuable source of information especially in highlighting carers perspectives of end of life care.

The information received from both the interviews and the focus groups have been combined in the findings to enable Healthwatch North and North East Lincolnshire to gain a fuller picture of the current position for service users and carers who are accessing the end of life pathway.

Interviews

Healthwatch North and North East Lincolnshire began by identifying people with experiences of end of life care services, either as a relative, carer or friend or as a service user currently on an end of life pathway. Alongside receiving referrals from services, such as hospices and hospital staff, information was also placed in our publications throughout the project and we spoke to people, about the project, at events. This was to ensure we had a range of experiences and to minimise bias by offering the opportunity to participate to a wider audience.

All participants were contacted by Healthwatch North and North East Lincolnshire staff over the telephone to confirm they knew their details had been passed on. We then sent each participant an information pack which included project information and a

consent form. This was to ensure participants understood the expectations of the project and what their part in it would include. Our Patient Experience Officers then made arrangements for participants to come into the Healthwatch North or North East Lincolnshire offices to conduct the interviews or arranged to conduct the interview over the telephone. Participants could decide whichever format suited them best. Where participants were unable to travel to the office, alternative locations were sought. All interviews were held face to face by our Patient Experience Officers or Managers. They were recorded with consent of the participant and transcribed later. These transcriptions were then used to create case studies of experiences and draw information for cross-comparison across the region. In total **14** interviews took place, six from Healthwatch North Lincolnshire and eight from Healthwatch North East Lincolnshire.

Focus Groups

Early in the project we identified a local support group, which supported people following bereavement called the 'Way Forward Group'. In North Lincolnshire we contacted the group facilitator to see if they would be happy for us to come in and speak with them. It was agreed that we could arrange a time to speak with the group. The group meet at the Carers Support Centre in Brigg.

Within North East Lincolnshire the 'Way Forward Group' is facilitated by the Carers Support Service and meet the first Thursday of every month at a local Wetherspoons. After a conversation with the Carers Support Service, it was arranged to visit the group on 9 June 2022 and the 7 July 2022.

Within North Lincolnshire the 'Way Forward Group' is facilitated by the Carers Support Service and meet at the Brigg Carers Support Centre. The focus group was held on the 23rd August 2022.

The Forge Project in North Lincolnshire has also shared the experiences of service users with Healthwatch North and North East Lincolnshire. The project supports those who are homeless or who are at risk of becoming homeless. <http://www.theforgeproject.co.uk/>

Social Media

Social media posts were developed to raise awareness of the project and how people could get involved, if they wanted to. The images used were that of the bluebell to help service users, carers and friends identify the project easily as this is the image used across North and North East Lincolnshire to identify those that are on the end of life pathway. Social media post were shared via Twitter, Facebook and Healthwatch North and North East Lincolnshire's websites.

See Appendix 1

Feedback – Interviews

The feedback from the case studies have been collated under each question, not all respondents answered all the questions.

A copy of the questions can be found in **Appendix 2**

Question 1

Please can you tell me how far into their illness the person was identified as needing end of life care / diagnosed as terminal? What conversations were had at that point with medical professionals? If a person was recognised as needing end of life care later on in their illness, was enough time given to record and implement their wishes?

For those people spoken to there were a range of illnesses and differing timescales as to when they were told it was terminal. The responses received are as follows:

“Mum was diagnosed with leukaemia about a year ago”

“Had existing disabilities and contracted sepsis and then Covid-19”

“A year into dad’s illness, he had a palliative tumour”

“Wife diagnosed with dementia 2019”

One lady spoken to did not recognise she was on the end of life pathway, when asked when she was told she said **“I just get care from carers due to MS and being in a wheelchair”**

Wife said **“my husband last year had achy legs and kept collapsing at home was then diagnosed with bone marrow cancer”**

Husband said **“I was not sure as initially my wife was misdiagnosed with a condition that affected her skin when in fact it was lymphocytic leukaemia”.**

Another lady whose husband had leukaemia said **“He was told in June...that he had leukaemia having had various things backwards and forwards to Scunthorpe General at the time, seeing the haematologist and then they said oh you’ve got this type of leukaemia that doesn’t really kill you but you just live with it and have blood transfusions... So that was fine and then they found that he had another type on top, which made it quite a rare sort of thing so then they referred him to Castle Hills and then when he got to Castle Hills they basically said to him there’s nothing we can do we can give you some chemo to mediate the process, make it more comfortable for you but you know it’s going to get you. Erm and I remember going over to Castle Hills and him telling me this and at the time the consultant there said you’ve got about three months and he actually lasted [longer]. The interviewee then mentioned that her husband had been “forgot about” whilst receiving treatment at Castle Hill Hospital “After the Christmas thing at Castle Hill they said well there isn’t a lot we can do now you’ve been having these chemo appointments and these things but now probably all we can do for you now is to keep you on a sort of level of certain drugs, which you take yourself and you [go for] transfusions at Scunthorpe...Eventually he got to the point where they said we’re on the end of life care bit now so we had this big pack of pills at home”**

A family member said **“I was not sure when she was told as she was in a Care Home”**

“It was discussed with the family”

Wife of a service user said **“He has made his wishes clear to the family, he would like the family there when he dies and is now saying he is ready to die”**

Husband said **"My wife wants to die at home"**

"We knew it was a one way street after diagnosis"

"I wasn't prepared when someone rang me out of the blue to discuss DNR"

"It was realistically, the second from last time she went into hospital which was round about this time last year. She came out on oxygen and she had never had oxygen prior to that and she was on that until she died at the beginning of September last year"

Wife said **"My Husband had cancer several times over 16 years, but he was finally diagnosed as terminal in July 2019"**

From the comments received most people were unsure when the end of life pathway started and whether direct conversations about end of life actually took place.

Question 2

Healthwatch asked about the residency of the person when they passed away and whether this was in line with their wishes. Responses varied due to differing wishes, locations and illnesses. For the most part, the service user's wishes for where they wanted to die were able to be granted, responses received are:

"Mum died at my house, until the last 10 days mum was at her own home but my daughter who was sharing the care with me had gone away and I couldn't manage alone so mum transferred to my house"

Daughter said **"At home and this was what dad wanted"**

Other responses received are:

"At Home"

"At the Care Home"

"He didn't want to die in hospital, he wanted to be at the hospice and staff made this happen"

"He died at the hospice and this is what he wanted"

"He died at home, he wanted to be there"

"He said he wanted to die at home and didn't want to go anywhere else so they [said they] would try and respect his wishes." The interviewee confirmed that the individual did die at home.

However, some family members explained that their loved ones had not died in the place of their choice. One family member said, **"What she really wanted to do was go into Linsey Lodge or home"**. Another explained, **"Dad died in hospital"**. Further responses include:

“The plan was for her to be in a Care Home, however I was surprised to find the long term plan was for care at home even though we were struggling with her behaviour. We fought to keep her in the care Home”

“No – as a family we contacted the hospice a week before mum died to be told that she wasn’t close enough yet and she wasn’t booked in till September. Mum died in April 2022”

Some of the service users or family members said they are still alive and they hope their wishes will be fulfilled.

Question 3

Did you feel that the team looking after the service user personalised the service to take account of the patient's individual needs?

This question covers such things as nutrition and whether their individual needs and wishes were taken into account. The feedback highlighted opinions about a range of services and a mixture of negative and positive comments were received.

A husband of a service user said **“No, the best person I ever met at the hospital was the respiratory nurse, I think it was respiratory, and she explained everything and she got involved in everything but this was 18 months prior. After that, my wife went in hospital I was allowed to see her first time, second time it was 2 and a half weeks before I was allowed to sit with her, I could take her clean clothing in an such like because of Covid-19 and then they transferred her to Ward 17 and I could go but I had to be booked in and booked out and it wasn’t until 3 days before she died that my son was allowed and sister in law and niece were allowed to see her”**

A service user's daughter, with regards nutrition said **“we had a dietician much earlier the Macmillan dietitian and he liked her, she was very good with him. He tried the build-up drinks but that wasn’t gonna happen. He tried that, she kept communicating but by the end the only thing he would eat was ice-lollies, that was it”**

Daughter said **“They were and he did want to stay at home, they were very good in that we had different carers coming to shave him, wash him and do things like that which would be difficult for family to do, maybe ok for me as a nurse but still not easy”**

The Wife of service user said of the hospice **“I think if he'd have asked for something like if he fancied an omelette and it wasn't on the menu they would do an omelette or beans on toast or whatever he wanted”**

They went on to compare the length of time people waited for buzzers to be answered at the hospital compared with the hospice, stating that there was a more immediate response from the hospice **“...hospice press the buzzer someone is there immediately and if it is a healthcare assistant who can't give you medication immediately they get somebody who can and there's none of this looking at your watch and saying you only had whatever... whatever they can do to keep out of pain they do it”**

The wife of a service user said **“He’d been allocated a Macmillan Nurse when he was over at Castle Hills and then he was allocated one in the community back in Scunthorpe and she used to come round and see him...We had an up and down period between the Christmas and the April, my daughter was getting married...and when we explained this to them at Scunthorpe General they were really really good and actually put in a whole load of extra blood transfusions...he did make it there and he walked her down the aisle...that was really good and she’s got those memories.”** The interviewee went on to mention adjustments made during her husband’s final days, which included another mattress being brought to the house and her husband being put onto drugs to manage pain **“the chap that came to the house spoke to him and said look we’ve got all these drugs we’re going to start to put you on this thing where you know it manages your pain. I mean he knew what we were all talking about here and the district nurse will come in on a regular basis but that only happened for maybe about three days and then he actually died.”**

Question 4

Whilst the person was receiving end of life care do you feel that records were kept up to date?

This question covers all plans; including care plans, Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) and Electronic Palliative Care Coordination System (EPaCCs). The answers provided also cover what impact it had on the individual if care plans were not kept up to date.

The daughter of a service user felt that **“notes were not kept up to date and she had to keep re-telling her story to every professional. Never saw an end of life plan”** and also that **“services did not communicate”**.

The daughter of another service user said **“due to being unable to visit, it is hard to know for sure what notes were correct. It all happened very quickly and we were only allowed to visit at the time of his death.”** In this case dad had been admitted to hospital due to sepsis and contracted Covid-19.

Another service user’s daughter said **“Care plan and ReSPECT documents were in place”**

A husband of a service user said **“The Care Home kept records”**

Husband of a service user said after a recent hospital admittance his wife was given **“she was not allocated a care worker to start with and was given an emergency discharge for 2 weeks. They were then given a care worker in December who phoned to say that unfortunately she was having 2 weeks away but put on another package for another few weeks until she could arrange a new care plan. At the end of December she was put on another short term care package to take her into the New Year”**

Daughter said that her dad did have RESPECT in place and went on to say **“RESPECT Yes, it’s the DNR basically, the last time he went in the ambulance took him to admit him when he ended up on ward 22, he was adamant he was taking that with him but he said he didn’t trust the hospital not to lose it so he made my brother photocopy it and**

clutched it in the chair they wheeled him in in and he was never the same, he didn't trust them to lose it or mess it up. I think because he knew about medical side of things he made sure that was in place early on"

Another husband of a service user said **"No, to the best of my remembrance I cannot remember somebody saying 'we are going to...' somebody did say 'we have done...' one of the nurses, we've taken off, because she was on paracetamol, blood thinners, rehydration fluids to try and keep her kidneys working but they were shutting down, but part of that was that I couldn't get her to drink water"**.

Some families were not sure due to the person still being on the pathway.

With regards the impact this had on service users and their families, it has had a negative impact. Families said they have felt let down by services not being there when they needed them. The following responses were received:

Daughter of a service user said **"Pain relief was not there when mum needed it"**.

Daughter went on to say **"the day mum died I rang SPA to get pain relief and they said they did not have a member of staff to come out so they would let the District Nurse know to come out and they start work at 8am. I rang District Nurse at 8am and they did not start till 8.30am, I rang them at 8.30am and they knew nothing about it. Came out to see mum and 20 minutes she died"** Daughter feels that her mum was in pain.

"This meant that the correct people were not informed that my Dad was in the last hours of his life".

Service user who is currently on the pathway said **"I am not aware of any care plans but I meet regularly with their social worker who I trust will adapt care as and when needs change"**. Service user was asked if they have made any decisions about the future if they deteriorate. Service user again did not seem to understand and said that the social worker would increase care if needed, but said that they feel this may not happen, but if it did family feels it best to have a live in carer as service user lives alone, daughter lives away and Mother is elderly and has health concerns of her own and so is not capable of providing care and support for the service user.

A husband of a service user said **"She was lifeless when I visited her"**

The wife of a service user explained **"No, I remember we got given this book, which again I probably still have and nobody ever filled it out...if I hadn't kept a diary we would have been struggling to remember stuff...no the record keeping was pretty poor from our point of view. I'm sure they had records but as I say at one point they forgot about him and...they actually did admit 'we seem to have missed having him in for his treatments' because we'd left without another appointment and then nothing had come through. Whereas usually you would have one made for you there and then."**

Question 5

How involved were you with any care plans?

The majority of service users or their families did not know what the care plan looked like or had seen one, they did know what care provision was currently in place.

A husband of a service user who passed away in May 2022 said **"They had started looking at a long term package in January and I was surprised to find the long term plan was for care at home"**. They were looking at care in the community, even though he had told them he had been struggling and others had also seen this too. Family did not want this but were told to look at making changes at home instead of being in a care home. The care worker then looked again and said they would side with the family and would let her stay in the care home.

The husband felt this was not what he or his wife wanted and were under the impression the plan was for her to stay in a care home.

The daughter of a service user said **"I do remember paperwork around not necessarily a plan, but paperwork about medication and numbers to ring if we needed which we did on occasion, if the catheter blocked. There was help available as and when we wanted. I am not ungrateful for the help we did get, but I wish we'd had more. The times I saw a car there the relief was amazing and if someone had been there more I would have felt better but I appreciate it's not possible. I thought they came as and when we needed them and built it up as things got worse, I can't fault them"**

Daughter feels that there wasn't a care plan in place as things changed she had to ring around services to get things and then when things were promised things did not arrive. Also the daughter said that if she rang professionals she would leave messages and people would get back to her days later. Daughter said that **"I am sure they are busy but when someone is at end of life 2 days later could be too late"**.

The daughter of a service user said **"We were not involved, we were updated, but at no point was anything discussed with us, due to Dad being in a coma and on a ventilator. Some of the staff were brilliant, and one nurse made my little brother a bracelet that said "dad" on it, and she made me a crochet heart that my Dad had had next to him"**

"I was aware and did ensure dad's wishes were on them"

Service user was not aware of care plans but explained they meet regularly with a social worker who she trusts will adapt care as and when needs change. The Service user was asked if they have made any decisions about the future if they deteriorate. The Service user again did not seem to understand and said that **"the social worker would increase care if needed"**, but said that they feel this may not happen, but if it did family feels it best to have a live in carer as patient lives alone, daughter lives away and Mother is elderly and has health concerns of her own and so is not capable of providing care and support for the patient.

The wife of a service user said **"We talk regularly about wishes but not with the staff"**

Husband said **"Care plan did not exist, I did everything. It was like they were treating her only for the initial skin condition."**

The wife of a service user said **"I don't think so. I don't remember but I could be vague about it. I don't remember a sort of plan, I think as things advanced we talked about options in terms of hospital, hospice then a hospital bed at home and I remember feeling"**

I am pleased it didn't happen in the end but I remember thinking I really want him to go to the hospice because the weight of the responsibility terrified me"

The wife of a service user explained that her husband had previously been diagnosed with non Hodgkins lymphoma and skin cancer and explained that care plans were in place and there was always a point of contact. Plans were always in place and communicated, however the wife believes that they were not individualised for her husband's needs. She explained, **"He didn't fit that pattern, they weren't flexible enough to fit around his needs"**. Further to this he was also diagnosed with bladder cancer, **"with his bladder cancer, there was never a point of contact, never a sole person who we could talk to or who we could ask"**.

Another relative of a service user answered **"No, no, because it was obvious that I'd be able to do it for him. That was probably something that would have done for somebody who was less able to help"**

Question 6

Those participants involved in the interviews were asked for information about the ReSPECT documentation and process, not all participants knew about ReSPECT or had completed ReSPECT documentation so did not comment. The following answers were completed by those participants who were aware of the documentation.

"We as a family are not sure this was ever taken into account"

The next comments are from the daughter of a service user and concern an experience of end of life care during a Covid-19 lockdown period, when visiting restrictions were in place. The daughter said **"Dad's wishes were not able to be fulfilled which haunts me every day. He always discussed his wishes because of his disability, and he said that he wanted my Mum to be there as she is a spiritual person. He wanted her there to make sure he was safe when passing over. My mum was told she wasn't allowed in the room"**. The daughter explained that due to them being divorced mum was not classed as the next of kin.

The daughter then talked further about the patient's and the family's wishes alongside their experience **"At the time of reaching the hospital in my Dad's final hours, we were told only my little Brother was allowed in the room as he was the only one who was "family". I am a step-daughter technically, but I have grown up with him as my Dad. To be told I wasn't family was hurtful. My little Brother was 17 at the time and was frightened to go in on his own, but we were told he had to go in with a nurse and no other family was allowed. My dad died whilst my brother was in the room, and this has traumatised him and he said the nurse didn't say a word to him to comfort or help him with what to do. When he came out and we were told Dad had passed away, I begged them to let me in to see him and say goodbye, feeling robbed that I had missed my last chance whilst he was alive. The nurse allowed me in as well in full PPE, and whilst in the room told me I could put my face on his, and touch him if I wanted, so I did. I was then de-gowned and de-masked whilst still in the room with Dad. Then taken to a tiny family room where I**

was able to sit with my Mum, Sister and Brother. We were not told to self-isolate or told anything, which we later found out that we all could have gone in if we wanted to but would have to self-isolate for two weeks. This could have cost my Mum and Sister their jobs, but I know they would have still been willing to do this given the chance to. In the family room, a nurse then came to speak to us and we asked what happens next. The nurse said that Dad would be washed at the hospital, wrapped in a shroud and put in a body bag which would be sealed and never unsealed again. We were not asked what he wanted to be dressed in, we did not know at the time that we would never get to see his face again, the nurse made it clear he would be 'a rotting corpse in a body bag' and she lacked compassion when speaking to us, she was very matter of fact and this has traumatised us all but especially my little Brother. My mum asked about a little note my brother had written for Dad, and asked where it was and if that could be left with Dad. The nurse replied "well I can't very well ask him where it is can I". They even questioned my Mum as to why she was there, when asked who she was my mum explained she was his ex-wife. The nurse said "well what this has [this] got to do with you". My mum said "I do not have to justify my relationship with him to you".

The daughter of a service user said **"The document was what dad wanted, however dad had a fall and I contacted SPA to see if the community nurse could come and see him as he [had] just come off warfarin and cut his head. SPA told me that because it was a head injury I had to call 999. This was not necessary it was a cut but I called 999 and an ambulance arrived and took him to hospital. The ambulance crew were not aware of his end of life plan. Dad was in hospital for 3 weeks due to this. After a week of being in hospital his cut on his head had not been cleaned all they did was put a plaster on it, when I asked about it they gave me some sterile water and I cleaned it myself. This was not what dad wanted to be in hospital and I feel they did not listen to me. When dad got out of hospital after 3 weeks, he went downhill and did not want to eat or drink and deteriorated fast. [The] ambulance crew did not have access and it was in paper form, I refused to leave the hospital (when he was admitted) [and refused] to leave without it as I did not want it to go missing"**.

As previously mentioned, one service user is not aware they are on the end of life care pathway. The service user has not had any conversations about future care or decisions with professionals, and seems to be under the impression this would not be necessary. Service user explained that the care regarding her MS is excellent and that she has not experienced any issues with this care and support. However, she did explain that when she goes to her GP, for something unrelated to MS, she sees a different GP each time and therefore has to take a list of her medication with her and explain her condition to the doctor. She said **"this takes a long time and [I] would find it easier to see the same GP or to have the professional"**. In terms of being aware of her condition and current medications. She also said **"I would find it beneficial to have continuity of care"** a reference to her GP Practice.

Healthwatch North and North East Lincolnshire also received the following comments from family members of service users:

"This did not happen for us".

“No I haven't heard of them. We did do a DNR towards the end”.

“Right to the very end, to the day he went into the hospice for his end of life it was his choice. He discussed things with us, but we always gave him...whatever is your choice, your body it's you that has to deal with it and when you've had enough you've had enough”.

Question 7

Do you know if Liberty Protection Safeguards were put in place?

This includes legal safeguards that are put in place when a service user lacks capacity to consent to their care and treatment. It is needed in order to keep the person being cared for safe. If they were in place did all those caring for the individual know they were in place?

“I don't think it got to the point where any of that was necessary...he had capacity basically”

“I don't know”.

The majority of respondents were not aware of Liberty Protection Safeguards or what this meant for the individual receiving care.

Question 8

Did a fast track continuing care assessment take place?

If an individual's condition is deteriorating rapidly, they may be approaching the end of their life, and a “fast track” assessment may be needed to allow an appropriate care and support package to be put in place as soon as possible.

The assessment enables patients to access health funded care without undergoing a full health needs assessment. The fast track assessment can assist with support in any setting such as: hospices, patient's homes or care homes. Fast track assessments should take place even if a person is already receiving another care package either through local authority funding or self-funding as they would then be eligible for NHS funded support.

If a fast track assessment was required the participants were also asked what was your experience of this? Were carers put in place to help with personal care? Were you asked to take part in personal care?

The following comments were received by Healthwatch North and North East Lincolnshire:

“No”

“I don't recall anything we just knew it was a very rapid decline and HT was well aware of that, she was very honest I remember I asked specific questions like how long has it gone because I wanted to rationalise it obviously they can't tell you when and she was

very clear we were talking days and very upfront about that. She was an amazing help to us, the carers and nurses were too”

The wife of a service user commented **“I can’t remember the words fast tracked being used no. [I] mean they never expected him to last like he did and that was obvious from some of the things that they used to say.”**

Question 9

If you provided personal care did anyone explain what caring for someone at the end of life was like?

Some of the relatives and family members explained that they were the sole carers for their loved ones, and did not receive any advice or guidance around what providing personal care would be like. Comments include:

“No we were left on our own.”

“I found caring extremely difficult but continued until the choice to stop was taken out of my hands, despite the impact it was having on me and my own health and wellbeing. I received a lot of support but still found it very difficult.”

“I provided personal care but nobody explained anything or showed me how, I was left on my own.”

We asked a relative if anyone discussed what she was comfortable to do at home for her Husband in terms of personal care, she responded **“No we were just sent home from the hospital”**.

Other family members who were not sole carers expressed that the care provided was **“rushed”**, and that they felt that carers didn’t know the patient’s wishes. They gave the following responses:

“No, my Dad’s wishes were not respected, discussed or even taken into account. None of the professionals ‘caring’ for Dad knew us or his wishes at all. There was no compassion or kindness except for one nurse who made this whole experience a tiny bit more bearable with her acts of kindness towards me and my brother”.

“When dad initially needed personal care HICA provided it and we had a very good carer. However, dad was often rushed and a 30 minute call was often 20 minutes. I was also not happy with the personal care dad received. They would often use the same flannel instead of using different ones. I was under the assumption that they used 1 for the top and 1 for the bottom. In the last few weeks I carried out his personal care.”

One interviewee said **“he didn’t really need any personal care until the last few days when the palliative thing kicked in and the district nurse who was coming round so up until then so no he was perfectly capable of looking after himself really. The only thing I did have to help with was his medications because in the last couple of months he developed a form of anxiety, which I was very very taken back by and so was he...he started to experience some sort of panic attack and it was all around his medication, he had so many different pills and he had those things with them in to that he could, you**

know. But he used to put them into these pill canisters so that he knew what he had to take at various points during the day. He just started to get really really anxious when he was doing it and really getting himself into a state...and I had to persuade him to let me take that over." The interviewee explained that there were other times when her husband would become anxious. When asked whether anyone had informed the interviewee about what looking after someone toward the end of their life would be like she said **"No I read up about it. There was always places you could go to find information and I read up about it. I think I was given a leaflet"**

Question 10

Did professionals recognise any developing symptoms or act on concerns raised by yourself or others? If so were adjustments made in a timely manner? Were adjustments made to medication quickly?

The Wife of a relative explained that her Husband had been displaying extremely challenging behaviour, and as his sole carer at home she was struggling immensely. She said:

"Once he was in the hospice, he was taken off benzo medication and given morphine instead. Dr had told me that my husband would now be in the hospice until he passed away. Within a few days my husband's side effects that he had been displaying at home, such as messing himself, not sleeping etc had gone."

Another Wife of a service user explained that she had begun to come to terms with her husband not returning home, and although this was difficult she said **"I felt as though I got my husband back"**. However, she went on to explain that due to the improvement in her husband's behaviour, a nurse had explained that her Husband **should be able to return home**. The Wife expressed concerns about this as she felt as though the hospice was the best place for him to be. She explained, **"The nurse used the term "improved" which I found difficult and confusing as my husband was receiving palliative care and we had been told that he would not return home now. It took a lot for me to come to terms with that and it felt like I was right back at the start again"**.

The daughter of a patient said **"every service failed my mum there was no sense of urgency"** and she said **"before mum died she said that she felt forgotten about"**

Overall, the experiences and feedback given to Healthwatch North and North East Lincolnshire indicate that professionals acted in a timely manner and in most cases the necessary adjustments were made. Further comments include:

"The care at the care home was excellent but she did experience a number of falls while she was there. Social services got involved at some point whilst she was staying there and transferred her to another care home. Not long after this she passed away. Once she was transferred she went downhill rapidly"

"They did and they were very good and they increased as things got worse and then we had several night sitters because before that we did shifts because he would try and get out of bed it was like having a child because he was so confused and would try to get

out of bed and was too frail, I was working and would come after work and sit with him some nights till 11 then my brother would go to bed and I'd wake him at 11 and rotate, but I didn't want to wake them if he's trying to get out of bed I think I snapped once and that will stay with me because I snapped at him. But thank god we did then get night sitters because that responsibility was taken away in that they were there and would watch him".

However, the Husband of another service user told Healthwatch North and North East Lincolnshire, **"My Wife would wake up in the night screaming in pain and nobody did anything"**.

The wife of one service user commented **"He did actually start to get really poorly because they forgot about him for a while. Castle Hills stopped giving him a next appointment and then nothing was happening and then he got poorer and poorer and then he ended up going in as an inpatient there and he really was quite poorly and to be honest at that point we thought we'd lose him but then with a combination of drugs and blood transfusions they brought him round"**. The interviewee had kept a diary of events at the time one extract revealed a lack of communication between hospital and patient. The extract said: **'we got a call from Ward 18 on Scunthorpe to say where was he? And that apparently he was booked in for the next four Saturdays but we'd had nothing about that.'** The interviewee also mentioned that her husband had experienced problems with his legs the Macmillan nurse rang the hospital with no luck so she sent him to the GP. The GP then sent them to A&E. From the diary kept at the time it was evident that this was not a suitable environment for the patient 'the letter he [GP] gave just said DVT? And we sat in A&E for an hour waiting in the noise and the light, which was difficult for him by that stage he didn't like to be in places that were noisy and well lit. The interviewee spoke about the problems the patient experienced with his legs **"they swelled up they were red. It was like a DVT but it wasn't a DVT...we had some real problems with getting them to look after him with things like that. It's alright when you're in the actual cancer ward but if you needed to have anything else done like there's a DVT clinic and he had to wait....he was really tired and he just needed to lay down and I just remember we were in this waiting room, there was nobody else around he'd been there hours and I remember getting all the cushions off the chairs and sticking them on the floor so he could lie on the floor and you know there were things like that which were just not conducive to a good situation for somebody who was near end of life."**

Question 11

What was your experience of being guided through the process?

The negative comments Healthwatch North and North East Lincolnshire received were as follows:

"I did not feel guided at all and not supported. It was mum's wishes to die at home and at a push if we couldn't cope anymore she would go into the hospice"

"I had no real support after her passing. Nobody professionally spoke to me about her wishes and will etc."

“I wasn’t guided through anything, we were left alone”

“Even though I could do it, and I did, the assumption was made that I would... the girls that used to come were brilliant with him and did everything that was asked of them, but they weren’t always there when jobs needed doing. Like when he had this stomach out and he came out with a tube being fed on a machine it was me that dealt with it, we weren’t even offered any support then with nursing, you just do it”

The positive comment Healthwatch North and North East Lincolnshire received about being guided through the process were as follows:

“Community Nurses kept me informed of what was happening and they were really good”

“The Macmillan nurses were professional, efficient, supportive and friendly. They could not have given me any more support”

Finally with regards being guided through the process, one service user seemed to have very little understanding of being on the end of life care pathway.

“In the early stages and the middle stages it was just a case of right this is what you need to take there wasn’t a lot of explanation. I would often ask what’s that for? And why is he having that?...there isn’t a lot of information sharing on what they are giving you and why they are giving you it.”... “In a lot of cases you had to ask that comes back to what I was saying earlier about having the confidence to ask and having the language to ask questions that you needed answers to”

Question 12

How well informed were you about what services were available? Did you feel anything was missing?

Healthwatch North and North East Lincolnshire received the following comments:

“Mum did use a commode but this became impossible so the daughter contacted Macmillan about incontinence pants for mum to be told they would get her some and it didn’t happen so she went and bought some herself. The liquid feeds also did not arrive on time.”

A wife of a service user said, **“I wanted a lifeline and for someone to contact me daily in that last week would have been really useful. As a family we do not feel supported at all”**

One relative said that they were **“not sure of services”**

A service user's daughter lives away and the service user's elderly mother lives close by. However service user explained **“I am fine and does not need support.”** Elderly Mother seems more concerned about service user's wellbeing. Service user attends a peer support group at the hospice but expressed this is not 'end of life care'.

Other comments Healthwatch North and North East Lincolnshire received were:

"I had no help after my wife passed, no professionals or carers or anything. I was left to deal with everything myself, with nowhere to go and nowhere to turn. The remaining savings that my Wife has left all went towards the funeral costs etc."

"I wasn't informed about anything"

"There was help available as and when we wanted. I just felt I wish, it sounds I am not ungrateful for the help we did get, but I wish we'd had more. The times I saw a car there the relief was amazing and if someone had been there more I would have felt but I appreciate it's not possible. I thought they came as and when we needed them and built it up as things got worse, I can't fault them. I just wish those that we know who haven't had that experience I'd like to how they fall through the net".

Question 13

Thinking about the professionals who looked after the person being cared for, were they helpful, compassionate, friendly, etc?

The majority of family members and relatives shared positive experiences about the compassion they received from professionals who provided care and treatment for their loved ones. Comments include:

"Community Nurses were supportive and caring and I felt were brilliant through the process. However, I cannot say the same about Macmillan nurses. Dad had 4 Macmillan nurses in less than a year and they kept promising things that never materialised. I was due to see them on the Monday and dad passed away on the Sunday, they did not ring about anything. One of the community nurses had asked if they had been in touch and I said no. it was only after this did someone contact me. I could never get hold of the GP, when I rang the GP Practice the receptionist would always put me through to the Triage Nurse, she was lovely but I can only remember speaking to the GP once when after speaking to the Triage nurse he came out to see dad"

"I feel comfortable with the carers who attend and usually it is the same ones. I trust them and they are nice, one I don't get on with as well as the others however she is still good at her job"

"The care home were really good"

"The night sitter was amazing, she was knee high to a grasshopper and could make him do anything we couldn't. She'd get him out of bed some nights and he'd appear in the living room tottering down with his hand on her shoulder. Nothing but praise"

One relative spoke about the final week of her husband's life, where she knew time was limited and so she had stayed with him day and night with only the belongings she had left the house with. She explained the kindness of the hospice staff throughout this difficult time and explained, **"well I came out yesterday with nothing I need a hairbrush, toothbrush and she said just a minute tootled off and 5- 10 mins later she came back and said room 5 was empty, 'I've got everything out for you if you want to go have a shower', there was a hairdryer, there was everything and that just meant so much so I was able to have a quick shower and dry my hair"**

However, relatives also shared some experiences of professionals who they felt could have been more compassionate in the care and treatment they gave to their loved ones. Comments include:

“The only professional we saw was a nurse who came once a week. She applied cream and bandages then left that was it”

“Some staff were brilliant and others were useless. Mum said she felt the GP had written her off and didn’t care. One night there was a knock on the door at 9.30pm. We were all tired and at this point I was sleeping on mum’s kitchen floor on a mattress. I didn’t answer the door but the GP posted a note through the door saying the blood results did not look good get her to hospital”

“There was another incident where we had taken mum to hospital and the A&E receptionist had told me to leave even though mum was confused and had sepsis”

“Services were not coordinated and no one seem to pass on information. I had to keep telling people about mum’s condition”

“Staff needed more care and compassion – carers that did come pulled mum about – they may have needed to do this but it was not explained to us at all”

“Yeah, it’s an absolutely difficult job. The original guy the original haematologist he saw at Scunthorpe...He was brilliant I thought he was great but we didn’t see him in the later stages he probably wasn’t his concern by then we only saw him right at the beginning when he was trying to work out what was wrong with him...Generally the consultants and nurses at Castle Hills were all exceptional they were just brilliant and he loved going there. He used to love it, it was a day out for him weirdly.”

Question 14

Have you heard of the Bluebell model or family voices? If so what was your experience?

**Please see the Glossary on page 37 for information about the Bluebell Model.*

This question was for those that had specifically experienced hospital services at the end of life so not all participants of the interviews had gone through this process. In addition, the Bluebell model was only rolled out fully in 2022/23 meaning that some of the participants, whose responses related to services provided before 2022/23, may not be aware of the model.

All relatives and family members who were able to answer this question, said that they were not aware of the Bluebell Model. One relative said **“No we have never heard of Bluebell”** and another commented, **“No it’s nothing more than a flower in the woods”**.

Some family members shared what their experience was like without the Bluebell Model in place. The Daughter of a patient explained her experience of collecting her Father’s belongings following his death. She told Healthwatch North and North East Lincolnshire:

“When going to collect my Dad’s belongings (5 days before Christmas 2021) as we were told that we had to wait 72 hours as they explained it had to be disinfected etc. I was

lead into the room where my Dad had passed away, to find his belongings left exactly where we left them. His clothes were where we last saw them, and I had to collect them myself. I was then handed his personal belongings in a bright orange bio waste hazard sealed bag, which felt so impersonal and clinical. All of my dad's personal things like his watch, just nothing more than "hazardous waste". "I was traumatised all over again".

Another family member said, "When Dad was admitted to hospital for those 3 weeks and he was on an end of life plan we were not aware of the bluebell model and dad only died a month ago".

Question 15

Overall, do you feel that the needs of the individual were met?

Healthwatch North and North East Lincolnshire received the following comments regarding whether the needs of the individual were met:

"No – we had to keep ringing people and asking for things. Mum was in pain at the end and that was horrible to watch just because services could not coordinate who was doing what. Even when we was trying to transfer mum to my house transport should have turned up at 2pm and we were already to go but they turned up in the evening. I phoned several times to be told there had been delays and they would be there soon"

"There was no sense of urgency even though I had told them mum was deteriorating"

"Absolutely not. We were left to our own devices with no support"

"My husband was trying to explain to the Doctor to not go by his bloods because he's had cancer twice and it didn't show up in his bloods. He got the stage when I got him there that day that he couldn't hardly walk he was in so much agony with his back. This man said 'no I'm going to send him for a CT scan, it's a kidney stone and I will see him in a months' time. And I was sat there thinking 'you won't see him in a months' time, he won't make it' because my husband was complaining and he never complain[s]. My husband was saying I am in pain/agony he'd had me to the doctors with him 3 times and up to the hospital twice. The doctor himself had said this was urgent in his referral and yet this consultant was dismissing him and we went home and my husband said 'he thinks I am making a fuss' and my husband tried to ignore it. I think that was the Tuesday or the Wednesday as we were leaving, in fact the nurse actually said to him (the consultant) 'this lady and gentleman are really anxious can I make it an urgent CT and he said 'NO, its just a kidney stone' and as we were going out the door she took hold of my arm and stopped me and said 'if you are worried, please bring him back to A & E' and on the Saturday I took him back to A&E and Dr xxx on A&E said 'If you had left it while Monday, [he] would have lost both kidneys' and that was the start of our experience with that particular department and it never got any better"

"yes, but I would say that more so with the community side of things, the nurse coming to the house etc. and at the actual cancer ward. When he had that seizure and he ended up in A&E and everything, obviously there was a real disconnect with the fact that you know. There was me... I'm a confident person who has had a reasonable amount to do

with the Health and Care services in my professional and personal life to know how to speak to people and how to get what we need. But if I hadn't been there we wouldn't have done and I saw that so many times when we'd be in the ward, waiting to see somebody or whatever, and there would be a couple there one of whom was obviously had some form of cancer and their partner, wife, husband or whatever and they were often quite elderly and you could see that they, when people came and spoke to them, you could see that they didn't know what was going on. They didn't know what questions to ask let alone what was actually being said to them and I actually felt quite strongly about the fact that if you're reasonable educated and reasonably savvy about and experienced about these things then you're fine but if you haven't got any of that you know and a lot of the time these were well meaning medical professionals but I don't think they could get their head around the fact that the language they were using just **didn't make sense to a lot of people**". Later the interviewee mentioned other services that dealt with conditions the person had **"that seems to be where it fell down"**.

Question 16

If you were involved in withdrawing treatment then did you feel you received all necessary information and support?

No service users or their families had any experiences of this to share with Healthwatch North and North East Lincolnshire.

Question 17

How well supported were you following the death of the person being cared for?

The following responses were received:

"We were not supported at all, we went through this alone and I would not want that to happen to anyone else"

"Community nurses asked if I would like support but I did not feel I needed it and I volunteer at the Carers Support Service"

"I had no help after my wife passed at all. It was as though we didn't exist"

"I knew because of my job about tell us once, I just did all the paperwork. It saved me having to ring anything other than the private stuff, state things were done. It was just the practical things we got on with, not thinking about what we needed. I found it harder caring for him and him not knowing me, rather than when he'd gone. None of it was easy. But there was almost the relief that someone isn't struggling"

"Nobody supported me at all. All I got was what was on the death certificate, I never even knew she was suffering from renal failure until I got that. She had passed away, Funeral Directors were good"

"You know they were 'we're really sorry blah blah blah' which is understandable but nobody said is there anything we can do or do you want any assistance, can you manage"

One relative stated that following the death of his Wife, he felt there was no support or comfort offered, and said, **"It was all so 'this is what's happening, this is what happened, off you go, enjoy the rest of your life'". It seemed like that's what they do every day so it is just something that happens, whereas for me it is the one and only wife I have ever had"**

A husband of a service user said **"I knew she was going because she had said so, 'I've had enough' but it's just that 'are you alright?'; is there anything we can do for you? Do you need anything? I would have probably turned round and said no I can manage but the point is, to the best of my recollection nobody actually said 'do you need any support or anything like that'"**

Another service user said that after their husband had died **"they (hospice) contacted me and invited me to a counselling appointment and then to a bereavement group. I just went once but it wasn't for me so, but it's good to know that's there"**

Question 18

What could have been done better or differently throughout the journey?

The following suggestions were received by Healthwatch North and North East Lincolnshire:

One service users daughter feels that if someone had phoned her every day in the last 10 days and just asked if she had everything she needed or if there was anything she needed to know that would have helped enormously.

Another service user's family said **"People to care and for mum not to feel like she had been written off and that she hadn't been left in pain"**

"Services to communicate better and to have things when you needed them, we wanted to care for mum but needed some support to carry it out"

"Better communication between services. Dad did not need to be in hospital for his cut on his head, dad did have DNAR in place and did not want to go to hospital unless it was for a course of treatment. We do not understand why he ended up there"

"Someone just to care enough to support us"

"The first time I phoned up, somebody somehow must have crossed wires because I said I'm from Scunthorpe blah blah blah , they said 'oh we don't cover that area' and it wasn't until early last yearthat I thought this is ridiculous so I got in touch with them and they gave me a lot of advice and they were very helpful.....and they said 'of course we do'. That was it"

A lady who's Husband had terminal cancer, was suffering with severe haemorrhoids and was left untreated due to her feeling like health care professionals were not treating him for anything other than cancer. She said, **"You've only got to say cancer and then can't have anything else wrong with you. You know well you're in pain I know it's in your head"**

or foot but they just jump straight to *'it must be the cancer'* and that's just what they did with my Husband"

One interviewee said what would have been good was "Just knowing that you could drop somebody email if you were concerned about something would just be brilliant but you couldn't you know you had to try and get hold of people on the phone if you were lucky, a lot of the time you would have to leave messages and they would get back to you...In terms of the hospital you couldn't get hold of anyone to speak to you there." The interviewee commented on the office for receiving bridge tickets at Castle Hill Queens Centre, which if improved would create a better experience for service users. **"The office that you had to go to for that were absolutely awful they made you feel like this was such an effort to give you these tickets and we need to see proof of this and proof of that and what do you mean you can't give us the proof, they were just dreadful and I had a go at them one day...and I thought if you're not assertive and confident like me again that would have been at point at which, you know. Some really quite rude person sitting the other side of a piece of glass who was not dealing with people's needs very effectively but you know that's not necessarily their fault it's the way they have been trained or not trained in this case."**

Feedback – Focus Groups

Way Forward Group – North Lincolnshire

We attended the 'Way Forward Group' held on Tuesday 23rd August at the Carers Support Service in Brigg. There were eight participants in attendance. The group did however pass on the views of other members of the group and friends thoughts and views on the end of life pathway.

The information received from the group has been categorised under the questions used in the interviews to allow for comparisons and correlation of data, the following responses have been received: --

Question 1

When was your loved one diagnosed as terminal?

This question was expanded upon with by staff of Healthwatch North and North East Lincolnshire, staff asked, when yourselves and your loved ones were first told about it being end of life was everything explained properly to you?

The group consensus was no

Question 2

Where were they residing when they passed away?

"He did not have dementia he had complex physical and neurological things and he was in a care home"

A lady in the group explained, **"I think it was just common sense were I was concerned because I knew my husband had had a second stroke and I knew that he didn't want to**

die in hospital so I asked them, well I brought him home anyway and he died eight days later”.

Question 3

Did you feel that the team looking after the service user personalised the service to take account of the patient’s individual needs?

A lady said “I did find it very difficult to get anything at all from Social Services or from the hospital. Like I wanted one of the [beds] and I couldn’t. They gave me one of these water bed mattresses and it was the district nurse who came in five days before he died that managed to get him a bed”.

Another lady said, “You’ve really gotta be tough cause when my husband. He was paralysed and they wanted him to have an ordinary bed. Well he was paralysed from the waist down. And I knew a nurse in the midlands and she had contacts there and err they said don’t have him home tell them you used to have him home until he got that bed and just stick to it don’t give them an inch and that’s what we did”.

Question 4

Whilst the person was receiving end of life care do you feel that records were kept up to date?

This question covers all plans; including care plans, Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) and Electronic Palliative Care Coordination System (EPaCCs). The answers provided also cover what impact it had on the individual if care plans were not kept up to date.

A wife of a service user said “when he went into the Care Home they started a file that asked me if he had a will, they asked me if he’d done power of attorney, which we had done and they also did a Do Not Resuscitate form as well”

Another lady said “we had a DNA paperwork set in place. I think it was either initiated by the GP or Lindsey Lodge and it was really helpful, my husband had a dread that if something happened he would just live life wired up to machines so we’d passed all his concerns on and it did work well, very well with the ambulance service because he didn’t want resuscitating there was one night, because we had oxygen and everything at home and something new happened that he’d never had and I thought that the ambulance service would come and their remit would be to get him into hospital, but it wasn’t, once they’d seen the paperwork they stayed, they helped with everything, they set a few things up with the district nurses and that and they were absolutely brilliant”

A lady said “- The doctor came to the care home, for my husband, and at the time if I said I was having it done he’d agreed and that’s how we got DNA, we both signed and that that was the end of it”

A lady explained that when “somebody is deteriorating if you have all that in place then the doctors knew and they said to me it does say do not resuscitate and I said yes that’s what he wanted and that’s what we agreed. The Doctor then said ‘if he did lose consciousness well if he lost his breathing we won’t be resuscitating him’ I said that is absolutely fine. In fact he went back and died in the home the next day”.

A lady explained that the documents and care plan were in place that when he was admitted to hospital from a Care Home the paperwork had gone missing. She didn't know if it had gone missing at the hospital or whether the Care Home hadn't sent it but due to this she felt her husband had had a horrible death in Scunthorpe hospital.

A member of the group had the care plan etc. in place for her husband but wasn't sure if she should take it with her to the hospital or whether it was on a computer system.

Members of the group described the ReSPECT or EPaCCS systems as just the DNAR and did not see it as a whole process.

Question 5

How involved were you with any care plans?

A lady said **"the other thing is like when we did forms at Lindsey Lodge they also want to know would he want pain relief?, would he want antibiotics? Sort of like a step thing. So it's not always just resuscitation cause he did want antibiotics and pain relief"**.

A lady did share her experiences and went on to say **"it shouldn't depend whose on, it should be a plan to follow for everybody shouldn't it"**. This comment referred to staff who were working and that everyone should work to the same plan.

Question 6

How involved were you in the RESPECT process?

"It was so helpful having done all that when he was in hospital I remember the doctor rang me in the middle of the night and said 'we have in our possession, from the home, all your documentation including his DNR, and we just want to confirm that that is what he signed and everything and I said yes and I think if he hadn't gone into a home I'm not sure whether we would have done that?'"

A lady said **"what is so important I found is that he agreed as well so that when it came to it, it wasn't just my decision, it was his"**.

A member of the group said, **"We discussed everything about getting power of attorney but we'd never discussed that, I'd covered everything else but I never thought about DNA"**.

A lady explained that the Care Home had spoken to her about the process, and that the Care Home had said **"if he dies here you may not be in a state to make that sort of decision"**. The lady went on to explain that due to it being explained that the DNA was put in place earlier as she was aware that if a Doctor was called they would try to resuscitate.

A member of the group explained that her and her husband were both involved in the process and that they had both signed the paperwork.

Question 7

Do you know if Liberty Protection Safeguards were put in place?

No members of the group commented on Liberty protect Safeguards.

Question 8

Did a fast track continuing care assessment take place?

Question 9

If you provided personal care did anyone explain what caring for someone at the end of life was like?

Question 10

Did professionals recognise any developing symptoms or act on concerns raised by yourself or others? If so were adjustments made in a timely manner? Were adjustments made to medication quickly?

The only response to this was the group saying, **"Yes that's right"**.

Question 11

What was your experience of being guided through the process?

"We all have different experiences".

Question 12

How well informed were you about what services were available? Did you feel anything was missing?

Members of the group shared that they had not been given information, they had picked stuff up as they had gone along.

A member of the group said, **"before I joined Way Forward I came here for some courses, at the Carers Centre and we had a course, which was called, the death café or the dying café but it's a set course and they gave us all?"**

A couple of other members of the group, also said they had been on a course.

Question 13

Thinking about the professionals who looked after the person being cared for, were they helpful, compassionate, friendly, etc?

One Lady said that **"We had support from Macmillan nurses, Lindsey lodge, palliative care everybody and they were all spot on"**

Another lady said **"Well I always found the ambulance service to be very good because often I had to ring the ambulance which they'd had asked me to do because my husband would fall. He thought he could do what he couldn't and he would fall and I would ring for the ambulance and they would come with the blow up thing and get him up that way and they were always excellent"**.

A lady said regarding the care her husband received, “- **he was on a syringe drive for quite a time, this was the eighth time so that was the big difference but he did also have that at home with the district nurse help and I couldn't fault any of that they were absolutely brilliant**”.

A lady said “**When my husband was in Castle Hill because he had a double heart bypass and then went to sleep came round all right and was talking and then he had a stroke and then these things follow, like Parkinsons and, apparently it's all combined, and they were absolutely marvellous**”.

A lady explained that her husband was in Castle Hill and then was transferred to Hull Royal and for five and half months she was travelling over the bridge to Hull, “**they were really good, at Hull, they got him walking; the physio therapist there were brilliant**”.

A lady shared her experiences, “**everybody was poorly on the stroke ward at Hull Royal but the physios used to come in and they were all cheerful and I mean there was times when my husband wouldn't move. He got depression and, you know, and they were lovely and they came in and said what's your favourite song and they get it, they were lovely**”. Her husband was then transferred back to Scunthorpe General Hospital, “**at Scunthorpe it was a different mater you didn't see the physios on visiting times**”

A lady said with regards her husband's care “**I think my husband was in Stepping Stones at Scunthorpe and I've got to admit the occupational therapists and the physio therapists was brilliant with him. The nursing staff, I had so many disagreements with them, they couldn't have cared two hoots**”.

A lady explained, “**For me personally I can always remember this ward sister and I think she dreaded me walking down to see her because she knew I was going to be asking questions and everything but I wanted to know what medication my husband was on and she wouldn't tell me and I just stood my ground and I said I've got very right to know what medication my husband was taking and what he isn't**”. The lady explained that he had gone into hospital due to a seizure and then when he returned home, “**they sent him home with the wrong medication, and if I hadn't of known what medication he was taking I would have given that to my husband**”.

Another lady agreed with this statement and explained that had also happened to them. Somebody in the group also said that this had happened to her husband but that it was a few years ago and it was in Hull. The lady went on to say “**but it seems to be very much that there's good and bad stories about everywhere and I know a lot is to do with the economy but it shouldn't be down to whoever's on that day**” and “**it shouldn't depend whose on it should be a plan to follow for everybody shouldn't it**”.

Question 14

Have you heard of the Bluebell model or family voices? If so what was your experience?

None of the group have shared any experience of this.

Question 15

Overall, do you feel that the needs of the individual were met?

None of the group shared any personal experiences of this

Question 16

If you were involved in withdrawing treatment then did you feel you received all necessary information and support?

None of the group shared any experiences of having to do this.

Question 17

How well supported were you following the death of the person being cared for?

The group feel supported by the group and have shared information.

Question 18

What could have been done better or differently throughout the journey?

The comments received identified other areas where members of the group felt that systems had failed or did not work in a joined up way.

A lady commented that **“The problem was that I had with the computer systems in hospitals don’t speak to each other. So Scunthorpe can’t speak directly to Hull”**. Other people within the peer support group agreed with this statement.

Another lady said **“Which is ludicrous when we signed over to say our information can be held by a national health service”** and **“There was a terrible mix up with my husband’s drugs being transferred from Scunthorpe to Hull”**.

A lady explained, **“it was like my husband had his stroke when he was in the Lake District so they took him into Lancashire hospital and when they transferred him 9 weeks later into Scunthorpe nobody could find any of his files or anything. There was no communication between Blackpool and Scunthorpe at all”**.

A member of the group suggested, **“maybe it’s more of a personal thing than a provider issue is maybe that could be encouraged – that as people get towards the end of their life their family, and it is painful to do, can sit down and discuss because when I mean it’s very distressing towards the end to be then said Well you know Would they want resuscitating?”**

A lady explained that her husband had had bone cancer and they had had to ring an ambulance. At the time her husband had to use a hoist to get in and out of bed. The lady had to hoist him by herself as the carers were not there at the time. She explained she was struggling to hoist him on her own but the ambulance men couldn’t help her as they said they were not allowed to assist. This she feels could have been different as **“what about road accidents, surely they’d be lifting them?”**.

Way Forward Group – North East Lincolnshire

The group meet on a monthly basis at a local Wetherspoon’s in Grimsby Town Centre. The group is facilitated by the Carers Support Service and staff from the Carers Support Service are on hand to answer any questions that members may have. The group is

based on a peer support model and supports members for 12 months after their loved one has passed away.

The group discussed their experiences of the end of life pathway and the support they received. Two members of the group spoke to Healthwatch North and North East Lincolnshire outside of the group and gave individual interviews.

The group discussed the support they received after their loved ones had passed away, they did not feel supported and they were just left to it. One gentleman said **"I had nowhere to go and nowhere to turn to"**.

Another gentleman said that **"nobody professionally spoke to me about her wishes or will etc."**.

The group also explained that they were unprepared for the cost of the funeral and several members of the group said they had used savings to pay for the funeral, **"her savings covered the funeral costs"** and **"remaining savings that my wife had left all went towards the funeral costs etc."**.

Within the group the members loved ones had either passed away in Care Homes or at home. For those that had passed away in Care Homes there were positives and negatives, none of the members of the group had stated whether being in a Care Home was the choice of the service user.

The group explained that some Care Homes were really good and sometimes they felt that the care received was not so good. One gentleman said **"she was being cared for in Cranwell Court, the care at Cranwell Court was excellent"**. The gentleman went on to explain that they moved his wife from Cranwell Court due to her having several falls and Adult Social Care got involved so his wife was transferred to Eaton Court Care Home. The gentleman felt that his wife had gone downhill once she had moved Care Homes.

With regards personal care of loved ones on the end of life pathway, one gentleman explained that a nurse came once a week to apply cream and change dressings but apart from this they had no other support. The gentleman was caring for his wife who had been diagnosed with chronic lymphocytic leukaemia.

The Forge Project – North Lincolnshire

The services users who access the Forge Project shared their views with members of staff, who then in turn shared them with Healthwatch North and North East Lincolnshire.

Manager at the Forge Project explained **"as our service users are quite transient and have complex needs/chaotic behaviours they don't always follow the same pathways into health services as usual. Some of the service user's journeys are not known to us"**.

The Manager of the Forge Project explained that one service user's sister cared for him towards the end of life. The manager said **"He lived on the streets for years and was given a long-term tenancy during Covid-19. He found this very unsettling as he had slept rough for many years and was a frequent attendee at The Forge Project. He was a substance misuser and sometimes our service users do experience health inequalities. He had difficulty getting a diagnosis as he was passed from the dentist and the doctor and when he was eventually diagnosed with mouth cancer it was very late"**

stage. He was a quiet person and it was felt that because of his lifestyle there were no appropriate pathways. He found it difficult to sleep in a bed and when he passed away his sister found him in the middle of his front room”.

The Manager of the Forge project explained the circumstances for another service user **“Another service user had been suffering from cancer two year's previously and after been told that she did not have cancer any more was found dead in a squat in Scunthorpe. Again substance misuse is always prevalent with some of our service users and they do not generally approach healthcare services. We are not sure how this service user died but she was not under medical care at the time of her death”.**

The Manager of the Forge project also explained with regards another service user **“Another service user had cancer for many years but did not access health services. He abused both alcohol and drugs. Like many of our service users he kept going until he expired”.**

These were four specific cases of service user of the Forge Project needing end of life support. The Manager further went on to identify issues for the service users and identify general concerns with regards accessing health services.

“Some of our service users do not have a GP although this has been better over the last couple of years”. The Manager also stated that “many of our service users die suddenly and it would appear that the cause of death is usually substance related, through natural causes or they experience a violent death. Often substances can mask underlying illnesses and often because of their behaviours it is not appropriate for some of our service users to go into a hospice. Many could need end of life care but this has been masked by their unhealthy behaviours and lifestyle”. The Manager went on to say “many homeless people are discharged inappropriately onto the streets and do not access follow-up appointments due to no fixed abode”.

The Forge project are looking at ways to ensure their service user's health care is more coordinated in the future. They have recently employed a support worker who focuses on health and identifying pathways into health services for service users. The Support Worker has recently attended the NLAG Accelerated Discharge event and it is hoped that by promoting the service to departments within the hospital this will alleviate any inappropriate discharges in the future. The Support Worker is also considering the possibility of getting a GP practice or health services to come into The Forge Project thereby bringing healthcare to their service users.

This would allow for early identification of terminal conditions, ongoing support and ensuring that the end of life pathway is accessed and fits the needs of this specific group of service users.

Findings

Communication

Communication between services has been identified by service users and their families as being a priority. If this is right then the process runs smoothly, however if it is not right then the care packages do not happen or work or they did not receive care when they needed it most.

Examples of poor communication between hospitals has also been highlighted in the feedback received. This has sometimes resulted in a disjointed service for the service users.

Unpaid carers were not given information as to where they could access support and information for themselves and in some cases they felt stressed. Communication about the steps and when things started to deteriorate were not always communicated to families.

Care Plans/Documentation

The majority of services users and their families are unsure of care plans and the ReSPECT documents. Most of those Healthwatch North and North East Lincolnshire spoke to said that they cannot even remember seeing a care plan or what it contained. This needs improving upon as unpaid carers and their families need access to this information, with the permission of the service user, so they use it as a reference point throughout the journey. This would also improve communication between agencies as it is a living document and updated on a regular basis. The ReSPECT document would also have the wishes of the service user within it and if they are admitted to hospital or hospice the information would go with them.

However, when care plans and all the documentation was in place it did ensure that pathways were followed and correct treatment for the service user was received.

Some service users and their families are unsure of the process of electronic documentation and are unaware of whether everyone can see it.

Support for Service Users

For those service users who are homeless access to early diagnosis is difficult but also to end of life care, the hospice etc. may not be a suitable environment but neither is living on streets. In these circumstances terminal conditions can be masked by alcohol and drug mis-use and often continuity of care does not exist, due to this group of service users being transient and having no fixed abode.

Emotional support / counselling available for those on the end of life pathway and their carers is often lacking

Support for Unpaid Carers

The unpaid carers of those on the end of life pathway told Healthwatch North and North East Lincolnshire that they often felt forgotten about. The types of support that they felt they needed differed at differing points in the journey, practical support was often not

forth coming when they needed it most. In one of the interviews carried out a daughter of a service user asked for incontinence pads however they never arrived and she went out and got some herself. This could have been a simpler process, if they could not be provided then information for the family where to source they should have been communicated.

Having someone available to discuss concerns both within and outside of office hours would have been useful to many of the unpaid carers, especially where patients had chosen to die at home.

Next Steps

Healthwatch North and North East Lincolnshire will monitor the progress of the end of life Strategy and how it is working in practice.

The report will be sent to the End of Life Strategy Lead

Acknowledgements

Healthwatch North and North East Lincolnshire acknowledge this is a difficult topic to discuss and we would like to especially thank all of the participants and their families.

Healthwatch North and North East Lincolnshire would like to thank the professionals who shared their views with us.

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[End of Life Care • NHS North East Lincolnshire CCG](#)

Glossary

The Bluebell Model/Principles:

Northern Lincolnshire and Goole NHS Foundation Trust have introduced the Bluebell Model on several acute ward areas to encourage discussion and earlier identification of end of life. The Model provides staff with the skills and confidence to identify and discuss patients' end of life care needs. The principles of the Bluebell Model focus on better communication with the patients and family, recognising the signs of someone dying and developing individual care plans for each patient. According to the Trust, there are 68 End of Life Champions who have been trained to lead on the Bluebell Principles and support colleagues in their life.

Sundries available for people include: toiletry bag for relatives staying with a family member who is receiving end of life care, a door sign that can be placed on the door or bed of a person receiving end of life care so that staff know. A bag for the personal belongings of a loved one who has passed away and a ring pouch for their jewellery.

Please find below the Bluebell Principles.

The Bluebell Principles of End of Life Care:

B – be prepared. Having the Bluebell symbol displayed will help staff identify this patient is receiving end of life care and care can then be planned accordingly.

L – listen. Listen to the patient and their loved ones. Let them guide you.

U – understand. Try to understand patient's and loved one's worries and fears and why they make the choices they do in regards to their care – we may not share the same views but we can try to understand what is important to our patients.

E – empathy. We must treat our patients and their loved ones with empathy and kindness.

B – be available. Giving your time to a dying person and their loved ones is invaluable. If they ask for your time and support, give this to the best of your availability.

E – encourage patients and their families to tell you their story. This will give valuable insight into what is important to them and enable more personalised care.

L – liaise. Good liaison and communication is key. Liaise with the patient (if able), their loved ones and colleagues to update of any changes noted. Refer for specialist advice is required.

L – learn. We can all learn from every patient and family that we care for. Each one is individual and each can teach us unique lessons about life and death.

ReSPECT documents:

The ReSPECT process creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices.

Appendices

Appendix 1

Social media images for North and North East Lincolnshire



Social media Posts

Social media North East Lincolnshire



If you or a family member has experienced the End of Life Pathway, we would like to hear from you. Please telephone 01472 361459 or email us at enquiries@healthwatchnotheastlincolnshire.co.uk to arrange a time we can phone you.



If you or a family member has experienced the End of Life Pathway, we would like to hear from you. Please telephone 01724 844986 or email us at enquiries@healthwatchnorthlincolnshire.co.uk to arrange a time we can phone you.

Appendix 2

End of Life Care Project - Interview questions

Who is being interviewed? E.g. patient, carer or family member

.....
.....

Date of the interview

.....
.....

Location of the interview (for example, face to face at HW offices
or over the phone / via zoom etc.)

.....
.....

Has the service user passed away or are they on the End of Life
Care Pathway?

.....
.....

Information we have already been informed about from referrer if
applicable

***Please note the questions have been worded as though it is a carer or family member providing the information. However, the questions would be tailored a little more depending upon who was answering the questions and the relationship to the person cared for.**

***The questions / prompts will need to be tailored by the interviewer as the conversation progresses. It will depend upon individual circumstances, for example, if a person was only young when they died they may have had other impacts such as the impact on**

dependent children / financial implications. There may be other differences for example: someone's experiencing terminal illness compared to progressive aging or progression of a long term condition.

Before we start, this is entirely up to you but would you like to tell us a little bit about the cared for person? (Icebreaker) Prompt questions / Notes <i>Can I ask how old they were when they died?</i> <i>What interests did they have / do have?</i>	
Please can you tell me how far into their illness the person was recognised as needing End of Life Care / diagnosed as terminal? What conversations were had at that point with medical professionals? <i>(If a person was recognised as needing End of Life care later on in their illness was enough time given to record and implement their wishes?)</i> Prompt questions / Notes <i>Try to identify when the person / family found out it was end of life. Was this early on in the process or late on. If it was late on did this impact on</i>	
Where did (person's name) pass away? Were their wishes met? Prompt questions / Notes <i>Hospital / Hospice / at home / Care home</i>	
Whilst the person was receiving end of life care do you feel that records were kept up to date? Prompt questions / Notes <i>Could cover – end of life care plans and whether information was updated on the Electronic Palliative Care Coordination System (if known)</i>	
If not...what impact did this have on the person being cared for? Prompt questions / Notes	

Did it affect comfort? Did it affect medication being updated?	
How involved were you with any care plans? Prompt questions / Notes <i>Please ask them to be specific about what care plans they had involvement in, for example, Recorded Summary Plan for emergency care treatment RESPECT (useful in case people can no longer explain their preferences to healthcare professionals – it can help guide their decisions based on what the person being cared for wanted)</i>	
Questions Specifically around RESPECT (For Carers) - How involved were you in the RESPECT process? (if not answered above) Did the patient understand the process? Do you feel that it accurately reflected the patient's wishes? When was RESPECT put in place (at what point of the service user's journey?)	
Was it ever updated? Did you feel it should have been updated? How accessible was it by other medical professionals throughout the journey?	
(Tailor this question to the care plan stated in the question above) How would you rate the care plan on a scale of 1-10? And please explain why Prompt questions / Notes <i>Did you feel having a care plan was useful?</i>	
Do you know if Liberty Protection Safeguards were put in place? Prompt questions / Notes <i>Legal safeguards that are put in place when a patient lacks capacity to consent to their care and treatment. It is needed in order to keep the person being cared for safe.</i>	
Is so... were all those caring for the individual aware.	

Prompt questions/Notes <i>E.g. Carers, district nurses, etc.</i>	
Did a fast track continuing care assessment take place? Prompt questions/Notes <i>If an individual's condition is deteriorating rapidly, they may be approaching the end of their life, and a "fast track" assessment may be needed to allow an appropriate care and support package to be put in place as soon as possible</i>	
Is so... what was your experience of this? were carers put in place to help with personal care? Were you asked to take part in personal care? Prompt questions/Notes <i>Including whether appropriate support and care was put in place in a timely manner</i>	
If you provided personal care did anyone explain what caring for someone at the end of life was like. Prompt questions/Notes <i>Did they feel pressured to provide the care? Where you given any training or guidance?</i>	
Did professionals recognise any developing symptoms or act on concerns raised by yourself or others? Prompt questions/Notes	
If so... Were adjustments made to medication quickly?	
If so... were these adjustments made in a timely manner? Prompt questions/Notes <i>Cover PRN medication Where was the person at the time? – hospital, hospice, at home (district nurse?)</i>	
What was your experience of being guided through the process Prompt questions/Notes <i>Basically did anyone provide support / help in understanding what the next stages were or why certain options may not be appropriate, for example, if someone wished to die at home but</i>	

there was a reason this could not happen Also where was this? - Care homes, hospital, hospices, etc.	
How well informed were you about what services were available? Did you feel anything was missing? Prompt questions/Notes Help may include about the condition / end of life care / help for carers, however, it may also include help for people with dependent children / financial assistance: Did you find information on nutrition? Where you informed about what benefits you / service user may have been entitled to? Did anyone mention lasting power of attorney? Where you informed about any support groups?	
Thinking about the professionals who looked after the person being cared for, were they helpful, compassionate, friendly, etc.? Prompt questions/Notes Including staff from care homes, hospital, district nurses etc.	
** FOR THOSE EXPERIENCING HOSPITAL SERVICES – Have you heard of the bluebell model or family voices? And if so what was your experience? Prompt questions/Notes Bluebell model – new initiative around improving communication with family members. The Bluebell model focuses on being available and having good liaison between staff and the family. Family will be supported through other things also, for example, tote bags will be provided for the patient's property after they have died (with the bluebell logo on). Family Voices - it's for those who want to raise concerns but don't necessarily want to talk to the nursing staff, for example, some people may think that nurses are too busy so issues don't get	

raised. Family Voices is a system where a diary is kept during the last three days of life – it's for the family to fill in how they think the patient is feeling, for example, are they feeling sick etc. Staff then pick up on the comments in the diary and initiate conversations with the family.	
Overall, do you feel that the needs of the individual were met? Prompt questions/Notes <i>Important to differentiate between need and what the person would have liked to have had</i>	
If you were involved in withdrawing treatment then did you feel you received all necessary information and support Prompt questions/Notes <i>Withdrawing treatment could include: nutritional support through a feeding tube dialysis – where a machine takes over the kidneys' functions ventilators – where a machine takes over breathing</i>	
How well supported were you following the death of the person being cared for? Prompt questions/Notes <i>Was any information provided for example a bereavement booklet from the hospital or information about how to register a death...If so who provided this</i>	
What could have been done better or differently throughout the journey? Prompt questions/Notes <i>For the person receiving end of life care and the carer</i>	

Appendix 3

Example of End of Life Advocacy

<https://advocacyfocus.org.uk/dying-matters/>

The coalition was set up in 2009 by the National Council for Palliative Care (NCPC) to bring about a fundamental change in society, where death can start to be seen and accepted as a part of everybody's life cycle – and not something we are afraid of speaking about – or planning for.

Feedback on the Report

The following response has been provided on behalf of the Northern Lincolnshire End of Life Steering Group:

"The Northern Lincolnshire End of Life Steering Group would like to thank Healthwatch for all the work that has gone into producing this report. This work has given us a different window into the experiences of people using services and enables us to

take the learning from it to inform the work we are doing. We are confident that our work will address the issues raised within the report including the importance of improving communication and our continued implementation of the electronic systems to share information between services and the roll-out of documents like the ReSPECT form. Our work has also already included the development of a new 24 hour helpline which has been piloted in North Lincolnshire during 2022, and work in the hospital called the Bluebell project which aims to identify patients who require end of life care.

The Healthwatch report has also provided us with areas we can improve on including how we make information available to patients and families about existing services and how they can access them. For example, The Carers Support Centre in NE Lincolnshire is where families who might be unpaid carers can go for support, advice and signposting, and we should advertise this more than we have done. The Steering Group is very grateful to the people who contributed to the work and for Healthwatch bringing this together into a report."