Dignity in death: people’s experiences of end-of-life care in Devon

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1. Executive summary

Devon has two Clinical Commissioning Groups (CCGs): Northern, Eastern and Western Devon CCG (NEW Devon CCG) and South Devon and Torbay CCG (SDTCCG).

The map on the right shows the four geographical areas of Devon and outlines which CCG is responsible for which area.

A CCG’s role is to commission services for the local population that are cost effective, responsive and of a good quality. The Devon CCGs are responsible for monitoring the cost effectiveness and quality of these services through contract monitoring processes.

One of the ways CCGs monitor the quality of services is through direct feedback from patients, public, staff and stakeholders.

This feedback could be received through formal complaints, informal enquiries, patient advice and liaison service contacts or serious incidents. Using the views gained from feedback we can then begin to see if there are areas of poor quality or poor experience that need further integration or exploration.

Between April 2015 to August 2016, South Devon and Torbay CCG received a number of formal complaint and informal feedback in relation to people’s experience of end-of-life care in the area. As a result of this feedback, we wanted to understand if this reflected the general experience of people using end-of-life services. We joined with NEW Devon CCG as this was an important area for both organisations to understand more about.

Dying and end-of-life care can be a difficult subject to talk about, but we were keen not to shy away from this topic and understand the experiences of people no matter how difficult these might have been. The National Institute for Health and Care Excellence (NICE) defines end-of-life care as care provided to people who are approaching the end of their life. This includes adults who die suddenly or after a very brief illness.

Generally speaking, people are approaching the end of their life if they are likely to die within 12 months or have a terminal diagnosis and advanced, progressive, incurable conditions or those with life-threatening acute conditions. NICE has a quality standard for the provision of end-of-life care for adults that is applicable to all settings and services in which care is provided by health and social care staff to all adults approaching the end of their life. The quality standard can be downloaded from the NICE website: www.nice.org.uk/guidance/qs13.
2. Process

Linking with key stakeholders (such as Healthwatch), provider organisations, hospices, patients, family members and staff, we developed questions based on the themes outlined in formal complaints and informal feedback received.

Between August and October of 2016, these were refined and taken to various boards, including the End-of-Life Strategic Board and the quality committees of both CCGs, to ensure the questions were focused on the right issues and to get the best possible results.

We developed two versions of the survey: one for patients who are actively receiving end-of-life or palliative care and one for relatives, carers, family and friends. This was so that we could seek the opinion of patients and those around them, as experiences can differ.

The survey ran from 1 October 2016 to 1 April 2017.

To receive a high response rate, the survey was made available online via both CCG websites, with links to the survey on other organisations' websites. Paper copies were provided to staff who visited patients at home, bereavement support organisations, GP surgeries and other key sites.

We also visited people who wanted to share their experience but were unable to complete the survey. Alongside this we ran a newspaper article and a social media campaign on Facebook and Twitter and spoke at a number of internal and community meetings to promote the survey.

During the survey we had a number of patients and families that came forward to share their experience more generally and we have included two cases studies within this report (with their permission) to provide context and to demonstrate some of the experiences more broadly. The case studies can be found in Appendix 1.

3. The results

The survey was answered by 155 respondents. One hundred and ten of these completed the survey online, with 45 completing paper copies. All answers are anonymous and responses cannot be identified to individual level. Respondents had the choice to leave contact details if they wanted to.

4. The questions

Demographic questions
Nine (5.81 percent) people who completed the survey identified themselves as a patient receiving end-of-life or palliative care. One hundred and forty-six (94.19 percent) people who completed the survey identified themselves as a relative, friend or carer of someone who is or was receiving end-of-life or palliative care.

We asked respondents to let us know which area of Devon they were from by entering the first part of their postcode. There was a wide spread across Devon and further afield. One hundred people gave their area as follows:
Dignity in death: people’s experiences of end-of-life care in Devon

There were five responses from outside of Devon or further afield. These were from the following postcodes:

BA22 (Somerset), BS5 (Bristol), EX23 (Cornwall), IM1 (Isle of Man), PL12 (Cornwall)

We asked respondents to tell us which service(s) their feedback related to. One hundred and forty-seven out of 155 respondents answered this question:

Please tell us which services the feedback relates to:

- Hospital: 77
- GP Surgery: 22
- Hospice: 29
- Community Nursing: 29
- Care / Residential Home: 44
- Out of Hours Doctor: 10
- Ambulance Service: 13
- Community Hospital: 17
- Other: 1
- NHS 111 (Non-Emergency Call Centre): 1

Patient questions
For patients who were actively receiving end-of-life care, we asked 10 questions focusing on communication, choice and information during the care that they are currently receiving. All questions had a number of options and the ability to leave comments. None of the questions were compulsory and some people chose to leave comments only.
Of the nine respondents who identified themselves as a patient receiving end-of-life or palliative care, only three answered these questions. None left comments.

1. Do you feel you were given enough information to know what to expect during the care you are receiving?
   - Yes 1
   - No 2
2. Do you feel that you and your relatives or carers are involved in decisions about care and symptom control?
   - Yes, I feel that we are all fully involved 0
   - I feel that we could be more involved 3
   - No, I don’t feel that we are involved at all 0
3. Do you feel that you could ask questions or seek advice if you needed it?
   - Yes 1
   - No 2
   - Sometimes 0
4. Do you feel that the healthcare professionals providing care treat you with dignity, compassion and respect?
   - Yes 2
   - No 1
5. Do you feel that healthcare professionals know and respect your wishes?
   - Yes 2
   - No 1
6. Are you receiving care where you want to receive it, for example, at home?
   - Yes 1
   - No 2
   - N/A 0
7. Have you communicated a preferred place to die?
   - Yes 1
   - No 1
   - N/A 1
8. Overall, are you happy with the care provided?
   - Yes 2
   - No 1
9. Please tell us what was good about the care received.
   - No comments received.
10. Please tell us what could have been improved or done differently.
    - No comments received.

Friends, relative and carer questions
For friends, relatives and carers, we asked 10 questions focusing on communication, choice and information during the care that the patient received or is currently receiving.
All questions had a number of options and the ability to leave comments. None of the questions were compulsory and some respondents chose to leave comments only. A selection of comments that respondents left accompany the question responses. All the comments received as part of the survey, whether or not they directly relate to the questions asked are included in Appendix 2.

Of the 155 people who completed the survey, 146 (94.19 percent) identified themselves as a relative, friend or carer.

1. **Has your loved one passed away?** Responses: 112
   - Yes: 100
   - No: 12

2. **Do you feel you were given enough information to know what to expect during the care your loved one received?** Responses: 106
   - Yes: 63
   - No: 43
   "We were supposed to receive monthly support calls from the community nursing team. These calls never happened."
   "Not at all. Ambiguous language used. Different family members received different messages. The severity of situation was not portrayed. This would have made a huge difference. Patients wife particularly. Everyone expected my generation to receive info and inform wife on their behalf. She deserved to hear things first hand and be able to ask questions."
   "We were guided step by step through the process. Any/all our questions were answered in an appropriate manner and our understanding was checked."

3. **Do you feel that you can ask questions or seek advice if you needed it?** Responses: 108
   - Yes: 66
   - No: 10
   - Sometimes: 32
   "I tried asking questions to the people who came to the house to administer drugs but they were busy and had little time but what time they had they tried to help"
   "Always via Hospice and Marie Curie, and GP surgery etc"
   "Though one did not always have the sense they were welcome."
   "I was encouraged to ask questions and given every opportunity to contact those who could give advice."

4. **Do you feel that the healthcare professionals providing care treated you and your loved one with dignity, compassion and respect?** Responses: 105
   - Yes: 88
   - No: 17
   "At all times the healthcare professionals were fantastic with how they dealt with us."
   "Yes for the most part but some instances were awful and the NHS totally let us down."

*Dignity in death*: people’s experiences of end-of-life care in Devon
"I genuinely do not know how we would have coped if the hospice hadn’t been there. In fact they enabled my wife to die at home which was what she wanted."

“Yes and No. Nursing Home left family member on own and were neglectful when she fell out of her bed twice. Little things to make her comfortable in her time spent there before she died were lacking.”

5. Do you feel that healthcare professionals knew and respected your wishes and the wishes of your loved one? Responses: 106

| Yes | 78 | No | 28 |

“They didn’t want to find out.”

“The ward staff, treatment team and Occupational Therapist were prompt and efficient in arranging equipment etc. but the organisation of the care package and the review of that, and proposed change after such a short time when my friend was not going to get better, were distressing and unhelpful.”

“Yes except for the Out of Hours GP who was totally disrespectful of my father’s fears - a message saying that an illness is terminal does not mean no care is to be given.”

“All of our wishes were discussed and met by everyone involved.”

6. Do you feel that your loved one is receiving/received care in their preferred place, for example, at home? Responses: 105

| Yes | 71 | No | 28 | N/A | 6 |

“Thanks to the charity hospice, we got a chair, mattress and other aids at home and then my husband went into the hospice to die. He was involved in the decision at all times.”

“He is now, there are still on-going issues around seemingly non-existent care provision, but at least he is at home.”

“After being discharged from Exeter then NDDH, my mother came back to the village for a few weeks then came home and received excellent are from Palliative care nurses.”

“NHS couldn’t wait to get mum out of hospital quick enough.”

7. Has your loved one communicated a preferred place to die/did they die in the place they wanted to? Responses: 106

| Yes | 63 | No | 39 | N/A | 9 |

“Wanted to go to a hospice. Instead he was in room on a ward. A room that people get moved to die. It’s pokey, no natural light and very small”

“He never verbally said where he wanted to be but he said he wanted to go home (therefore we assumed that was where he wanted to be) due to his rapid decline it was not meant to be.”

“My parents were in denial about how quickly mum was going to decline, and I think that they did not want to put a proper plan in place.”
8. Overall, are you happy with care provided to your loved one? Responses: 101

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“Communication has been terrible and staff are very defensive when questioned. In the early days after his admission, the care was not good; staff attitudes were poor and mistakes were made with drug administration on several occasions. Once he moved to a different ward, the day to day care by staff on the ward was very good and my father was full of praise for them.”

“110% happy”

“Overall clinical needs received attention. Mental, emotional health not attended to by the NHS. Private care and visitors vital.”

“Father resists having the level of care he needs.”

9. Please tell us what was good about the care your loved one received. Comments: 86

“Everything. I got my husband home for his last 4 days and received wonderful care from Bay Care. Care at Torbay and Dartmouth hospitals was great. I and my husband were well looked after by staff.”

“District Nurses were fabulous. Gentle, caring and professional.”

“It was delivered in a personal way, especially in the ELF chemotherapy Unit at the RD&E and the Hospice, not just to my daughter but to the rest of the family. Nothing was too much trouble.”

“Paramedics and ambulance personnel brilliant.”

“Struggling on this one! I suppose at least she wasn’t constantly moved and she did manage to die in privacy, although no one knew when she died because this happened overnight and I had gone home exhausted to see to my son. We had a phone call first thing you say she had died sometime overnight.”

10. What could have been improved or done differently? Comments: 88

“COMMUNICATION TO FATHER AND FAMILY. ‘What’s happening today?’ or ‘what’s going on?’ are frequent questions which should not result in the answer ‘I don’t know.’”

“A little more care could have been put into how mum was positioned in bed when we went into see her just after she had died - she just didn’t look “comfortable”.”

“GP surgery not particularly helpful. Very difficult to get a GP to visit most things done over the phone possibly the pneumonia may have been picked up slightly sooner had a go visited which whilst I appreciate would probably not have altered the outcome it may have reduced any discomfort my mother was feeling.”

“Letting the relatives know what is going to happen. No way ever transferring without letting the relatives know. Much more access to a doctor. Making sure a care plan was in place before my mother was discharged. Having the geriatric ward open.”
We then asked an additional six questions to friends, relative and carers about what happened when their loved one passed away. These questions focussed specifically on areas where the CCGs had received feedback via complaints and informal enquiries.

11. Once your loved one passed away, were you given time and space to mourn?  
*Responses: 89*

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“I had to deal with the normal family arrangements and grief and serious depression set in later. I was close to suicide on a number of occasions. I had to initiate getting any support and therapy.”

“The staff were very kind and bought us tea and coffee. We were allowed to say as long as we wanted to say our ‘goodbyes’.”

“Private room provided, time to spend with them after passing. At no stage were we rushed at all.”

“It is difficult to say goodbye when you’re aware the other patients in the surrounding beds. I was not happy with the lack of privacy in such a vulnerable moment. A blue curtain is neither soundproof nor sufficient. Especially when the other patients were making comments regarding his death (‘it’s a part of life’ does not provide any comfort, especially from a stranger).”

12. Once your loved one passed away, did healthcare staff explain what had happened, the next steps and provide you with contact details and information about how to ask further questions?  
*Responses: 84*

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“At the hospice I had already asked what would happen when he died. I was shown where he would go and what would happen. I had already chosen the funeral director.”

“The hospice did but no-one else even asked.”

“Provided with leaflet on next steps to take regarding obtaining death certificate etc.”

“A leaflet was handed to me.”

13. If you had questions following your loved ones death, were you able to raise them easily?  
*Responses: 77*

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“I know we could have asked the staff any questions we may have had. We were expecting his death and the 3 or 4 days before he died we were kept informed on what was happening.”

“I wanted to understand her cancer more, but still have no real idea other than it was rare.”

“We already knew most of it but the GP was excellent and it helped knowing it was always the same GP who had continuity.”
14. Were you able to receive a death certificate in a timely manner? *Responses: 92*

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15. If no, did you receive an explanation of when the death certificate would be available? *Responses: 15*

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16. Did you find that bereavement services were easy to access and available when needed? *Responses: 80*

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“*Yes but only because we understood the system.*”

“*What bereavement services.*”

“All help was given by funeral directors only, no support from NHS.”

“I eventually found a ‘bereavement’ office down a tucked away corridor within the hospital but no one could tell me what it actually was therefore and it was closed when I went there.”

17. Of the options below, what would you prefer to happen once a loved one has passed away? (rank in order of preference with 1 being the most and 7 being the least) *Responses: 82. The results below show the average rating of each option.*

- An immediate discussion with a senior doctor or nurse to talk about what happened (*Responses: 56*)
  
  4.9

- Time to come to terms with the immediate impact in private, but with the option to speak to staff the same day (*Responses: 68*)
  
  2.4

- A resource pack with useful contact details, information about support and practical advice (*Responses: 65*)
  
  3.1

- A helpline where you can speak to someone who understands what happened and is able to provide you with support and advice (*Responses: 62*)
  
  4.2

- The ability to speak directly to the senior clinician after the event in your own time either by telephone or face to face (*Responses: 62*)
  
  3.8

- A formal meeting with the clinicians involved after the event in your own time (*Responses: 61*)
  
  5.4

- A combination or the ability to choose any of the above (*Responses: 72*)
  
  3.1

**General questions**

We asked all respondents (patients and friends, relative and carers) respondents a further four questions looking at the NHS in general terms.

18. Generally speaking, do you think that the NHS provides a good level of care to patients at the end of their life? *Responses: 90*
19. Do you feel that the NHS provides enough support for loved ones, relatives, friends or carers when someone has died or is receiving end-of-life care?
*Responses: 89*

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“Yes but difficult to access if at home.”

“Only because legally they are not allowed to help people to die according to their wishes with patients views clearly stated while in sound mind.”

“Our experience is still on-going, and I’m not looking forward to dealing with the NHS again over Dad's care. It will be a battle.”

20. Do you think it is easy to get the right support or advice for patients or those caring for them at the end of their life?
*Responses: 93*

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“Depends on how good your GP surgery is.”

“Yes, but the NHS needs to ensure that it correctly signposts and encourages that patients and their families link into the support and advice available within the NHS and through different organisations”

“It depends on where you live.”

21. Do you feel that NHS staff are adequately trained and have the confidence and compassion to be able to talk to patients and those who care for them about death and what happens at the end of someone's life?  *Responses: 89*

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<th>41</th>
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“Some staff are excellent but most are not.”

“Unfortunately they are so stretched for time that they are unable to provide a sufficient amount of time to explain and console.”

“In general, I doubt all the NHS staff have these skills, though hospice staff are magnificent.”

“With my experience everyone was brilliant but perhaps other wards who are under more pressure E.g. Medical wards and A&E it is all about having time which I know upsets a lot of nurses who want to give the care but just can’t.”
5. Conclusions

Some clear themes for areas of improvement have emerged from the survey and the responses received, largely, these can be broken down into the following themes:

- Communication
- Training
- Staffing
- Funding
- Variation in care
- Time pressures
- Compassion
- Expectation setting

However, it is also clear that there are some hugely positive experiences of end-of-life care within Devon, such as how staff treat patients and their loved ones, relatives and carers and their dedication and compassion shown in most cases.

There will always be differences in approach to the way in which NHS staff and organisations approach end-of-life care, however a common, joined-up approach to sets of principles will remove some of the variation expressed within this survey.

6. Next steps and recommendations

Variation in care will always exist and it is necessary when responding to the individual needs of a patient depending on their clinical symptoms. The following 10 recommendations are made to the end-of-life strategic boards in Devon, to improve people’s experiences of end-of-life care.

1. Explore the viability of Devon-wide specific end-of-life training for all front-line staff that sets a minimum basic level of care and trains staff how to deal with end-of-life in a compassionate manner
2. Create a ‘one route’ feedback mechanism for patients, family members, friends and carers to feedback about their experience in end-of-life care and remove instances of ‘wrong doors’
3. Produce standardised Devon-wide literature to set expectations around what happens when someone dies, who to speak to if people have concerns and outline frequently asked questions, exploring the use of different media to promote this work
4. Consider longer, more responsive opening hours and wider promotion of bereavement services, with a clear offer of what they provide and the ability to access services online and via social media
5. Explore the creation of ‘bereavement suites’ within acute hospitals, providing a private space for un rushed, emotionally supportive environments for people who have recently lost a loved one in hospital
6. Develop a role of ‘end-of-life champions’ within each organisation who are able to support staff, patients and their loves ones, have expertise around end-of-life care and are able to provide practical and emotional support – these could be volunteers, clinical staff or administrative staff
7. Review the outcomes of the survey and ensure these influence end-of-life care strategy across Devon
8. Feed end-of-life experience into the Peninsula Improving Experiences of Care Network to ensure the voices of the patient and their loved ones are heard at a
commissioning level and can influence service development

9. Creation of an end-of-life resource page on CCG websites which can be linked to from other websites, giving clear and accurate information around end-of-life care in Devon

10. Link the results of this survey to the regional work on-going around the ambitions for palliative and end-of-life care in Devon

In January 2018, these actions will be reviewed and an update of the progress will be published.

7. Further information and contact details

If you would like to speak to someone about this report in more detail, or you would like to share your feedback about NHS services in Devon, you can contact the patient advice teams for Devon.

For North, East and West Devon, contact the Patient Advice and Complaints Team (PACT):

Phone: 0300 123 1672
Email: pals.devon@nhs.net
Write to: Patient Advice and Complaints Team
Freepost EX184
County Hall
Topsham Road
Exeter
EX2 4QL

www.newdevonccg.nhs.uk

For South Devon and Torbay, contact the Patient Experience Team:

Phone: 01803 652 578
Email: patientfeedback.sdtccg@nhs.net
Write to: Patient Experience Team
FREEPOST RTEZ-YHRC-RZKZ
Pomona House
Torquay
TQ2 7FF

www.southdevonandtorbayccg.nhs.net
Appendix 1

Case Study 1: Rebecca’s Story
Rebecca’s mum was in hospital, having been admitted as an emergency following a fall in her home. Rebecca couldn’t fault the care given to her mum during what was a very traumatic and stressful time, however she felt that the communication with her mother and her family could have been better; they were not included in discussions about what would happen when their mother was discharged.

Rebecca’s mother passed away a few days later and although everyone was very nice and compassionate, the family didn’t know what to expect when their mother had died and were not told about what to do, who they could speak to if they had questions or what needed to happen next. This left them feeling unsupported and added to their grief.

Case Study 2: Diary of a Lab Rat – Ellie’s Story
Click on the icon below to read Ellie’s story. This story has been shared with us with the kind permission of Elli’s family. Paper copies of Ellie’s story can be made available on request (see page 14 for contact details).

Appendix 2

Click on the icon below to see a summary of all of the responses that were received as part of this survey.