

Executive Summary

1.0 Introduction

NHS Newcastle Gateshead Clinical Commissioning Group (NGCCG) are undertaking a review of end of life services for adults in Newcastle and are developing an End of Life Strategy and Action Plan for Adults. As part of the review NGCCG identified a gap in evidence around people's experiences of end of life care and also their preferences at end of life particularly with regard to seldom heard groups. An engagement project took place between July and November 2016 which gathered the experiences, views and expectations of end of life care from people living in Newcastle. Patients currently on the palliative care register and people from five seldom heard groups took part. Within the latter group, both carers of people who had died within the last two years and people with no experience of end of life care services were targeted.

Two hundred and twenty-four people shared their views as part of this project:

- 8 patients and/or their carers who are currently receiving palliative care
- 147 people from Black and minority ethnic communities (BME)
- 31 people who are D/deaf or hard of hearing
- 22 people who are homeless
- 2 people who are blind and visually impaired
- 14 people who are living with a learning disability or difficulty

2.0 Findings

The findings discussed below are consistent with what is known about the general population in terms of what is important to people at end of life but this engagement has highlighted the scale of issues for seldom heard groups and added colour to the national picture. For example, there is already much information about the communication needs of the D/deaf community but the project has shown it is not just about hearing problems and issues of deference have also been highlighted.

2.1 Experience of end of life care services

For patients currently receiving end of life care, experiences were all very positive. They had support from caring, knowledgeable health workers, were able to be cared for in their own home and reported good communication between health professionals.

Furthermore, they all felt involved in decisions about their care. However, when explaining their response some people actually cited examples of being informed of decisions around their care or being able to ask questions about it. Whilst patients are clearly happy with their level of involvement and being mindful of the fact that it is not always possible to be involved in every care decision (nor will everyone want to) these responses could suggest a misunderstanding around what actual involvement in decisions entail as per the NHS Constitution.

Carers of 23 people who had died within the last two years (and one who was still caring for someone) reported a more mixed experience, highlighting positive aspects but also some key issues with the services they had received.

Communication

Communication between health workers and patients and their carers was a key issue for BME and D/deaf and hard of hearing participants. A lack of access to interpreters or

written information in a language other than English was identified with several examples highlighted where communication was impossible without family members being present to interpret information on the patient's (or carer's) behalf or carers having to lip-read what doctors were saying to them. This is concerning as these patients are not being offered the opportunity to be involved in their care or are only involved through the use of family members who are not trained and should not be expected to pass on complex health information to patients. Carrying out an interpreting role prevents carers from being able to be fully involved in decisions about their loved ones care and may, as one participant highlighted, be put in a position where they have to interpret very emotive information about withdrawing treatment to their own relative (the wife of the patient). This lack of communication support was evident in hospital and hospices and there was a belief amongst BME and D/deaf and hard of hearing participants that this would also be the case in care homes, resulting in their isolation. Sharing information about the communication needs of the patient with all care staff was also an issue as was a lack of support for carers who have communication needs and look after a patient at home.

Cultural needs

Services not meeting the cultural needs of patients and carers was another issue which arose. It was felt that there was a lack of staff awareness of the needs of D/deaf and BME patients and carers. For the former for example, there is a need to recognise a culture within deaf communities of deference to hearing people which often means they accept, without complaint, any services offered. For people from some BME communities, a lack of access to staff from the patient's community, a lack of support around their religious practices and a lack of same-sex staff to care for the patient and uphold their religious beliefs was reported. For example, in relation to faith needs, the family of one individual recounted having to "fight" to get a separate room in the hospital where they could recite the Quran to the patient.

Identifying patients at end of life

For one homeless person who was caring for a close friend who was also homeless and had drug and alcohol addictions, their issue was that the person was not identified as approaching end of life early enough and therefore no end of life care was received.

Awareness of end of life care services

The engagement has revealed a lack of awareness of what end of life care services actually include (167, 87.0% of participants) and this was most noticeable among BME participants.

Support for carers

Aside from communication needs, the engagement identified a gap in terms of support for carers after the death of their loved one; some said they received no support at all.

Recognition of next of kin/main carer

There were several examples where carers were overlooked or not able to get involved in decisions about the care of their loved one; for example, because a hearing family member was contacted instead or they were not officially recognised as such.

2.2 Preferences around end of life care

Discussing end of life care

Only 33 (15.7%) participants had discussed their wishes. This is not unsurprising however as much evidence exists which shows that death is still a taboo subject within

society and people do not like to talk about it; within this report people suggested it was too emotive a subject to talk about. Moreover, for some people it is simply not part of their culture or religious views to discuss these things. Other reasons for not discussing their wishes were because they had either never thought about it or felt that they were too young.

Place of death

When asked, almost half of people (45.8%) said that they would prefer to die at home; it is interesting to note that this figure is noticeably lower than the 70.0% of people suggested by the Dying Matters Coalition. A further 19.6% said that they had no preference about their place of death and 10.7% said they would want to die somewhere else such as their country of birth or at “Allah’s will”.

Other wishes

A peaceful and respectful death was most commonly mentioned. BME participants also wanted care from staff of their gender and if possible, from their background, who spoke their language. One fifth of participants (20.4%) held strong views about being kept alive and if and when they would want medical intervention and this was the area most frequently discussed by D/deaf and hard of hearing participants. For them there was concern that their communication needs would not be met, causing additional stress and giving the patient no dignity. Almost one fifth of people (19.0%) asked that their religious and cultural views be met whilst in receipt of end of life care. Participants specifically spoke about wanting to have a “Muslim burial”, for their “religious rituals [to be] upheld” (and in particular for the body to be released to the family in a timely manner) and several people wished to be buried in their home country. Moreover, people asked that no post-mortem was carried out without the family’s permission. For all wishes identified see 3.2.2.2.

Being able to communicate with staff was also key as was having same-sex staff (including when handling the body) and staff from their background who understood their cultural needs. Considerations around caring for the body were also highlighted as were prayer facilities and visiting the patient. Newcastle Hospitals NHS Foundation Trust has a ritual washing room and prayer facilities available to all patients and carers. For all cultural needs see 3.2.3.

3.0 Recommendations

Some of these recommendations are specific to end of life care services and others apply to any health care service. It is acknowledged that some of the recommendations relating to wishes at end of life are already in place however this highlights an issue around people’s awareness of these services and entitlements. Moreover, other recommendations may also be in place but highlight a need for improvements in these areas.

Discussing end of life care - consider a media campaign which encourages people, at any age to talk about their end of life care and what a good death would look like to them. There should also be consideration of targeted campaigns at a community level, for example, engaging with faith leaders around some BME groups or local organisations that support homeless people. Alongside this, there should also be information available around who to contact for additional help, be it practical advice or emotional support and this help should be accessible for all.

In addition to this, healthcare staff also need to initiate conversations around end of life care wishes. Although it is recognised that no particular healthcare staff have a duty to introduce these conversations, there needs to be an acknowledgement that it is everyone's responsibility. The roll-out of the Standards Project will be a useful tool in this respect. It is also suggested that GP Time In/Time Outs are used to share these messages where they could be a rolling agenda item.

Awareness of end of life care services – consider an educational awareness programme with seldom heard groups involved in this research in the first instance.

Identifying homeless patients at end of life - It is suggested that awareness training for any staff involved in the health care of homeless people is conducted to ensure that identification occurs in a timely manner.

Communication support

There are a number of areas where communication was a barrier to good care and support to both patients and carers with communication needs, as reflected in the recommendations below. However, the implementation of the Accessible Information Standard across Newcastle should go some way to alleviate the issues identified below. However for services such as care homes and hospices outside of the remit of the standard, the recommendations will still stand.

- Ideally, GPs should capture information about their patients' communication needs and this information should pass with them through the NHS services they use. However, to ensure this information is up-to-date and reflects the patients current needs, when a patient first arrives on a hospital ward, in a hospice or care home or begins to receive support from a service, there must be a system in place whereby their non-clinical needs are assessed and any information recorded and, crucially, passed on to all staff caring for the patient. The needs of the main carer should also be assessed. This assessment should also cover cultural needs (discussed below)
- Patients and carers should all be offered support not have to ask for it
- In hospital environments in particular it is suggested that qualified BSL and other language interpreters are available at all times. If face-to-face support is not possible, the use of a telephone interpreting service or a video relay service where appropriate, is recommended. Text messaging should also be offered to patients and carers as a means of communicating. Any communication support should also be available if the patient is receiving medical care at home or in another service
- A review of the process of booking interpreters should be carried out across all end of life care services to ensure that procedures are being followed
- Currently there is only one qualified Social Worker who can use BSL in the North East and to qualify for this support D/deaf people must have additional needs. Consider re-instating the support of BSL social workers to those who do not have additional needs
- Written information should be accessible, either available in other languages or written in plain English. The Patient Advice and Liaison Service holds some useful information and should be used where appropriate

Cultural awareness and need

- There is a need for cultural awareness training for staff providing end of life care so that they have the knowledge and understanding to be able to offer support in the most appropriate way. Any training should include information about the procedures involved in the preservation of the body and also how to explain to people the reasons for undertaking post-mortems. This should include all seldom heard groups involved in this project in the first instance. It is known that this training exists within the Hospitals Trust but there is perhaps a need for refresher courses after a certain period of time, to be put in place. Training is also needed within all other services caring for people at the end of their lives such as care homes and hospices and this should include both health professionals and other support staff
- As with communication needs, when a patient first begins to receive support from an end of life care service, it is suggested that there is a system in place whereby their cultural needs are assessed including any requirements regarding how the body is cared for after death and this should be disseminated amongst all staff caring for the patient
- There should be a physical, private space for prayer available in any environment where patients are receiving end of life care. These services are available within Newcastle Hospitals NHS Foundation Trust but there is perhaps a need for greater advertising of the facilities
- Where a need is identified, provide same-sex workers as the patients and continue this once the patient has died and the body is being cared for. If this is not possible patients should be informed in advance
- Consider the provision of information around returning to their country of birth at end of life or being buried there and working with Mosques and Imams in this respect
- In addition, some cultures and faith groups have particular requirements around moving the body and also how quickly the body is released to the family. It is recommended that wherever possible their requirements are upheld. Newcastle Hospitals NHS Foundation Trust has a ritual washing room but it is suggested that these facilities are available in all end of life care services such as hospices and care homes

Care at home

- It is suggested that when patients start receiving care at home that there is an agreement between all parties that this care is adequate to the needs of the patient. To ensure that patients and carers are fully aware of the scope of such services - exactly what they will be getting, how long the visits should be etc. patients and carers should also have access to a care plan
- It is recommended that every effort is made to ensure that provision of care at home meets the communication and cultural needs of people receiving care
- For carers who have communication needs and are looking after a patient at home it is suggested that a specific care plan should be produced which explains what to do if the patient's health deteriorates and they need medical help urgently

Last stages of life - once it was clear that the patient is in the last stages of life they should be moved to a private room in a timely manner; any restrictions on visiting times and numbers of patients should be lifted to enable family and friends to visit the patient at any time. Newcastle Hospitals NHS Foundation Trust do offer

open visiting for anyone receiving end of life care, with more than two family members allowed at the bedside and this should be made clear to visitors. Consideration for other patients however must be given.

Recognition of next of kin/main carer - the main carer should be identified by all services providing end of life care to the patient and this information be captured and disseminated amongst the necessary staff. There should be an agreement that this person will always be contacted first with appropriate communication support in place to facilitate this and only in an emergency would another contact be used. However, it is acknowledged that it may be difficult to identify who the 'main carer' is where for example there are family breakdowns.

Support for carers - after the death carers should receive accessible information explaining the next steps, useful organisations to contact and any bereavement services that are available; these services should be accessible to all. It is expected that the roll-out of the Standards Project will assist GPs and hospital staff to disseminate this information.

Patient involvement in end of life care - Two GP practices which are part of the Standards Project declined to take part in this research as they felt uncomfortable asking these patients for their opinion. This perhaps suggests a need for education for GPs around interacting and involving patients who are receiving end of life care.