



**Last phase of life -
experiences in North London**

September - December 2017

healthwatch

Camden Barnet Enfield Haringey Islington

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Summary

Introduction

We spoke to 46 people about their experiences of last phase of life care, via in-depth interviews. We held one-to-one interviews with eight people from Barnet and nine people from Camden. We did three group interviews, one with five older African people, one with 10 Somali women and one with 14 carers from Barnet. The interviews took place between September and December 2017.

Key findings

- Once there is recognition that the last phase of life has been reached, support is generally good, and hospital staff at both Barnet General and UCLH were praised for their skill, care and compassion.
- Too often the recognition comes very late.
- For respondents from BME communities, late diagnosis was often cited as a problem, several felt that their loved ones had been fobbed off by GPs, so that cancers were advanced before a referral to secondary care was made.
- For some, getting the right community services to help someone die at home or in a homely setting was problematic. In one case the CCG officer with authority to approve a fast track CHC payment was on holiday so the person was stuck in hospital longer than necessary. In other cases, the lack of care workers who spoke the same language as the dying person was a barrier.
- Having staff understand specific cultural issues around death was important. Good experiences included the hospital removing foreign objects such as cannulas and catheters and giving the family time and privacy to clean the body, or the staff at Jewish Care reassuring the family about the timetable for burial. Bad experiences included a family being left at home with no support and the detritus of death around them, or a staff member of the opposite gender being assigned to clean the body. These things caused intense upset.
- Among the African people we spoke to, the role of hospices was not well understood, and some reported having no information about the palliative care available.
- In almost all cases, the biggest issue was staff awareness and attitude, not the actual nature of the service on offer.

Key messages

- It is important to have an explicit conversation about the end of life.
- The way that a terminal diagnosis is presented is crucial.
- Family often find the conversations stressful.
- Palliative care is not always well explained.
- Finding out what the dying person's wishes are is very important.
- All people involved in the care need to have this information.
- People hugely value kindness, responsiveness and practical help.
- People want information and explanations.
- Staff being too busy to explain and listen could make people feel undervalued and unsupported.
- There were gaps in services, which left people feeling unsupported.
- Residential care was not always meeting needs adequately.
- Involve the family at all stages, and respect their input.
- Hospital can be the best place to die for some people, especially if they offer private space.
- The kindness and attentiveness of staff are essential factors, whatever the care setting.
- Poorly co-ordinated services cause stress, people want a multi-agency approach.
- Services should be proactive in offering support and information to carers.
- Carers want their role and their knowledge about the dying person to be respected.
- Carers need support in navigating the practical issues they face.
- People appreciate quick responses, such as prompt issuing of death certificates or removal of medical equipment.
- Religious and cultural requirements around the way a body is handled after death need to be respected.
- Services could be improved by having the right expertise available.
- More and better promoted information is needed.
- Services should improve advice for families, including financial advice.

General findings

Conversations about end of life care

The key messages

- It is important to have an explicit conversation.
- The way that a terminal diagnosis is presented is crucial.
- Family often find the conversations stressful .
- Palliative care is not always well explained.

We asked people what conversations they had about end of life care, and about what was important for them about conversations on end of life.

Having an explicit conversation

Although many people find talking about end of life hard, everyone we spoke to agreed on the importance of having a conversation about it. This had not happened for everyone. None of the women in the Somali focus group could recall an end of life conversation. The majority of people (both patients and carers) in the Barnet interviews couldn't recall a specific end of life care conversation, though they think they must have had one.



"No one talked to me about end of life care, I knew he was very ill but I was not prepared for him to pass away so quickly."

"Now that I have spoken to you, I realise that someone should have spoken to me about last phase of life, I should have been provided with support, even though my son and my husband were unwell for long periods of time, it was still a shock to me when they passed away. I had to deal with everything on my own, it was very difficult as I had not prepared for their sudden deaths."

One carer wanted workers to talk to their relative about dying because they couldn't face this, but they didn't like to ask them.

People who could remember being spoken to were not sure of the status of the discussion, i.e. was it documented, who knows their wishes?

Telling people that their illness is terminal

People want their doctor to tell them if their illness is terminal. They want clinicians to ask them how they want to die.



"Talking about death is not hard as it is culturally acceptable but medical staff need to respect our cultural and religious needs."

"Clinicians need to ask what is it that they need to know about a person to give them the best possible end of life care."

People want their families around when doctors tell them they are dying. For older people from the Somali community, language is often a barrier, they don't understand what they are told.



"I was left alone, for what seemed a long time, I wished my daughter and son were with me at that time."

"I wasn't being looked after properly. They weren't letting me know what was wrong with me in the first place, however, they let me know I had cancer but they took long to tell me - I was told just like that without a care or thought about how I was feeling with this news."

"Medical staff should always wait for family members before having such life changing discussions."

Supporting families over time

A number of people said they found it stressful when told that someone was facing imminent death but then the person continued to live:



"The doctors always say that someone is going to die in a week/two weeks etc. but then the person lives much longer, they should not predict death in such a way as its stressful for the family'."

"We had many discussion on end of life care and death, every time my father became unwell (he had many illnesses) it was endless, it became exhausting."

"Even though I knew my loved was going to die, I still had hope."

Explaining palliative care

Patients like to be reassured that it's ok to stop active treatment in favour of palliative care. People need to understand what palliative care is and what hospices can provide for the dying person and family. Palliative care isn't just for the terminally ill, older people and people with chronic disease need to know about end of life care and talk about their preferences.



Example of when things could have been better

"No one talked to me about end of life care, both my husband and son died in hospital after prolonged stays, all I got was phone calls in the middle of the night saying that they are unwell, by the time I arrived in hospital at 4am my son had already passed away."

"When my husband passed away, again I got a phone call at around 2am in the morning, I rushed to the hospital, and this time I had about half hour with my husband before he died. I would have liked to have been told that perhaps my husband and my son were in last stages of life, I would have liked to have informed family and relatives to come and pay their last respects."

Feeling well supported at this phase of life

The key messages

- People hugely value kindness, responsiveness and practical help.
- People want information and explanations.
- Staff being too busy to explain and listen could make people feel undervalued and unsupported.
- There were gaps in services, which left people feeling unsupported.
- Residential care was not always meeting needs adequately.

We asked people about how well supported they felt. There were very mixed experiences reported. Good experiences centred on having supportive staff, to explain, reassure and arrange practical help. Often there are several Last Phase of Life workers involved and people lose track of who belongs to what service, but this doesn't particularly concern them. Overall, experience had been more positive for the people we spoke to in Barnet than those from Camden, although the services at UCLH came in for praise.

Help in the community

People praised their GPs for being kind, compassionate and responsive on the whole, particularly during the final weeks e.g. making urgent referrals, fast-tracking prescriptions, doing home visits, returning calls, completing Attendance Allowance forms and death certificates quickly.

Community health workers (district nurses, community physiotherapists and Occupational Therapists (OT)) were much appreciated for the tangible support they gave that enabled people to stay at home.



"The district nurse was very good. She kept an eye on things and spoke to the GP for us if needed."

"We had a wonderful OT who taught me some techniques so I could help my husband sometimes. It made us feel we could manage at home a bit better."

Everyone in the Barnet focus group spoke positively about having a good rapport with community health workers. One talked about feeling well supported by home care, particularly night care:



"I feel that the home care support I got was very good, I can't complain about that, I could not have coped without this help."

People appreciated being able to draw upon community health workers' palliative care knowledge to know what to expect.

Example of a responsive service

Using telecare to monitor oxygen saturation levels for one person with COPD, made them feel anxious because it showed their condition was deteriorating and they decided to stop using telecare, a decision workers respected.

Where things had not gone so well, comments focused on lack of information, staff who did not have time, staff who did not explain, not respecting the wishes of the patient, not involving carers, older people feeling they were "written off", and a lack of understanding of cultural differences. In the African groups, there was little knowledge about hospice services and negative views on residential care. A few people also mentioned a lack of adaptations to make caring easier at home, and some people told us that late diagnosis of their family member's condition had caused difficulty.

Lack of information

People wanted explanations about medication and what should be done when.



"No one explained anything to me or how to get any information about what was available, I was very lonely and isolated'."

Many people said they had not been told what support is available for dying person and the family. A community worker commented that more information should be made available to different communities on end of life care and what support is available.



"I heard about people in Hospices living longer than expected, is it a place where people are 'waiting for death?'"

Staff not having time for people

Often doctors and nurses are very good and appreciated by families, but there are a few who don't seem to have the time to explain things to members of the family. There was a theme about older people feeling they are a burden to others, with comments that staff are too busy, and have no time to listen until it's too late.



"I felt as if I wasn't valued and that I was just a product. I felt emotionally neglected at times as there wasn't great support or communication."

"The staff seem over worked, they are unable to spend enough time with a patient in order to explain things properly."

"Being left for long hours alone, hospitals can be very lonely."

"One (community) nurse was so bad that I reported her and she was replaced with a most wonderful person....all nurses should be better trained in working with people who are dying and their families, I should not have had to report a nurse in the first place."

Lack of services/unsuitable services

Some people said it was difficult to look after their loved ones at home as it was not suitable for the dying person or the council did not make appropriate adaptations at home in time.



"We would have preferred for him to die at home but because the council would not make our home suitable for his needs, we could not do that."

"I have heard that is a lot of support for people with cancer but I did not receive it until I was very weak and getting worse."

"When we took my mother out of hospital, it took a long time to get all the support we needed, she ended up dying without the right support being put in place, there one hurdle after another."

Residential care

In the Camden interviews, some concerns were raised about nursing homes. An African carer commented on the home her mother had been in:



"There isn't a lot of freedom, it is really routine based, and switching things up could've improved quality of life rather than having to do the same thing every day or follow the same procedure."

A Bangladeshi carer reported that *"nursing homes was a big no-no for the family"* even though the person did go to one in the end but ended up in hospital as the nursing home staff did not know how to deal with his medical conditions *"they phoned me to ask if they should call an ambulance. I thought this was appalling"*.

Two of the older African people described their experience of residential care:



"There isn't a lot of freedom, it is really routine based, and switching things up Health services want to get rid of you to a nursing home. Where it's like a school very restricted, treated like a statistic or a number not a human being. You are going to die soon anyway."

"My environment (in the home) wasn't particularly inviting or comfortable, the service wasn't of my standard which made me extremely miserable."

Taking account of people's views and wishes

Key messages:

- Finding out what the dying person's wishes are is very important
- All people involved in the care need to have this information
- Involve the family at all stages, and respect their input

Most people in the Barnet interviews felt involved at some level of the decisions about care of their loved ones but felt it could be improved. In one instance a relative was taken to Barnet Hospital A&E with an infection and died a few days later, leaving relatives upset when they learned his dementia illness had been terminal. No one had told them this before and no-one at the hospital enquired about his Last Phase of Life preferences, which was to die at home.

In the Camden interviews there were some good experiences but also concerns that not all health staff respected the wishes of the patient e.g. in terms of confidentiality.



"They - the medical team - listen to my father's wish, he wanted to die in comfort."

"Because she lost the ability to verbally communicate it was difficult to know how she was feeling or what she wanted."

"Just make sure that the family is involved at all stages of care and listen to the family."

"Managers and staff (care/nursing home) should be grateful if family want to be involved in the caring of the sick person and respect the families/carers wishes."

Example of where things were done well:

A paramedic attending a 999 call from the family, confirmed a relative was dying and respected the individual's wish to die at home.

"Doctors did listen to my husband's last wish, he wanted to die at home in Ireland, everything was organised quickly. Staff in Ireland were briefed with his needs and was able to care for him with dignity and respect. All the files were transferred, everything put into place, all I had to do was ask."

In responding to this question, people tended to focus on the support they were looking for, or were offered. We had a lot of comments about support both before and after death.

Support before death - for the dying person

The key messages

- Hospital can be the best place to die for some people.
- The kindness and attentiveness of staff are essential factors, whatever the care setting.
- Poorly co-ordinated services cause stress.

The positive experiences people told us about covered services being responsive and flexible, and individual staff showing empathy. The negative experiences included staff being disrespectful to the dying person, unresponsive services and poor communication and poorly co-ordinated services.

Positive hospital experiences



“Even though we were not of the Christian faith, the hospital chaplain came and visited my father a few times, which was nice.”

“The RFH medical were really good, they asked if we wanted to take her home, but we never really had the chance as she died very quickly. I feel that we were well supported by the medical team at the RFH, they looked after my daughter constantly and helped her with her pain.”

“Because my sister in law was so unwell and not able to communicate, we felt home was not a suitable place for her to be taken care of. The hospital staff both at UCLH and RFH were very good and accommodating. She died in hospital. She was in a separate room so friends and family were able to visit anytime they wanted.”

Respect for the dying person



"Staff were familiar with my father's needs and was able to care for him with dignity and respect."

"I didn't like it when they spoke to my mother loudly even when they knew she could not hear them because she was either drowsy from the medication or in severe pain... I was angry when they told her off to eat her food in the most disrespected manner...I was very angry when they didn't listen to her the few times she tried to talk."

"I heard the staff talk about my mother's illness loudly to another staff with others around listening"

"She was in a separate room so friends and family were able to visit anytime they wanted."

Unresponsive services



"I was in pain all the time. I wished I had pain killers. In the end when I got help things got better, my question is why did the help come so late."

"Since I was here there was no help. They couldn't cure the disease as I am still waiting for my results after several tests."

"When she was in hospital she became very distressed as she was not being fed, the nurses took food away from her if she did not eat during the set times, she was wetting herself and there was very little help. Clinician need to have relationship with the family. We had to get a private carer to take care of my mother in law at home in the end as the service at the hospital was not suitable at all for her."

Poorly co-ordinated services



"Sometimes for days no one came to change and clean my mother's wounds. This would not happen if the service providers talked to each other."

"Choosing to die at home is like asking for the impossible, the care is not consistent and not planned properly... I am thankful to those who did their job to the best of their ability".

Support before death - for carers

The key messages

- Services should be proactive in offering support and information to carers
- Carers want their role and their knowledge about the dying person to be respected
- Carers need support in navigating the practical issues they face

Support and information for carers

Many people reported that workers were kind and compassionate to them as relatives/carers, as well as to the person dying. However, some felt overlooked.



"Everyone was very nice once they discovered that my husband was dying, but I would have appreciated if someone had talked to me as his wife and explained the care he needed."

"The district nurse used to come quite frequently and ask if he wanted anything, which was nice but no one asked me if I needed any help."

"The doctors did speak to my brother and son, they did not spoke to me directly even though I was the main carer."

One person suggested hospices' wellbeing services should be offered to relatives as well because they might need extra support for themselves while their relative is using a hospice's services.

Lack of general knowledge about Last Phase of Life pathways means carers rely on workers to provide timely information. Where this didn't happen it was distressing. People didn't seem to know about end of life care and what support was available for them or the dying, and information provided to people seemed a bit hit and miss, depending on who was talking to them.



“People need to be made aware of what support is available ‘out there’. We only found out about organisations such as Camden carers by accident.”

Practical issues

People found accessing the Continuing Care Budget difficult even if workers fast-tracked applications - in one case a delay happened because the CCG officer with the power to authorize a decision was on leave. There can also be shortfalls in what the Continuing Care budget will pay for nursing homes and what homes charge. It can mean that relatives waste valuable time shopping around to find an affordable home for someone who is in the last few weeks of life.

In the Somali group, no one was helped with any welfare advice, no-one said that they totally understood what a care plan was. No one said they felt fully involved in a care plan.

Support before death

The key messages

- People appreciate quick responses, such as prompt issuing of death certificates or removal of medical equipment
- Religious and cultural requirements around the way a body is handled after death need to be respected

There were some good experiences, for example GPs signed death certificates quickly, weekends included, if a deceased person's needed to be buried within 24 hours for religious reasons. But for others, the process after death had been distressing, mainly due to the way the body had been handled.



“After her death I wanted to lay out my mother, but the young nurse refuse, I felt that my right to say my last goodbye to my mother had been taken away.”

People told us that often objects like catheters and T lines were not removed from the body and this has to be removed by the people who are body washers (it is a specific religious requirement to wash the deceased person's body and remove any foreign object from the body before burial).



"I have seen and heard that medical implants are not removed from the body, it is then left to the people who wash the body before burial to try remove it; This is often distressing, not possible, disrespectful to the deceased and most of all Muslims are not allowed to be buried with implants (which can be removed)."

A carer had been distressed by a two week wait for a hospital bed to be collected from their sitting room after someone had died in it.

There was also concern about post mortems; families were not always clear on the purpose of the post mortem and were worried about body parts being removed.



"How do I know that the organs have not been removed from the body?"

"We don't trust doctors when it comes to autopsy, they need to explain it [the reason] better and ensure us that organs have not been removed"

Specific issues

Cultural and religious preferences

When we asked people about having their views and wishes taken into account we included cultural and religious preferences. There were some very positive experiences but we also heard about failures to find out what the family's preferences were. People also felt that community health staff did not bother to find out about the culture of the people they were caring for.

There is a risk that culturally insensitive services mean that some families miss out on helpful services or are offered services which feel alien to them. In the Somali focus group all the women said that they did not understand the role of a hospice and why people were sent there. They said that often family members are not given help about or explanation on medical equipment etc.

A community worker commented:



"On cultural issues staff need to be open minded and willing to learn that they will encounter situations that they did not learn in their training and not being judgemental. Language varies, it makes it very difficult for people to explain their illness e.g. there is no word for arm, it's just a hand all the way."

Support for religious beliefs was another theme, one suggested that issues of religion are too complicated for staff to be bothered to understand them. Another said the attitude encountered was *"that's not my belief why should I bother"*.

Sometimes things had gone well:



"My husband's religious needs were taken into consideration, he had the best comfort a dying person can have."

"No one talked to me about what we wanted, but my mother died at home, she had warmth, visitors, reciting of the Qur'an, we would perfume her, massage her, and she had the home touch from her loved ones not some frigid cold medical care waiting for her to die."

"My father's body was cleaned immediately, everything was removed, and he was treated with respect."

Sometimes things could have been better:



"They seemed to be doing things against our culture and religion, for example disregarded our prayer times, when we asked to pray with mum. Another example would be giving her wash whilst younger people were around, whom she regarded as her children."

The role of palliative care

A number of Somali women said that they were happy when their loved ones were allowed to die at home as it is culturally preferred, it met their cultural and religious needs.

This was nuanced by the women being very specific in saying that they needed appropriate and adequate help with looking after their loved ones at home.



"No one talked to me about palliative care or what it was, it is such an alien concept in our culture. I did not know what help my mother could get or I could get, no one explained anything for example I did not know that I could call the GP to get her medication when it finished, I thought I had to wait for the district nurse to give more supplies when we would finish her medication."

"Helping a person going through sickness is a good concept (palliative care) but the concept needs to be explained as sometimes it can be at polar ends of someone's belief i.e. pain takes away sin in the afterlife but if it was explained clearly then it would help people make difficult decisions."



Being culturally sensitive

"I was really happy to take care of my mother at home as it is in our culture to do so, my daughter gave up her job and became her full time carer partly because we had not come across anyone who spoke Somali and we felt they would not understand my mother's needs as an older Somalian woman. I did not feel well supported by anybody. I did not think they understood or wanted to understand our culture or religion..."

"The nurses who used to come and visit my mother really did not want to talk to me or my daughter about what we thought my mother needed, we felt that they were just doing their duty and could not wait to leave. Many times we offered them tea and coffee as this is part our culture but it was always haughtily refused. The exception was one male nurse and he was lovely, he would sit and talk to us about my mother, he would advise us about things to look out for such as bed sores etc. More nurses should be like him, he did not make us feel 'little' and a burden."

Treating people with equality and respect.

Several of the older African people and a number of other interviewees said they did not feel respected by the service providers. One carer described how when the family brought food in for their mother, because she did not like the food on offer, the staff wrinkled their noses:



"Mum was asking for food from home, and every time we brought food the staff would pin their lips to their nose, because they thought the food smelt funny, they would even try to open the windows, this was very humiliating."

"It would have been better to just be honest that the smell of the food is unusual for them, and some people will be uncomfortable with it, we could have found ways of taking her out to eat in the car or somewhere else. What we wanted the most was for our mum to eat something in order to take some nutrition."

Faster diagnosis

One issue we did not ask about but that recurred in a number of interviews was late diagnosis. GP services were cited as the barrier in every case.



"We kept going back to the doctors, it took them four months to refer us, we did not know what to do, we were like hamsters in a cage... The GP treated us like another number, very little patient care. I am still very angry with that GP, I will never forget their face, the ENT specialist said that if they had seen my husband earlier then he had stood a better chance."

"Mother was diagnosed with kidney disease in Germany, they did not diagnose here. Correct diagnosis is bad here, it takes a long time which is why we took her to Germany."

"Why did he have to go to A&E with so much pain to be diagnosed? Sometimes I think that they [primary care] don't bother to care about us, they think we just make up pain."

"I feel let down by the GP services, GPs need to diagnose quicker so people can get the right help early in their illness."

"Why did it take so long for the doctor [GP] to refer? He just kept saying it was stomach ulcer and kept giving her medication. He only referred her for endoscopy when my daughter started vomiting constantly and was in constant pain."

The characteristics of good services for people in the last phase of life

Key messages

People value:

- Kind, competent, responsive and respectful staff.
- Getting expert advice and practical support.
- Services being attuned to cultural concerns (e.g. about burial).
- Getting emotional support.
- Having private space.

There were a number of positive comments on specific services, shared here as they illustrate the things people value, which cover staff being kind, competent and respectful, services offering expert advice and practical support, services being attuned to cultural concerns (e.g. about burial), getting emotional support and having private space. The four services highlighted here are Barnet Hospital, Jewish Care, North London Hospice and UCLH. We also received some positive comments about the Royal Free, about some GPs and about community health services. (People were not always certain who provided their community services). GPs were commended for being kind, compassionate and responsive. Community nurses and OTs were appreciated for giving practical help as well as being caring, making people feel they could manage at home.

A community worker summed up the characteristics of good staff:

- They should be empathetic, engaged.
- Good communicators, make people feel valued and loved.
- Be able to build a good rapport.
- They should ask questions show concern.
- They should listen, to the patient.

Barnet hospital:

The named nurse provision for respiratory and cancer community patients at Barnet hospital was highly praised for offering emotional and clinical support & continuity of care, which had prevented admissions for some people, but also facilitated fast admissions when needed.

The caring attitude of ward staff was a big factor in how well supported people felt.



"I can't fault the workers at Barnet hospital; the doctors, nurses and staff. So kind and caring. Absolutely fantastic. It's spotless too."

"Larch ward is wonderful. Chaotic at times but humane. The staff are lovely. Not a calm place and it lacked privacy, but wonderful nevertheless."

North London Hospice

People experienced tangible and sometimes immediate benefit from the hospice's expert in-put, which reassured them effective support for dying was on hand e.g. tweaking medications for better effect, arranging a night sitter, providing expert information etc.

Patients and carers felt understood and supported with clinical, practical and emotional matters and valued the person-centred, holistic approach.



"They know what they're doing. You can ask for advice or have a chat about anything. You can say things you're not going to say to your family because it might upset them. You're freer. Everyone is in the same boat here and that helps."

"It's a very pleasant place. You can have a laugh, but you can also be yourself if you're feeling low. I'm reluctant to go out too much these days because I'm embarrassed in case people notice I'm not well, but I don't feel that here. I look forward to coming - it gets me out and gives me something to do."

Services were flexible and responsive to patients' fluctuating needs, and people felt involved in decisions about their care.

Jewish Care End of Life Care Support Service

The mix of palliative, cultural and religious expertise was highly valued.



"I was worried my father would die on the sabbath and I didn't know what I needed to do if he did. They reassured me they'd guide me through it if he did and that was really helpful. They were just wonderful in every way - I can't praise the End of Life Care Service enough."

Carers said it was a big relief when a palliative worker became involved and started co-ordinating services.

Having access to charitable funds to pay for essential homecare allowed one person to die at home when no other funds were available.



"The End of Life Service talked to the care agency and everyone else involved as far as I'm aware and organised everything. It was absolutely fantastic - they took care of everything and that was really helpful. They were just wonderful in every way - I can't praise the End of Life Care Service enough."

UCLH

People appreciated the expertise at UCLH and also the care taken to find out the wishes of the dying person and the family. The flexibility to allow family to visit as needed was valued.



"I have no regrets about my father's care at UCLH - it's not often you get great care, but when you do - you should appreciate it'...the medical team was outstanding, they showed respect for my father and gave us a side room so we could be with him."

"They spoke to us and listened to what we wanted. They respected our wishes."

"My son used to stay in hospital two or three months at a time, they used to give him a separate room and a bed for me to stay with him."

How support could have been improved

Key messages:

- Have the right expertise available
- Improve information
- Take a multi-agency approach
- Improve advice for families, including financial advice

We asked people for their suggestions on how support could have been improved. Many of the responses mirror points they had made in the earlier parts of the interviews.

Expertise



“Specialist training is needed to deal with complex conditions e.g. neurological conditions, but paid carers often lack this.”

“Paid carers need extra time to build a rapport with people who have dementia. This should be made possible with suitable time allocated.”

“Staff to better understand the religious and cultural needs of the dying and their families. This includes removing medical items from the body.”

“We need to bury our dead as soon as possible so the body needs to be released quickly, not many people know about emergency town hall registrars – these information should be made available to people who are in end of life care.”

Better information



"Specialist training is needed to deal with complex conditions e.g. neurological."

"external support services could be better promoted in hospital wards/hospices etc."

"Better information on what support (social) is available in the community."

"Support was okay but could have been improved by someone talking to me and explaining how best to look after my husband better at home and the medication side effects."

Multi agency approach



"Major impact on care if medical and social services worked hand in hand."

"Multi agency teams should meet with family/carers before decision is taken about care/nursing homes or hospices."

"Multi agency meeting with family/carer before transfer to nursing /care home."

"Make sure you meet with care home/hospice staff before making a decision."

Better advice



"Services providers also forget that families also need support and advice about what to do when someone dies and where to get help and advice for example help with burial costs/services."

"Information about burial costs and help with burial costs would be great as a number of families are on low income and the sudden cost of a burial on a family can be huge."

"Someone should sit down and talk to families/carers about basic things to be aware of such as multiple copies of death certificates, a basic checklist of what to do and contact number should be created as the bereaved families do not have much headspace to deal with it all."

"Planning a funeral, after death there is absolutely no help at all."

"My mother was awarded a personal budget but no one advised us to put aside money for tax, so after my mother had passed away we ended up with a big tax bill."

Other comments



"We forget that the elderly also need palliative care, it's like having a 'birthing' friend, most palliative care is provided for people who are terminally ill."

"A person's transfer should not be done by just handing over a file or a care plan, the family needs to agree what is a good care plan."

About the people we spoke to

We spoke to two men, the rest of the interviewees were women. They were mixed in age although the majority were over 40 (in the Barnet group they were all over 60). Most were carers, three were service users. They came from a range of backgrounds, including several different African countries, Ireland and Bangladesh.

The interviews took place in December 2017.

Our thanks to the volunteers and community organisations who helped with the interviews and to all the people who spoke to us.

About this report

This report and the research which informed its findings was done as part of a programme of engagement on the North London Partners Urgent and Emergency Care programme.

North London Partners is the sustainability and transformation partnership for North London, formed of health and care organisations from the five London boroughs of Barnet, Camden, Enfield, Haringey and Islington.

The five local Healthwatch in the North London area are collaborating to promote citizen engagement in the work of the partnership. This includes an extensive programme of engagement on Urgent and Emergency Care, led by Healthwatch Camden.