



End of Life Care – Consultation Questionnaire Responses

Below are the responses for the Questionnaire that the Stoke-on-Trent LINK developed to seek the views and opinions of local people about their wishes and needs for the delivery of services for End of Life Care.

For each question, there are two interpretations of the responses. ‘Percentage responses’ and ‘actual responses’, this allows a broader understanding of the data.

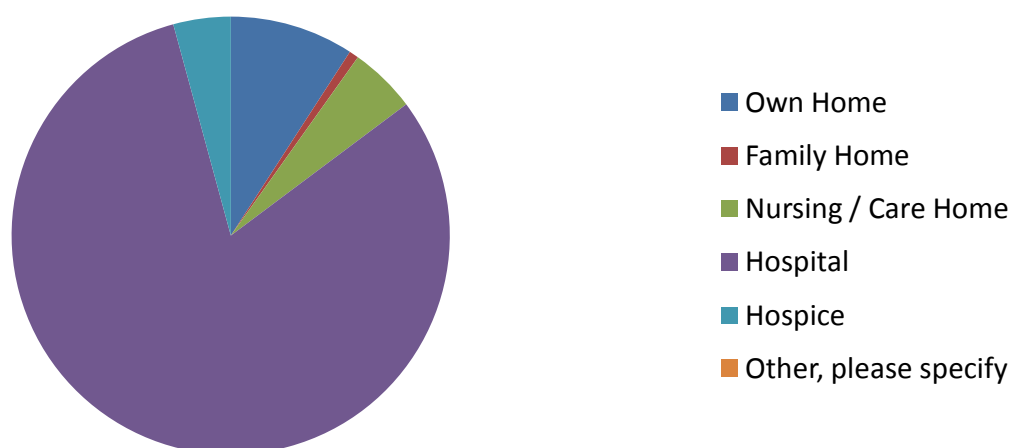
If you need any help or guidance in accessing this information, then please call the LINK office on 01782 416983.

Question 1: In your experience where do most people die?

Own home	9.0%	13
Family home	0.7%	1
Nursing / care home	4.8%	7
Hospital	79.3%	115
Hospice	4.1%	6
Other, please specify	0.0%	0

Additional comment in the ‘other, please specify’ box:

Balance between home and hospital

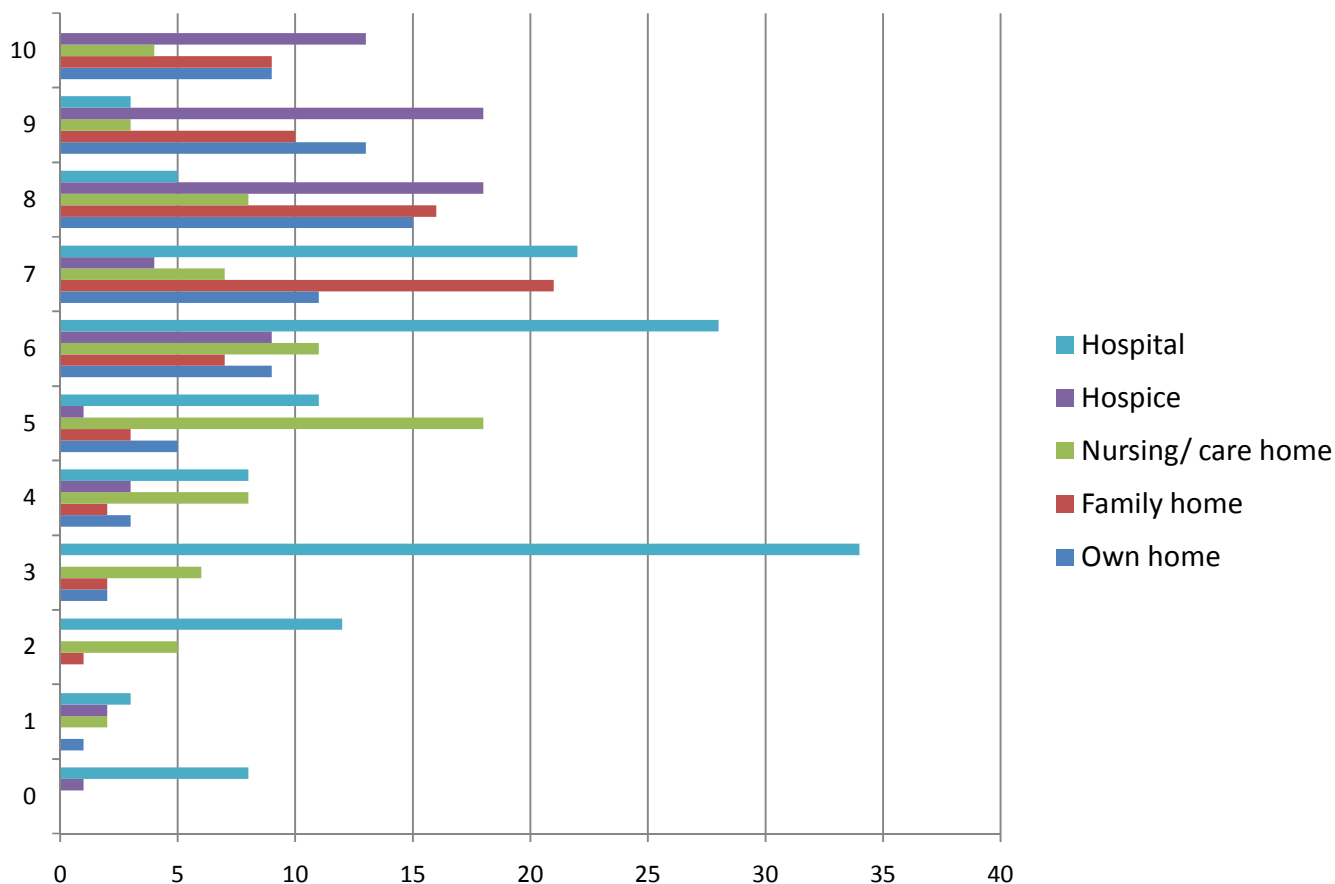


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Question 2: Looking back at the place of death and any End of Life Care you know about, would you say that people involved were happy / comfortable with the nursing / health care received? 0=very bad 10=excellent

	0	1	2	3	4	5	6	7	8	9	10
Own home	0.0%	0.7%	0.0%	1.4%	2.1%	3.4%	6.2%	7.6%	10.3%	9.0%	6.2%
Family home	0.0%	0.0%	0.7%	1.4%	1.4%	2.1%	4.8%	14.5%	11.0%	6.9%	6.2%
Nursing / care home	0.0%	1.4%	3.4%	4.1%	5.5%	12.4%	7.6%	4.8%	5.5%	2.1%	2.8%
Hospice	0.7%	1.4%	0.0%	0.0%	2.1%	0.7%	6.2%	2.8%	12.4%	12.4%	9.0%
Hospital	5.5%	2.1%	8.3%	23.4%	5.5%	7.6%	19.3%	15.2%	3.4%	2.1%	0.0%

	0	1	2	3	4	5	6	7	8	9	10
Own home	0	1	0	2	3	5	9	11	15	13	9
Family home	0	0	1	2	2	3	7	21	16	10	9
Nursing / care home	0	2	5	6	8	18	11	7	8	3	4
Hospice	1	2	0	0	3	1	9	4	18	18	13
Hospital	8	3	12	34	8	11	28	22	5	3	0



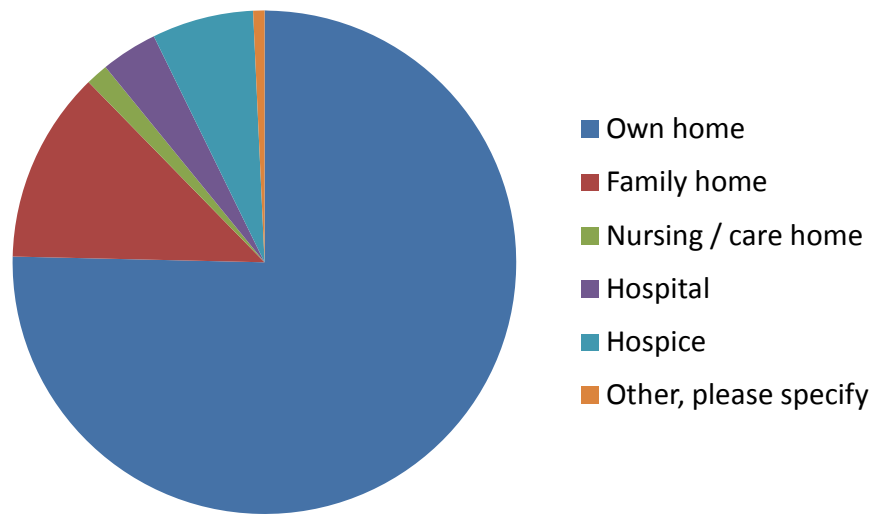
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Question 3: Where would you or your relatives prefer to die?

Own home	71.7%	104
Family home	11.7%	17
Nursing / care home	1.4%	2
Hospital	3.4%	5
Hospice	6.2%	9
Other, please specify	0.7%	1

Additional comment in the 'other, please specify' box:

Balance between home and hospital
 Own home, but if appropriate for family in care or hospice



Question 4: Research into [patient choice at End of Life tells us that most people would prefer to die at home; yet 60- 80% of us will die in hospital even when there is no problem medical reason for us to be there]. Can you think of the important things that should be in place for someone to be safe and comfortable at End of Life in their own home?

For example, Elements of Medical Support or Social Care

- Peace and quiet, the knowledge that carers have appropriate help and support; adequate pain relief. Spiritual needs met.
- Adequate dependable medical support. Domestic help if necessary. Overnight support if required. Adequate medical beds and nursing equipment.
- Physical and emotional support for family and carers if not professionally trained. The appropriate equipment provided straightaway.
- Pain free medical support backed up by expert experienced social services. Delivered care at home. Planned death, friends and family support if possible. Choice.

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- Medical support/social care
 - Doctors, nurses 24/7. Someone to collect & deliver medication if needed. Care workers. Meals on wheels. Pastoral care.
 - Doctors, nurses. Make sure the patient takes their medication and that they are provided with their meals.
 - Continuity of doctors and nurses. Keep family/carers informed of medication and why. Same carer's each day & punctuality essential. Ask the patient if possible and carers what they think would be helpful. If this is not possible explain why.
 - Care packages. Community matron input. Hospice support. District nursing support. Support of family. Bereavement advice. Legal advice if necessary. Personal care support.
 - Support for them and their families. Access to medication, pain relief and professional advice.
 - More medical support such as that provided by Macmillan nurses. Greater involvement by GP's/social workers to avoid the necessity of hospital stays for conditions that could be dealt with at home with just that bit extra attention.
 - A well co-ordinated series of supports, led by an NHS worker (probably a GP) who understands the family's wishes and is able to negotiate the NHS
 - Having experienced this we were told to get care in by the doctor but not where to get it! So many people work these days that care bought in should be dealt with quickly to support the person.
 - Individual assessment and support according to need.
 - Support from a HCSW
 - Raising awareness of death and end of life so that the community at large are more comfortable discussing these issues. Responsive care system to support relatives and carers.
 - Equipment such as hospital bed and medical supplies. Pre-emptive prescribing and a robust, flexible care package as needed. Also help and support for the family.
 - Specialist nursing care. Support and advice 24 hrs if necessary. Knowledge of who is caring ie GP and district nurses. Equipment available when needed.
 - Easy access to qualified palliative care nursing staff
 - Having their family around them. No pain. Staff around them who understand and will give family time.
- Free Parking
- 24 hour nursing care with EOL expertise and medical backing. 2 carers often needed for moving and handling of the patient. Hospital type bed. Specific support for carers. Specific support for psychological needs, particularly children affected.
 - Explanation of what to do when someone dies at home.
 - Help, support and care for all in the home.
 - Support from appropriate medical staff, support from social services or care staff. Information for the family about caring for a dying relative. Information concerning aids that can help in the looking after of someone. Any benefits or help that may be available. Support for those looking after a dying person.
 - Care calls, medication assistance. 24 hour sitters at end of life. Any equipment that will aid and assist

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- They need someone with them 24 hrs a day for personal care and to help them through the process of coming to terms with what is happening and making them feel as comfortable as they possibly can.
- Adequate pain relief and help with caring. Also help with benefits for patient and carer.
- Appropriate medication, nursing support. Nursing knowledge of palliative care. Appropriate equipment.
- Nursing care so that relatives can be family not nurses. Moral support available even if only by phone and not just office hours.
- Have appropriate care available for the person nearing the end of life and for the family and carers. That the care provided is for the benefit of patient and family and not for the providers. Having meals and personal needs given at appropriate times.
- Easy access to medical and psychological support for friends and relatives
- Equipment medication, support for carers/respice
- Ongoing assessment of patient's condition by specialist nurse. Easy access to pain relief. Someone available to speak to at any time, day and night, particularly at night.
- Medical and social care support
- Peace, quiet, intimate knowledge of the person - not to be dying with strangers. No pain, best possible comfort in terms of mattress - soft lighting - not too much intervention.
- Emergency pack of medications. Hospice@home staff. Good district nursing care. Visit by a doctor
- 24 hour care which is not charged for in the last 2 weeks. Night care to give carers a break. Ease of access to services. Freedom from pain and symptoms.
- 24 hour medical care and pain relief available at home if required
- Support to enable relatives to care for the person ie needing expertise on how to handle them. My dad begged to go home but was told his bed wasn't suitable, so had to stay in the hospice, just because of a bed.
- Nursing care, medication, resources
- Person centred care plan. End of life comprehensive care plan. Continuity of care, one person to link all the agencies together throughout the illness of the person.
- Family support and love
- Social care to assist family members with personal care and also to offer support. Care from specialist nursing teams and family GP. Loan of equipment if necessary
- Social care to assist family members with personal care and also to offer support. Care from specialised nursing teams and family GP. Loan of equipment if necessary
- Palliative care. Basic help with personal care like being kept clean and kept comfortable. be able to listen to music and have friends visit.
- Necessary care and equipment to enable comfort and safety when being cared for at home. Promotion of dignity and independence where possible.
- If more people wrote an end of life statement then it would be made quite clear that they understand the risks of being allowed to remain at home if seriously ill and are prepared to accept them. This would ease the difficult decisions for family and professionals involved.

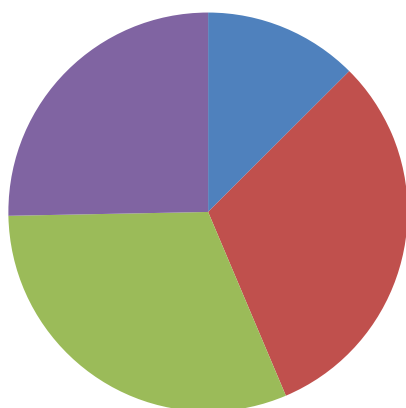
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- Family member
- Home suitable, bed available ie separate from partner if required. Support from family/friends. Support for family and friends. Info about what will happen and what to do next for patient and family. Be able to get home fast enough to be in time to die at home. Arrangements to be made by hospital sooner so that patient can return home in time. End of Life meds available to allow a pain free timely death.
- Simply having their family around them and things that have brought enjoyment to their life eg anything with some sort of sentimental value. it would be far better for someone to pass away after having held on to some memories of their life as opposed to waiting for and fearing death.
- To ensure the same health team/professional attends consistently throughout the period. End use of bank nursing or implement a customer focused induction. My personal experience of bank nurses has not been good.
- Trained palliative nursing care staff and appropriate equipment eg profiling bed, hoist etc. Clear information, guidance and support for patient, family and carers allowing choice and dignity.
- Definately physical & emotional support for family members helping to care for the patient
- Emotional support for family members caring for a patient
- In my experience I have asked people that have been at the end of their life what they would like to have to make them more comfortable and they said peace and quiet
- Equipment to maximise well being to the end
- Someone to provide with tic. Someone to respect the dignity of person who is at the end of their life. Someone to comfort that person and provide with any medical support necessary
- Family present, pain free. Spiritual support. Clean, tidy with my teeth in. In private with my affairs in order if there is time.
- Pain relief, nursing/social assistance, privacy, time, nutritious meals, choice, counselling
- Access to caring/befriending services working alongside family help and support.
- Medical care, company
- Medical support, social & family support. Dignity & respect concerning personal choices about the illness or process of expected death. Emotional support including respect for religious beliefs and disposal of remains.
- Appropriate care and support package including any aids and adaptations required
- Daily visits from medical/social care staff
- Network set up so with one call, however many times this number is dialled, a member of professional staff will arrive to help the patient and family
- That all the medication is on hand to ease the pain. That all the loved ones are around, all the right medical staff are there.
- Equipment support
- Financial affairs in order. Support and appreciation of family carers. Availability of nursing support 24/7. End of life care plan in place and is known to all concerned including OOH service.
- Provision for visitors. rapid availability of clinical support and advice for carers at death
- Support for family and carers

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Question 5: NHS Stoke on Trent is paying for a Rapid Response Service in the community. What would you like to see this service provide? You may answer more than one choice below.

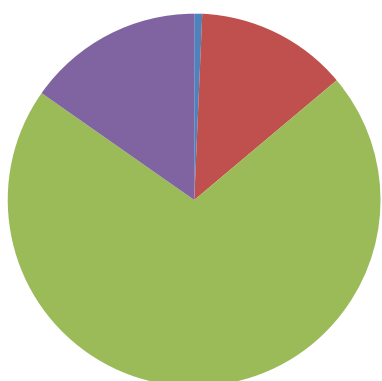
Arrange to admit the person to hospital or hospice	34.5%	50
Provide medical support at home so hospital admission is not required	85.5%	124
Provide emotional / practical support at home	85.5%	124
Provide help and support after a person has died	69.7%	101



- Arrange to admit the person to hospital or hospice
- Provide medical support at home so hospital admission is not required
- Provide emotional / practical support at home
- Provide help and support after a person has died

Question 6: A new five-bed Generalist Palliative Care Unit will be placed in the Hayward Hospital. What do you think this unit should be mainly used for?

Support for patients with cancer	0.7%	1
Support for all patients with life-shortening illness	13.1%	19
Support for anyone approaching the end of life	71.7%	102
Short stay beds to sort out medicines and other problems so the patient can return home	15.2%	22



- Support for patients with cancer
- Support for all patients with life-shortening illness
- Support for anyone approaching the end of life

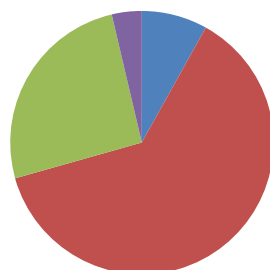
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Question 7: In your experience is there ample opportunity for the dying person, family, and friends to receive spiritual and emotional support before and after death?

Yes	7.6%	11
No	58.6%	85
Don't know	24.1%	35
Other, please specify	3.4%	5

Additional comment in the 'other, please specify' box:

- Nurses should be able to ask if a person wants prayer. In hospital spiritual needs are not met - no minister available
- This depends on whether they belong to a church or other faith community. Some churches are better than others at caring for the sick, elderly, dying and bereaved.
- Especially in hospital
- Opportunity may be available but resources expertise often not.
- Yes in the hospice
- There is, however families today have moved more and more away from christian or other faiths so tend to be unaware of availability other than the undertaker booking a church service. Bereavement counselling is becoming more available which is a good thing.
- Depends on how quick/slow the process is and whether expected or not.
- There is opportunity but doubt if it is ample
- There is some opportunity but whether you receive it depends on what other services you are linked to.
- I think the hospices are very good and have support if needed. Not after death though. There isn't anything other than local church after death
- This depends on individual circumstances. If you are a member of a faith community or have supportive family and friends the answer would be yes. Regrettably, for most people I suspect the answer is no.
- If plenty of time to make feelings known and someone will advocate for you then it is easier to get the death you want
- Having lost both my parents to cancer and my eldest daughter diagnosed with a tumour aged 8, during each of these I found myself praying as and when the need occurred for me.
- Improved links with churches



- Yes
- No
- Don't know
- Other, please specify

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Question 8: Do you have a key message you would like to feed back to the Commissioners about End of Life Care?

- I have alzheimers disease & know I am unlikely to be fully aware of my surroundings at the end of life if the disease runs its course. I could face my own death with less anxiety if I knew my carers, especially my husband will have appropriate & adequate support.
- Cleanliness and kindly support is of paramount importance.
- If in a close family they should be there at end of life of family member is they wish. If not, then someone should be available to stay with the dying patient. Emotional /spiritual support should be available to all.
- Death and dying is a taboo - no-one wants to talk about it but we all have to go through it and my experience of it from parents and in-law is undignified, grimness and terribly lonely. There has got to be a better way. Palliative care is essential but everyone deserves a good death.
- Yes - one day it will your turn to die.
- Make sure what the person wants and if possible comply with their wishes.
- If people can choose where to have operations they should be able to choose where to die. However support is needed for both patients and relatives if this is to happen as people are already caring for the dying unsupported.
- It seems there is a willingness on the part of the local NHS to address end of life care issues. My key message would be to follow this through with gold standard practice.
- If you are going to do questionnaires make sure they are designed to give you the information you want, that the spelling is checked and the question not too shocking!
- The patient and family's wishes should be known and followed. Panic by a carer who cannot cope should not result in hospitalisation for end of life.
- My dad died under the Liverpool care plan - despite the terms of this plan he was often neglected and afforded the dignity he should have received. He dies in an open ward literally starved and dehydrated to death - it was worse than you would treat a pet. When we went to see him immediately after his death we were told to mind the smell as his organs had broken down. There is no dignity in this at all. Nurses hadn't the time to care for his basic needs as he approached death. My mother on the other hand did not want to go to hospital but the OOH doctor didn't explain that she had a right to die at home or what sectioning is really about. Please bring some emotional support to being with a loved one at death. After my mum dies we were told by the ward staff to go to the chapel of rest and remove her jewellery. Knowing no different we went and found it was totally inappropriate advice and very distressing, it could have been done by the undertaker.
- More support is needed for people wishing to die at home
- Need flexible menu of services to give patients real choice of place of death.
- The Douglas Macmillan Hospice provides great care but beds are being used for respite beds when there are many out there needing their specialist care and cannot be admitted.
- That the end is as best as possible for all family and staff. That everyone is as happy as possible.

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- If we want to offer the patient the choice to die at home, we need to be able to offer 24 hour support that equates to a dedicated service that can be accessed rapidly and is flexible to meet patients and carers needs. this is likely to include health and social care elements.
- An appropriate place of care should be a priority at end of life - not in a general hospital ward
- Listen to what the public wants as opposed to what you think that they require. Also think about their psychological needs as well as their physical needs.
- Think of the patient and the carer and make services appropriate either freely or at an appropriate cost to the ability to pay. Council government that proper finances and availability is there for all.
- More support for relatives and friends to enable them to allow the patient to die where they wish to wherever possible.
- Care in the community is still very dependent upon family members/informal carers. There is gaps in service between health and social care and this often leads to inappropriate hospital admissions.
- Insufficient consultation with relatives or carers of the elderly
- Palliative care from specialist nurses and doctors and available response day and night when needed. Continued assessment. Carer support at its best please - we all gonna go!!!
- Put yourself in the place of someone dying alone in confusion and discomfort or pain surrounded by strangers. is this want you want for your death?
- Everybody diagnosed with a life limiting illness should be asked about their preferred place of care/death and should be documented and everybody involved with the care should be informed about it.
- Support at home needs to be more readily and urgently available. Procedures should be streamlined to get the care that is needed in place quickly. End of life care should not be subject to the vagaries of local authority funding problems. End of life care should be free. People wishing to die at home should have access to personal budgets.
- I understand how expensive it is for care to be given in the home but you only die once. The hospitals/hospices are so busy that patients are just left alone in their beds for hours on end as relatives can only really visit and then leave. Most people die alone no matter how many visitors. If care could be provided at home, I think the patient and the relatives would feel more at peace about the end looming. It really is just medical and physical support that make it impossible. A visiting nurse a few times a day would probably be cost effective against a hospice place. Logistically it could be a nightmare but armies of volunteers run hospices, I'm sure they could be utilised in the home also.
- The person should be treated with dignity and respect and should have the ability to discuss their own wants, needs and aspirations and not practitioners who they know. Customer led service not practitioner led.
- Sensitive considerations of each individual family's needs. Well trained staff as demonstrated at the Douglas Macmillan home.
- End of life care is not only important for the patient but also for the family members to ensure they feel their loved ones have received the best possible care in the environment they choose.

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- End of life care is not only important for the patient but also for the family members to ensure they feel their loved ones have received the best possible care in the environment they choose
- There has been a fair amount of comment generated by recent consultations. My message to the commissioners would be to sift through the responses, take note of what people have said and act accordingly
- More support
- If a person wants to die at home and they can do, they should be cared for in any way to meet their needs medically and to make them as comfortable as possible in their time of life left, They should be treated with dignity and have the respect from all who care for them.
- In order to ensure the wishes of the people affected are respected those wishes should be made in writing and left with the next of kin and GP. End of life statements are important
- Having lived many years in Africa, the services provided for end of life care here are excellent - general nursing standards high
- There is not enough money, end of life care patients and families are missing out. The best deaths are well planned with support for patients and relatives and friends.
- I have just applied to university to do nursing and in terms of palliative care, I strongly feel that it is about building a support network around the patient and the family and offering the highest level bereavement support for the family so as they are able to come to terms with their loss.
- Personal experience of my mother's death was appalling in relation to her care. I am confident this is a situation mirrored nationally. Fortunately for PCT's, families are in emotional turmoil at such times - hence few complaints are submitted. Two years ago I gave up smoking, promising myself I would start again when I was 70. Having worked temporarily for social care & health, I have now brought forward my smoking start date to 65 yrs of age. Hopefully by adopting this approach I will not be subjected to the prospect of ending up in a private nursing home.
- It is all too easy to single out cancer and overlook other life limiting illnesses that can be equally devastating to those involved. palliative care should be for all and tailored according to the individual choices, treatment needs and circumstances.
- Access to nursing support. Respire for carers. Access to specialist advice
- More support in social care is necessary in the community
- To be open with people about their prospects so that a choice can be made and a support package put in place. To be open with the patient/resident and family about DNR on case notes
- To raise staffing levels, training and openness and thus support staff alongside the person dying, the family and friends. Staff to support one another
- Help provide increases home befriending support
- At a time when a person feels control slipping away it is important to enable the individual to have choice, dignity and a say in their living and dying
- Involve those with recent experience of a family bereavement
- As the name suggests, we need to CARE and more often than not, there seems to be monetary discussions not feelings considered

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- This is a personal individual time and should not be treated as a one shoe fits all.
- Read "Compassionate Cities" by Allan Kelleher
- Support families and carers in making decisions rather than making the choices on their behalf
- Put more money into end of life care so people can have a choice

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