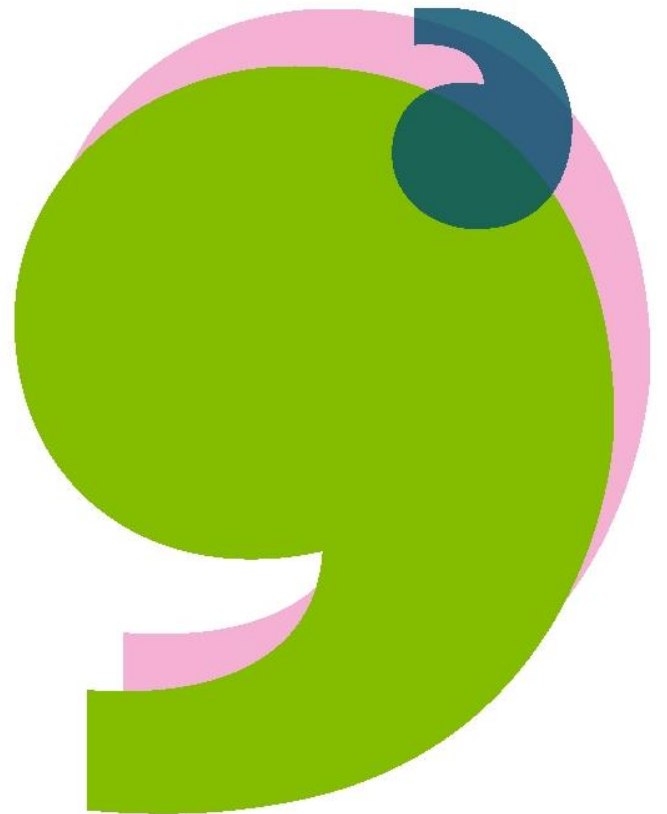




**Patient experiences and views about
palliative and end of life care. 2018**



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Appendix A: 14 stories - Patient experiences and views with type of feedback (1:1 feedback, survey responses, and focus group transcripts), location of experiences and recommendations arising from patient story..... 23

1.0 Executive summary.

14 individuals that live in Herefordshire, shared their experiences of palliative and end of life care and their views of what they would wish for, at the end of their own lives.

6 participated in focus groups, 5 responded to an online survey and 3 gave 1:1 feedback.

The findings are to be fed into a West Midlands Quality Review Service, Formative Review of Herefordshire Palliative Care Pathway scheduled for 31st January 2018. The report will form part of the evidence that will be submitted by and gathered from representatives of services connected in any way with end of life and palliative care in Herefordshire.

The 14 individuals told us about their experiences of end of life and palliative care in several settings including:

- Care at home,
- In care homes,
- In hospice,
- And in hospital.

Many individuals related more than one experience.

Each person's account (in **green** in appendices) led to the individual lessons in this report and noted beneath each account (in **pink**). These are pooled and streamlined to form the overall recommendations of this report.

The national Choice in End of Life Care Programme Board recently published 'What's Important to Me: A Review of Choice in End of Life Care ', (February 2015).

We have used these themes to order the responses of the 14 people and their recommendations.

The report makes recommendations relating to:

Patient has involvement in, and control over, decisions about their care.

- Care planning.
- Information needs.
- People that do not wish to record or discuss their end of life wishes.
- Help to make difficult decisions.

Patient has access to high quality care given by well trained staff.

- Training and customer care.
- Early diagnosis.

- Recruitment of quality trained care staff.

Patient wants access to the right services when they need them.

- Joint working and service coordination.
- Funding.
- Employers.
- Suggested service improvements.

Patient receives support for their physical, emotional, social and spiritual needs.

- Mobility.
- Spirituality.
- Travel.
- Crisis management.
- Pain relief.
- Euthanasia.
- Practical home solutions.

The right people know the patient's wishes at the right time.

- Sharing end of life care plan.
- Avoiding unnecessary interventions.

The right people know the patient's wishes at the right time.

- Taking carer's opinion into account.
- Children and young people.
- Respecting and listening to carers that know the dying person well especially when they are unable to speak for themselves.
- A holistic approach.
- Support after death
- Carer's personal health and support needs.
- Considering carer in financial service decisions.

The patient is cared for and will die in the place of their choice.

- Supporting patient choice.
- Choosing to die at home when you don't have family or family are unable to care for you.
- Treatment and home care.

It is hoped that palliative and end of life services and Commissioners will consider the views, celebrate and share good practice and respond to patient recommendations by finding ways to improve practice where necessary.

Please tell us if you have used these recommendations so we know how this work has made a difference.

2.0 Recommendations.

Recommendations relating to theme 1: Patient has involvement in, and control over, decisions about their care.

Relating to care planning.

1. Upon diagnosis of a life limiting and deteriorating condition, arrange to meet to have an open and honest conversation and give full information and support to person and family to understand about their options, condition, medication, treatment and intervention and the benefits of creating an end of life care plan.
2. Signpost to information and support that will help people to understand their realistic options, sources of financial help, the importance of recording wishes (accepting that they may change), and important considerations such as lasting powers of attorney, wills, funeral planning.
3. Encourage person to share their wishes with their families and carers especially where the person wishes to die at home.
4. Involve person requiring end of life care/palliative care, and their family, before decisions are made, at an early stage of treatment in discussing their wishes and options, including:
 - DNR and hospital treatment to prolong life.
 - How to choose not to have aggressive treatment.
 - Reviewing plans.
 - Family/ carer involvement.
5. Allow practitioners opportunities to gain an understanding of people's expectations and information or support needs.

Relating to the booklet: Planning for your future care.

6. Use the booklet - Planning for your future care on power of attorney and advanced care planning as a good resource that would help people to consider their wishes.

Relating to information needs.

1. Explain what palliative care entails, what to expect and what to do to initiate support as soon as possible so person and carer can discuss their wishes.
2. Support people to find the information they need as circumstances change e.g. Care home availability and type, dying at home without family, access to care in a rural area, access to hospice at home.

Relating to people that do not wish to record or discuss their end of life wishes.

3. Encourage people to record their end of life wishes recognising that some do not wish to.

Relating to help to make difficult decisions.

4. If possible respect the person's wishes over anyone else's but give help when necessary to make decisions when patients and their families need it at a difficult, emotional and confusing time.

Recommendations relating to theme 2: Patient has access to high quality care given by well trained staff.

Relating to training and customer care.

1. Continue to offer good quality hospice care, caring nurses, skilled nursing, patients never ignored and medication to manage pain effectively.
2. GP's and consultants to be trained to confidently and sensitively discuss end of life care and to offer clear information to the dying person and their family about what to expect, how to look after a dying person, what support they can access, when to call for help and what to do when a person you are caring for at home dies.
3. Practitioners to be mindful to avoid unnecessary treatment that prolongs life or disrupts remaining life unnecessarily against person's wishes and to avoid giving false hope by avoiding difficult conversations, focussing on one aspect and not considering whole picture with patient.
4. When people have chosen to die at home, all staff involved in Health and social care to be reminded to respect that they are operating in a person and their family's homes.
5. Treat older people, people with dementia and disabled people with respect and take time to explain information in a way that they can understand without treating them paternalistically.
6. Practitioners to complete paperwork in a timely way to support people receiving palliative care.
7. Ensure care companies can use all necessary equipment that has been set up.
8. Take action to improve the training and practice of District nurses to be:
 - Consistent, well trained, organised, compassionate and professional.
 - Ensure that pain relief is promptly arranged and use of morphine driver. Sensitivity when listening to, discussing and responding to pain with family and carers.
 - Able to give practical equipment advice to ease the lives of carers at home and to maintain a hygienic environment. Behave and communicate professionally and arrange and keep regular visits.
 - Listen to carer concerns about events or episodes that dying person is experiencing when they or GP is not there and take steps to witness episodes and offer necessary medical care and support to person and carer.

- Supportive and sympathetic to family and carers remembering that a sharp word or negative comment is particularly impactful to people who are tired and emotionally drained.
- Competent to deliver pain relief and clear about procedure.
- Mindful about asking the same questions over and over as this can be difficult for family.
- Apologetic if they get it wrong, are stressed or over stretched/ rushed.
- Never argue or undermine carer in front of dying person who has reached a stage where they can't respond but may be able to hear.

Relating to early diagnosis.

9. Contact patient when scan shows a serious condition.
10. Greater use of annual check-ups to detect emerging conditions and for early diagnosis e.g. to pick up possible heart conditions.

Relating to recruitment of quality trained care staff.

11. Pay care workers more so that families can have more faith in the quality of their skills when caring for dying people at home or in a care home.

Recommendations relating to theme 3: Patient wants access to the right services when they need them.

Relating to joint working and service coordination.

1. Improve joined up working between hospitals, GPs, hospice at home, district nurses and community services.
2. Resolve situation about District nurses, discharge and the need for re-referral to help people in a stressful situation caring for a dying person at home.
3. Ensure timely deployment of equipment e.g. oxygen and make sure that instruction is given to carers.
4. Provide clear advice about who to contact when person dies in the night and ensure that calls to 111 leads to someone attending and families know when this will be.

Relating to funding.

5. Council and NHS to provide fast-track opportunities to access any available financial help for dying person and their family/carers.

Relating to employers.

6. Be clear about sick pay and signpost for help with benefits or mental health needs following death of loved one.

7. Consider producing a pack that families and carers can give to their employers to explain how they can help their employee before and after death of the person they care for.
8. Consider producing a pack for employers when an employee presents with a life limiting condition to explain how they can help and support their employee up to and when they must leave.

Relating to suggested service improvements.

9. Include commonly used out of county care in Herefordshire End of Life diagram
10. Consider offering people and their carers that choose to die at home help such as:
 - Supplying some resources such as incontinence pads that would be provided if person were dying in a hospice or in hospital as extra costs from a chemist adds to stress for families supporting somebody dying at home.
 - Access to a 24-hour telephone line (such as the hospice).
 - Provide care support a lot earlier so that families can have some quality time with their loved one before they are unable to communicate.
 - Enable some hospital-only treatments to happen at home.
 - Consider additional social care support for conditions that could cause hygiene of environment to decline and make life unpleasant for carer and dying person.
 - Improve triage to allow urgent appointments two days following at GP where necessary.
 - Consider how appropriate it is to delay an appointment for a week when someone has two weeks to live.
 - Schedule GP home visits as soon as possible following diagnosis.
 - Do not record refusal on practical grounds as a missed appointment.
11. Ensure GP services have sufficient resources to support people who wish to die at home and their families.
12. Consider improvements to prevention and early diagnosis such as:
 - Encourage people to seek help earlier for symptoms that can indicate being pre-diabetic and to improve healthy lifestyles.
 - Use television more to raise awareness of the danger of diabetes.
 - GP's to advise patients clearly when they should come again to surgery regarding ongoing conditions e.g. high blood pressure.

Recommendations relating to theme 4: Patient receives support for their physical, emotional, social and spiritual needs.

Relating to mobility.

13. Support people to stay mobile for as long as possible. Provide training for care workers around encouraging mobility in the home.

Relating to spirituality.

14. Consider how spiritual support is made available to people in the End of Life pathway.

Relating to travel.

15. Consider dying person's physical and support needs and limitations with regards to travel to appointments at short notice.

Relating to crisis management.

16. After resuscitation e.g. during a crisis in hospital, offer to talk patient through this experience afterwards at home so that they can understand what happened and make decisions about future wishes.

Relating to pain relief.

17. Ensure good pain management including:

- Pain free death at home avoiding unnecessary pain.
- Different sorts of pain relief or control of pain relief so that they can remain in control and lucid if they can, and involved in choices of care and treatment.
- Arrange syringe driver at the right time.

Relating to euthanasia.

18. Note that some members of the public would wish to discuss Euthanasia.

Relating to practical home solutions.

19. Offer practical solutions for handling difficult situations at home e.g. incontinence.

Recommendations relating to theme 5: The right people know the patient's wishes at the right time.

Relating to sharing end of life care plan.

20. Share care plan to all involved.

21. Improve palliative care on the wards to improve sharing of end of life care plans and views on DNR.

Relating to avoiding unnecessary interventions.

22. Support patients to avoid interventions that prolong dying against their wishes.

Recommendations relating to theme 6: The people who are important to the patient are supported and involved in the patient's care.

Relating to taking carer's opinion into account.

23. GP to take carer's concerns seriously to diagnose patient as early as possible.
24. Prioritise dying person's wishes about withdrawal of treatment over family, take every opportunity to discuss options with dying person and record their wishes to avoid conflict between carers/family recognising that families can disagree.
25. Explain condition at as early a stage as possible so that patient and their family can make a care plan preparing for end of life. If patient is reluctant, but couple are elderly consider, the needs of the partner as well as the patients so that they are not left unprepared and without help.

Relating to children and young people.

26. Involve young people at a level they can understand in planning for the death of a relative and take care not to overprotect them so that death does not come as a shock and causes long term anger and or depression.
27. Support young people as they grieve with help such as counselling and support groups.
28. Consider alternatives to medication and always advise of the side effects of antidepressants.
29. Continue to allow families including children to visit person in palliative care in hospital.

Relating to respecting and listening to carers that know the dying person well especially when they are unable to speak for themselves.

30. All staff in Health and social care to recognise and respect the expertise and knowledge of family and long-term carers about the person with a terminal diagnosis especially where that person has difficulty expressing their views e.g. a person with autism. Ask family and long-term carers how they manifest or communicate pain and other needs. Work sensitively in partnership with them to support the person's progress towards a pain free dignified death.

Relating to a holistic approach.

31. Recommend a holistic approach that looks after the whole family.

Relating to support after death

32. Improve support for family after the death.
33. Explain options after person dies an expected death at home so that family can adjust and don't feel rushed if they wish to retain the body for longer to say their goodbyes.

Relating to carer's personal health and support needs.

34. Recognise the support and health needs of the carer looking after a person who is dying over a long period at home for example:

- GP to check that carer is gaining the support they need and organise a change of personnel where personality conflicts occur.
 - If more people can die at home, consider how emergency help could be offered e.g. help for elderly carers with falls and physical needs.
 - Listen to person's wishes but encourage them to check family are able and willing to support death at home too.
 - Consider how to fast track carers assessments when death is likely to be soon.
 - Provide advice re gaining a fresh carers assessment as condition of cared for person worsens. Or ideally assess to take deterioration into account.
 - Support carers in taking care of their health needs during and after death of the person they care for.
 - Consider needs of elderly carers dependent on very little care support including their health needs and likely knock-on effects of caring for somebody dying at home.
 - Consider supporting lone carers by providing earlier night time support from St. Michael's hospice.
 - Recognise that it can be frightening for carer that has no experience of death and medical care.
 - Greater consideration for people who have been carers over a long period or carers of successive people or relatives at home.
 - Offer families caring for people dying at home access to bereavement counselling, mental health support and time to recuperate before returning to work.
 - Consideration of health of elderly carers including mental health.
35. Consider offering support to families coping with traumatic hospital experiences especially children. Encourage schools to understand and offer counselling/ support/ pastoral care.

Relating to considering carer in financial service decisions.

- 36. Social services to consider cost and travel distance for family when finding a care home for end of life care.
- 37. Consider solutions to give families time to arrange suitable residential or home care if necessary following hospital treatment.

Recommendations relating to theme 7: The patient is cared for and will die in the place of their choice.

Relating to supporting patient choice.

- 38. Enable patients to choose where they die.
- 39. Support people to develop end of life care plans and die at home if they wish.
- 40. Provide clear information about care home choices and costs so that person can decide their preferences and share with their families.

41. Advise patients about their condition and the likely medical needs that they will have and whether a home death is feasible. Including the risks of medical delay to reach a home in a rural outreach and the advantages of onsite availability of medical care and expertise, advantages of home care v hospital care v hospice v care/nursing home.
42. Look at reputation of care homes which are not perceived as being as caring as the hospice.
43. Encourage good end of life care in care homes ensuring suitability for developing condition e.g. Dementia, so individual is not moved around unnecessarily during palliative care.
44. Encourage hospice at home.
45. Explore warden supported homes as an option for end of life care.
46. Support patients that have conditions that go up and down that wish to die in a care home or hospice to decide when they need to consider moving from the family home.

Relating to choosing to die at home when you don't have family or family are unable to care for you.

47. Support people to die at home without the care of a family, for example offer access to an advocacy service.
48. Make information available to people who live alone with conditions that can develop rapidly so that they know what options they could expect for end of life care and if it would be possible to die at home.

Relating to treatment and home care.

49. Support patients to get home from hospitals as soon as possible after necessary operations during palliative care.

3.0 Acknowledgements

Healthwatch Herefordshire would like to thank the individual members of the public that shared their experiences of palliative and end of life care and their views on their own wishes, which has enabled us to create this report.

4.0 Disclaimer

The views expressed in this report are representative of 14 participants. The 14 participants came forward as a result of publicising the opportunity:

- In groups that Healthwatch engages with.
- To public that make enquiries relating to end of life and palliative care.
- To organisations that have service users that have experience of end of life care.

The views may not be representative of other Herefordshire service users but are authentic independently gathered views.

It is hoped that palliative and end of life services and Commissioners will consider the views, celebrate and share good practice and respond to patient recommendations by finding ways to improve practice where necessary.

Please tell us if you have used these recommendations so we know how this work has made a difference.

5.0 Introduction.

14 individuals that live in Herefordshire, shared their experiences of palliative and end of life care and their views of what they would wish for, at the end of their own lives.

6 participated in focus groups, 5 responded to an online survey and 3 gave 1:1 feedback.

Their responses were transcribed mainly in their words (*quotes in green italics*), with some alterations to preserve anonymity or to clarify (in blue).

We have put the responses in the Appendices in full as this gives an authentic record of the feelings and impact of people's end of life experiences. This will be more useful to practitioners as a learning tool.

The findings are to be fed into a West Midlands Quality Review Service, Formative Review of Herefordshire Palliative Care Pathway scheduled for 31st January 2018. The report will form part of the evidence that will be submitted by and gathered from representatives of services connected in any way with end of life and palliative care in Herefordshire.

Herefordshire Clinical Commissioning Group published their strategy:

Palliative and End of Life Care Strategy Children, Young People, Adults, and Older People in 2015.

In it they set out their vision:

The vision is for palliative and end of life care to support both individuals and their carers offering services to both, where appropriate, to meet their physical, psychological, spiritual, cultural and social needs during palliative care, end of life care, and in bereavement.

From diagnosis, through to end of life care and bereavement support, delivery of this vision will ensure that people will be supported, in the context of their lives, to live good lives and die well irrespective of their care setting.

This requires a philosophy of care that is patient-centred and which takes a holistic approach to advance planning, co-ordinating and delivering high quality, reliable care that enables people to retain control, dignity and, crucially, choice in how and where their care is delivered to the end of their life.

Making this vision a reality requires ownership, leadership, and collective intelligence at all levels of policy, planning, commissioning, education, and delivery of palliative and end of life care. The national Choice in End of Life Care Programme Board recently published: 'What's Important to Me' - A

Review of Choice in End of Life Care'. (February 2015). The themes which emerged are illustrated in the following diagram:

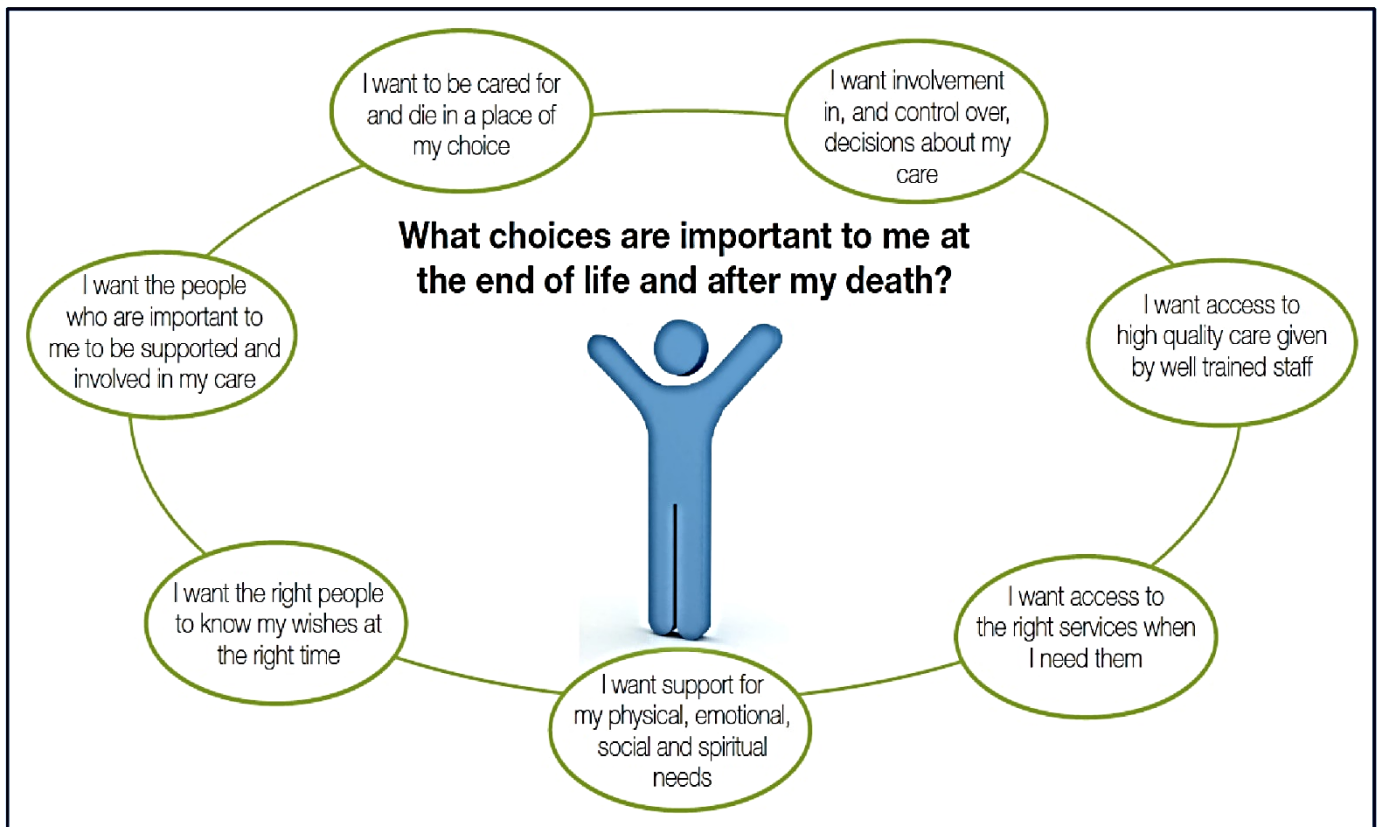


Figure 1: 'What's Important to Me', identified themes

We asked people to tell us about their experiences of palliative and end of life care - what was good and what could be improved. We also asked them what they would want for their own end of life care.

We have used these themes to order the responses of the 14 people and their recommendations.

6.0 What people said.

The 14 individuals told us about their experiences of end of life and palliative care in several settings including:

- Care at home,
- In care homes,
- In hospice.
- And in hospital.

Many individuals related more than one experience.

Each person's account led to the individual lessons in the appendices and noted beneath each account (in pink). These are pooled and streamlined to form the overall recommendations of this report.

It is important to stress that there are many examples of excellent practice, caring practitioners and supportive professional care staff. The recommendations naturally concentrate on areas that palliative care and end of life care services would wish to improve for people who are dying and their families.

Theme 1: Patient has involvement in, and control over, decisions about their care.

Online responses:

- Disagree strongly 0
- Disagree 1
- Neither agree nor disagree
- Agree 3
- Agree strongly 1

Participants agreed that involvement in decision making is very important while acknowledging the difficulties of timing, who to involve, sharing information and accommodating changing circumstances.

There were good examples of involvement of both patient and family.

Most people wanted to know the facts at diagnosis and during treatment.

Most were in favour of encouraging people to plan for end of life from simple principles to more detailed wholesale planning including powers of attorney and funeral arrangements.

Focus group participants liked the booklet - Planning for the Future - an example of information that is provided by the NHS to help this process.

Participants noted that there are some people that would not wish to record wishes or talk about their care.

Participants pointed out that they need to have sufficient information to plan and that some aspects could not be predetermined very easily. They recognised that they would need help from services to adjust plans and understand palliative care and what is possible.

Participants commented that even with information it can be very difficult to make decisions and plan for every eventuality especially when people are tired and emotional. There are times when people need good sound and expert advice and help to make the difficult decisions e.g. weighing the benefits of treatment or operations towards the end of life.

Theme 2: Patient has access to high quality care given by well trained staff.

Online responses:

- Disagree strongly
- Disagree 1
- Neither agree nor disagree 1
- Agree 2
- Agree strongly 1

Participants raised concerns about the need to train practitioners to:

- Discuss end of life care with people.
- Respect that they are operating in people's homes.
- Deliver appropriate pain care.
- Discuss developing situations clearly and sensitively giving information needed by person and their families/ carers.
- Give information that helps people to understand palliative care.
- Recognise carer and family expertise and knowledge of dying person and to work in partnership with them.
- Understand and use equipment.
- Avoid unnecessary disruption.
- To administer and share information efficiently and in a timely manner and arrange and keep regular visits.
- Give good customer care at all times.

Participants suggested areas that could improve early diagnosis or give an opportunity for earlier end of life care. Discussions included taking advantage of annual health checks and making sure that patients were contacted with results of scans and tests.

It was felt that paying care workers a higher wage might attract more skilled and qualified care workers to support people to have confidence that they could achieve their wish to stay at home for as long as possible towards the end of their lives.

Theme 3: Patient wants access to the right services when they need them.

Participants wished to see services working well together including frustrations with:

- The process of discharge and referral between services.
- Having to repeat themselves.
- Not having confidence that all practitioners know their wishes.
- Efficient administration e.g. to set up DNR (do not resuscitate).
- Lack of information and understanding next steps.
- Lack of consistency.

Participants were concerned about the lack of speedy resolution regarding funding upon receiving a terminal diagnosis with little time remaining.

Participants were concerned about financial matters and lack of consistency across employers. Though not the subject of this review it was felt that the production of advice might be helpful particularly to the recovery of carers after the death of the person they are caring for.

Participants suggested improvements to services including:

- The supply of incontinence consumables.
- Help to identify helpful equipment.
- Information that they had lacked e.g. what to do after death, when to seek help after diagnosis.
- Enabling certain hospital treatments to happen at home.
- Earlier deployment of care support.
- Ways services could encourage earlier diagnosis.

Theme 4: Patient receives support for their physical, emotional, social and spiritual needs.

Online responses:

- Disagree strongly 0
- Disagree 1
- Neither agree nor disagree
- Agree 2
- Agree strongly 1

Participants were concerned about:

- Help to maintain mobility as long as possible.
- Spiritual support.
- Support following crises, resuscitation, hospital admissions, to explain intervention and any consequences and how to prevent unnecessary treatment and discomfort.
- Pain relief.
- Unnecessary travel.
- Practical solutions to home care needs.
- Euthanasia.

Theme 5: The right people know the patient's wishes at the right time.

Online responses:

- Disagree strongly
- Disagree
- Neither agree nor disagree 1
- Agree 2
- Agree strongly 2

Participants wished for their care plans and personal wishes to be shared and understood by all practitioners involved in their end of life care.

Participants wanted to be helped to avoid unnecessary interventions that don't prolong quality of life.

Theme 6: The people who are important to the patient are supported and involved in the patient's care.

Online responses:

- Disagree strongly
- Disagree
- Neither agree nor disagree 2
- Agree1
- Agree strongly2

Participants were concerned that practitioners consider:

- The views of carers/ families when supporting a dying person to plan end of life care.
- Consider the needs of children and young people in the families of a dying person.
- And respect the expertise of carers and family about the person who is dying especially if they are unable to speak for themselves.
- Holistically the needs of the dying person and their family situation.
- Information and support for carers and family after death of the person they have cared for.

Many participants related the effects of caring on their own health and how lack of support had made it very difficult and affected them well beyond the death of the person they cared for. They cited many ways that services might help to ease their situation.

Participants raised the difficulties encountered trying to sort funding and other practicalities at a difficult time emotionally. It was felt that it ought to be possible to fast track processes when a person is given an imminent terminal diagnosis to lessen the stress for families and the person dying.

Conversely to give families more time to practically sort suitable accommodation following a traumatic hospital visit and the imminent need to discharge patients when home is not suitable and family have to juggle work, finances, and other practicalities.

Theme 7: The patient is cared for and will die in the place of their choice.

Online responses:

- Disagree strongly
- Disagree
- Neither agree nor disagree 2
- Agree 1
- Agree strongly 2

Participants highlighted the information and advice they need to be able to choose how they would like to be cared for when they are dying and where they would like to die.

They want to be told what is possible, recognising that some conditions may not be possible to care for at home.

They felt that the reputation of hospices is of a caring place and care homes is less favourably viewed which may not be fair. They'd like to see this change and for there to be more quality alternatives that avoid moving people around as their condition worsens.

They wanted support to know when they should make decisions to move or increase support when they have conditions that fluctuate.

They wanted to know how they might be supported to die at home when they live alone or have carers that could not or are unwilling to look after them.

Participants were concerned about getting home as soon as possible after episodes of hospital care when they have chosen to die at home.

7.0 Conclusion.

The report is based on participant experiences and the lessons which could be learnt from these experiences.

It is based on their wishes for their own end of life care as they reflect on their experiences of supporting a friend, relative or acquaintance that died or is dying.

While it concentrates on areas that may be improved there are many positive comments that reflect the skills and expertise and the many good practices in Herefordshire.

It is important to read the participant's stories to gain a full picture.

Once again Healthwatch Herefordshire appreciates the time and emotional journey that participants took to share their experience and ideas.

We know that participants would wish for Healthwatch to thank all the caring and skilled professionals that supported them as carers or patients.

8.0 Appendices.

Appendix A: 14 stories - Patient experiences and views with type of feedback (1:1 feedback, survey responses, and focus group transcripts), location of experiences and recommendations arising from patient story.

Story 1 (1:1 Feedback) Herefordshire.

Young person with OCD leading to anxiety and depression experienced mother's death. Mum was ill seemed to recover then became ill again and moved to hospice. *Mum was happiest and most comfortable I've ever seen her in St. Michael's hospice.*

Young person was given the impression mum had longer than she had and was not prepared for death. They felt they would have gone more often if they'd known. Mum was very happy in the hospice.

Medication was given for young person's anxiety when mum became ill which made it hard to feel. At time felt helpful but upon stopping medication anxiety levels were much higher. *GP did not warn of this.* This has led subsequently to increased difficulty grieving, anger and depression and being signed off from work. *Could do with understanding needs of a person with mental health. Antidepressants are not the answer.*

Counselling (Talk, Talk and St. Michael's Hospice) and support in a young person's support group (Hope Support) have been more effective. *St. Michael's grief counselling for 17 weeks. Good to come to home as no buses. Hope Support helps a lot.*

Young person feels that adults were overprotective and the young person would have had fewer issues afterwards if they had known what was likely to happen, spent more time with mum and been allowed to grieve.

Individual lessons:

1. Involve young people at a level they can understand in planning for the death of a relative and take care not to overprotect them so that death does not come as a shock and causes long term anger and or depression.
2. Support young people as they grieve with help such as counselling and support groups.
3. Consider alternatives to medication and always advise of the side effects of antidepressants.

Story 2 (Online survey feedback) Herefordshire.

My Experience:

- *Supporting father in law and both parents through dementia to end of life.*
- *Father in law reluctantly went into rest home and was never happy there.*
- *Parents had 24/7 care at home, both had episodes of care in hospital due to infections and were disorientated, confused and were not encouraged/allowed to walk to the bathroom and so lost the use of their legs. They were individually given DNR status in hospital, but when my father came home, and I tried to talk to the GP about end of life care at home he became very agitated and refused to talk to me, saying that if he felt that dad needed antibiotics he would send him into hospital again.*

When either needed to see the District Nurse they kept being discharged after a particular problem had been resolved, so that we had to keep asking for re-referrals.

- *It was deemed impossible to give them IV antibiotic treatment at home, so they had to endure more than one episode in hospital for IV antibiotic treatment, which just prolonged their slow journey to the grave.*

End of Life Care for myself

I would like to be able to prepare a Living Will or some such, so that my wishes would be taken into account at my end of life. If I were to be diagnosed with a significant cancer once I was in my 70s, I would like to be able to choose not to have aggressive treatment but be able to access palliative care at home for as long as possible. I would like to be given the facts and options, so I can make an educated decision.

I would like more joined up care between hospitals and GPs and community services.

I understand the Liverpool Care Pathway has received some bad press recently, whereas I am very much in favour of that Pathway. The problem I think is that it needs careful consultation with the relatives involved, which is not always easy/practical.

Individual lessons:

1. **Support people to stay mobile for as long as possible. Provide training for care workers around encouraging mobility in the home.**
2. **Enable people to die in the place of their choice.**
3. **Enable some hospital-only treatments to happen at home.**

4. Involve person requiring end of life care/palliative care, and their family, at an earlier stage in discussing their wishes and options, including DNR and hospital treatment to prolong life.
5. Training for GP's to discuss end of life care.
6. Resolve situation about District nurses, discharge and the need for re-referral to aid carers.
7. Encourage people to plan for end of life providing facts and options for treatment including being able to choose not to have aggressive treatment.
8. Improve joined up working between hospitals, GPs and community services.

Story 3 (Online survey feedback) Herefordshire.

My husband died in hospital on a busy surgical ward. They did their best but the palliative care nurse only phoned the ward and did not visit after the initial meeting.

My husband had to have an emergency operation. It was I that brought up discussing his wishes before the operation knowing he had a chronic heart disease. The registrar seemed relieved but had not broached the subject himself.

I would like palliative care either at home or in the hospice. The hospice has a very good holistic approach that looks after all the family. I would like someone to discuss the facts with me and my family before any decisions are made. If possible my wishes should be respected over anyone else's but there are times when one needs someone else to help make decisions. I like open and honest information.

Individual lessons:

1. Improve palliative care on the wards to improve sharing of end of life care plans and views on DNR and encourage hospital staff to ask patients and their families openly.
2. A holistic approach that looks after the whole family.
3. Discussion of facts with person and their family before decisions are made.
4. Provide open and honest information.
5. If possible respect the person's wishes over anyone else's but give help when necessary to make decisions when patients and their families need it at a difficult, emotional and confusing time.

Story 4 (Online survey feedback) Herefordshire.

We struggled, at times, to access the spiritual support that the person has requested.

What could be improved?

Support for family after the death.

If you experienced end of life care what would you want to be different?

I would like to die where I choose and I would not want to be 'kept alive' when there is no hope.

Individual lessons:

1. Consider how spiritual support is made available to people in the End of Life pathway.
2. Improve support for family after the death.
3. Enable patients to choose where they die.
4. Support patients to avoid interventions that prolong dying against their wishes.

Story 5 (Online survey feedback) Herefordshire.

I and my family knew my husband's wishes as did the Surgery staff. Fortunately, he was enabled to die at home.

My husband died 10 years ago when the NHS was not under as much strain as it is now. His care could not have been improved upon, though when in hospital liaison between hospital and surgery was not that good.

I have completed a Lasting Power of Attorney setting out my wishes - basically to die at home if possible, but do not want my family to have to care for me, so would need help from outside. I do not want to be 'kept alive' by artificial means or resuscitated.

Individual lessons:

1. Improve liaison between hospital and GP surgery.
2. Encourage people to complete plans for the end of their lives including lasting powers of attorney.
3. Support people to die at home without the care of their family.
4. Support patients who do not wish to be 'kept alive' by artificial means or resuscitated.

Story 6 (Online survey feedback) Herefordshire.

The recent end of life care I was part of happened very quickly from the time the person became terminal. The person had autism, had lived with me for 12 years so I had knowledge of how she indicated pain. The St Michael's palliative nurses were fast tracked to attend by & large were supportive but didn't have control of medication.

The carers were mostly fine but a couple needed to realise it was mine & persons home. They were there to help in conjunction with my help & advice. The district nurses who attended didn't take on board that people show pain in different ways. That I knew the person & was trying to advocate for her. The day, night she died I was told twice she needed to be thrashing in pain before they would start the morphine driver. Once it was said in front of her sister.

I have complained to district nurse who came to collect equipment after death. It was not only one nurse who didn't acknowledge pain. The team leader who came the previous day also didn't acknowledge what I was saying. She was a senior nurse & said she would take it up with them. I complained to Dr who came to certify death & Dr who registered death. I didn't put it into writing because I have done a lot of that & get same replies, staff training etc. I believe the quality of the d/nurse support has declined since my last experiences around 3& 4 years ago.

The other glitch was I rang 111 the night the person died at 5am. No one attended. I had to ring surgery at 8 30. They had no knowledge. I was fine but thinking of families who had no experience of home death it could have been traumatic. It seems to me home death has been "professionalised"

I personally want to die at home. If I am no longer able to voice my opinion I want my family's views to be listened to & acted upon.

Individual lessons:

1. All staff involved in Health and social care to be reminded to respect that they are operating in a person and their family's homes.
2. All staff in Health and social care to recognise and respect the expertise and knowledge of family and long-term carers about the person with a terminal diagnosis especially where that person has difficulty expressing their views e.g. a person with autism. Ask family and long-term carers how they manifest or communicate pain and other needs. Work sensitively in partnership with them to support the person's progress towards a pain free dignified death.
3. Learn lessons from this story and give feedback and training to district nurses and team leaders ensuring they have sufficient expertise and skills in:
 - Appropriate pain care and use of morphine driver.
 - Sensitivity when listening to, discussing and responding to pain with family and carers.
4. Provide clear advice about who to contact when person dies in the night and ensure that calls to 111 leads to someone attending and families know when this will be.
5. If a person is no longer able to express their opinions listen to family views and act upon them.

Story 7 (Focus Groups feedback) Herefordshire.

My mum passed away in January - not an overly positive experience.

- *Diagnosed with lung cancer in. Problems with foot could not walk properly. Doctor noticed out of breath sent for scan shadow on lung spread to brain attacking nervous system and that is why her leg was affected. This was three months earlier. It was 6 weeks from diagnosis to passing.*
- *Told without medication could die within 2 weeks. Involved immediate family. She told us all did not want to have treatment if it just prolonged her life say 6 months. Her personal choice.*
- *Saw consultant (Herefordshire Hospital) who gave 2-week prognosis. Following brain scan that gave rise to diagnosis gave her medication - steroids to reduce swelling that gave a little respite and movement back though still needed help to walk.*
- *Second consultant she asked how long she had - he said let's not focus on that we have given steroids and let's get your lungs sorted lets focus on that everyone is dying so let's focus on that. She thought perhaps some light at end of tunnel so she kind of changed a little bit and became open to having some medication.*
- *Thursday consultant said we need to have you in for a scan this weekend coming, and we can see exactly what we are dealing with but that has to happen. On Friday 9.30 phone call - cancellation need to have appointment at hospital at 11.00 it took about an hour to get in car let alone get dressed. We said we could not make it in an hour and a half it's just not possible. They said ok. Saturday my stepdad got her up not knowing if appointment would be Saturday or Sunday. Did not hear anything. Sister rang up. Was told because had refused Friday appointment she would have to wait another week for the scan until the next Thursday. She didn't refuse it could not physically get there.*
- *So nothing happened for two weeks. Had lost all movement in her arm. It had also taken her voice she couldn't speak now.*
- *Had an appointment approximately first week of January. Had scan and given appointment to go down for chemo in Hereford. She didn't want to go at this point, but we said well let's give it a go. She was waiting for 10 hours and sat in a wheel chair for 8 of those hours. My sister **commented** so they found her a more comfortable reclining chair to sit in. And the end of that day she finally*

had some chemo but she was too weak, so they gave her a half dose. But she developed a very bad sore on her bum from sitting in the wheel chair that probably gave her more discomfort than anything else.

- *The following day they told her she had to go to Cheltenham to have a kidney function test or she couldn't have any more chemo. So, she refused she begged really, she said she couldn't sit in a car she was in so much pain so we didn't go to that. Looking back, she was close to passing so to have chucked her in a car - wasn't happening.*

At start had she made it clear to consultant that she did not want treatment or to family?

- *I wasn't there so I can't say for sure that she did. But she wouldn't hold back so I wouldn't be surprised. But she may not have. I can only say what I heard. To us it was very clear. She felt quite strongly about that. Her sister died two years before of cancer, so she was very frightened of the dying process and she didn't see the point in prolonging it if it wasn't going to go anywhere.*
- *She died on Thursday. Within a week on the Sunday my stepdad could sit her up - make her look presentable - she was very proud she wouldn't go out of the house without make up - we decided to take her grandchildren to see her so she was well enough that it wasn't going to upset her or upset the children, but we thought it was important that they saw her. So, we did that. Her voice was very croaky, but she could get her words out.*
- *So on the Wednesday I was working at the time and had no phone signal until I came out of the dip I was working in. At 4.00 she had deteriorated my phone was pinging messages that we needed to go to the disabled aids to get her a commode as couldn't get to toilet. I darted around to get her this commode that she was never going to use but they were all saying go and get it cos they couldn't deliver it. I stayed with my mum when one of her district nurses came around. She had deteriorated now she didn't want to see anybody my mum didn't want to see her friends she didn't want them to see her like that.*
- *So that was the Wednesday then the district nurse come around to give her a driver I've learnt since that when they give you the driver that is kind of when you are not going to be alive much longer than that really. So, they did the driver which is in a case and its locked in a case and so my mum spoke to me while they were doing that she asked me how long she had left to live so that was the last thing she said to me but I couldn't answer I didn't know and I didn't want to lie so I kind of said I don't know.*

- So anyway, that was the Wednesday. She was quite relaxed my step dad had bought a recliner, so she was comfortable the drugs were working doing what they got to do. I went home.
- Then on the Wednesday evening I had a phone call from my father in law to say I don't know what is going on, but her breathing is going *unusual*. So, we went there all her family were there then. So, we stayed with her the Wednesday night about a couple of hours sleep but we were all there.
- Thursday morning my wife popped around she had deteriorated, and I said just prepare yourself because she - in one day she looks pretty bad. At 2.00 in the afternoon. My sister had found out that St. Michael's hospice had some teddy bears that you can give to your children from Nan. Myself and my wife drove to St Michael's hospice to get a teddy bear to just get out for an hour. Beautiful place a lady gave us them. Anyway, as we were driving back - only out of house for an hour. I was 5 minutes from house my sister said a district nurse had come around to change the driver. And my sister said where is the key for the driver? And I said, what do you mean? And my sister said, the key, the district nurse hasn't got a key to open it. So, I said, well I don't know. So, my sister said, well you were here when the nurse did it. I said I'll be there in a minute. Anyway, I walked through the door - and I have no reason to be negative toward doctors, nurses, whatever - but immediately, the nurse had a look on her face that she wasn't happy. So, I walked in. The nurse was stood there, my mum here, and me here. A normal sized living room. And I said to my sister, why do you need a key? So, my sister said, well the nurse does not have one. So, I said, yes but you are not going to lock something and then leave the key with the people cos there is no point in locking it up is there? So, the nurse said its procedure. I said right ok. So, the nurse said, anyway you wouldn't be able to access the driver because you need a code. So I said, that makes less sense to me that you need a key! Locking it up? Hand on my heart she shouted "Excuse me you are being very rude you've just walked into a situation. And I was about to respond - no you've just walked into a situation, but my sister said, let's not argue, my mums there now. So, I was there, stood there, thinking - this nurse has just made me feel like I should not be in my home where I spent 20 years living ...
- So, I'm trying to make sense of this in my head ...have I done something wrong here? Have I been aggressive? I've been awake most of the night so am I thinking clearly? So, trying to figure this out. It took me about an hour to get it straight in my head and I thought no I was right to say that because this is nonsense and my mum would expect me to say something. I asked my wife who works in a professional situation and said was I out of order there? She said

you are not the professional here. Regardless of what you said she should not have responded like that.

- *So, the nurse did all that she did her driver and all that. And then said I'm going to have to get a key now so she walked out of the room - disappeared.*
- *My brother said when she had walked in she didn't say anything to me she has just been on the phone now saying she is going to be late for her next appointment. So, she wasn't happy.*
- *So, I'm looking - she has left the driver fully loaded this huge syringe of drugs in the middle of the living room with no lock or anything. She hadn't even taken it with her. I said is that procedure? My dad said don't say anything when she gets back because I just want her to give your mum the drugs and her to go.*
- *So, half an hour goes by she gets the key and comes back. Now I thought in that time you might have had a bit of thinking time she might have gone -even if she didn't think she was wrong -said I know the situation is not good, that shouldn't have happened let's focus.... She didn't mention it. She is there she is doing her work another nurse turns up they look at each other one nurse says to the other what are you doing here? I'm just doing whatever - other says that's what I'm supposed to be doing. So both looking at each other cos it is clearly a mix up - anyway as to who should be there - I'm biting my tongue. Anyway, one nurse goes. They are talking about NHS not having any money you can chuck all the money in the world at it if you don't plan and organise basics it's just wrong in my opinion. So the nurse did her thing and left. No apology.*
- *I kind of figured out in my head that I didn't let my mum down by - I mean I didn't even challenge that nurse I just asked a question I kind of figured that out...*
- *I have to say as well - my mum from point of diagnosis to the six weeks didn't have one visit from her GP. So, on the Wednesday the one district nurse was great - identified that and said that should never happen. I will be ringing your surgery tomorrow and you will have a visit from doctor. So doctor came out the next day (Thursday). But what we did not realise was that my mum should have had a DNR do not resuscitate so if anything had happened and we'd have rung an ambulance they would have had to resuscitate. That was never put in place.*

Do you know if there was an end of life plan?

- *I don't think there was an end of life plan my sister has got a lot of stuff written but I don't know.*

- *The GP came out still didn't bring the DNR with her she said I'll come back out after surgery finishes.*
- *She is clearly dying now her breathing slowing down - we are totally aware of what's happening. She had all her family with her the GP came around. My dad is really concerned now. The GP said this is secondary stage breathing it is slowing down she is dying basically. The GP she put our minds at ease that she wasn't in pain or anything and then mum died about half an hour after GP left. Passed away.*
- *What I also find bad is that when she passed. We weren't really prepared because of the time scale. We had asked the GP what we do when she dies ring 911/111 I can't remember. Anyway, whatever it is I rang and I'm given a list of options. One is to arrange an appointment with a doctor, one is to make an appointment with the dentist, and one is - are you waiting for a call back? So, I'm thinking, there's nothing about someone passing so I rang to make an appointment. They said yes, yes, we can help you. You get asked these questions and I did all that. I must advise you it could be up to 6 hours before you get a call back from the doctor.*
- *So, I put the phone down and about 20 minutes later I got a call back from a doctor same questions same answers and we'll get a doctor to you that could take 2 hours. 2 hours went by a doctor came. So, did all that so I said what do we do now, and he said ring an undertaker. Mum had said which undertakers she wanted so I rang there. Said it would take 5 hours. So, all about 5 hours which I would have thought was a really a horrific thing. If you had told me that that would happen I'd be horrified, but everything... it was time to use...it had relaxed my mum she looked like my mum again. So, I used that time really well. So that's my experience.*

Did anybody sit with the family and explain the process of death and what would happen to your mum? Or to your mum?

No, No.

Did your mum want to be home?

Yes.

Did your family want her to die at home?

- *I think so they wanted what she wanted to be honest.*

- *It all sounds negative but - She had a Macmillan nurse I didn't meet who was great apparently, a couple of the district nurses were really nice but there seems to be an inconsistency from one nurse to another and even consultant. One consultant great another not so great. I know that's sometimes a personal take on that person but there does not seem to be a consistent level of personal interaction with people - maybe that is something you must learn. Every nurse that came is going through the same stuff again the same questions again it's a barrage of constant questions being asked and its well we just had a nurse here 4 hours ago and you are about to ask the same questions again and it's all written down...maybe its protocol.*

Was there anything left there with your mum?

- *Yes, so she had like a box with some medication my sister had some stuff. I looked at nurse's name because I was told I should put in a complaint. But I didn't because I don't think it's an easy job to be honest with you.*
- *I have tried to take a negative and turned it into a positive.*
- *That nurse would have known that the hearing is the last to go and my mother would have heard that but couldn't say anything. I've seen the nurse out and about but I just think it's her thing but not mine but if it stops it happening to someone else perhaps I should.*

Early Diagnosis - could anything else have been done? Doctor seems to have spotted something she had not presented with...

- *I think we have to take responsibility ourselves a little bit my mum was quite a heavy smoker all her adult life and I was speaking to my brother and he said years before she said one New Year's Eve that she had lung cancer and then the day after when he asked her about it she said I didn't say that. If she had that feeling you've got to take yourself...people are scared aren't they...So, whether they could have... they can't diagnose if you are not in the surgery. I do wonder had she gone 12 months before whatever...She always said even if she got ill she wouldn't stop smoking - she was a committed smoker! So, you have to take a bit of responsibility.*
- *My auntie was diagnosed early they told her they reacted quickly because she didn't go to the doctor often.*

What would you like when you die?

- *I think ideally, I'd like to be at home but I'm not sure. I think for that to happen I'd want consistent care coming with the people coming into my home. I wouldn't want my children to sort of see what I saw to be honest. I think a*

bit of knowledge; a bit of compassion being shown, and information and I think it could be a really lovely way to pass. But, it's got to be handled right. And that's all it is compassion and knowledge and I'd want to be at home surrounded by and that's the nicest thing that I have with my mum is that the family were with her and it shows respect to her doesn't it? And that's what I'd want in an ideal world. If it was that type of illness.

So, would you want to be able to plan it and know what to expect and make sure everybody knows what you want?

- *I think so yes.*

How far ahead would you want to plan it?

- *I'd start planning it now. I've got - and I don't mean that in a morbid way. Music is important to me, so I'd think what music I want played in my funeral all that sort of stuff I don't believe in over planning because we don't know what is going to happen.*

So it has to be a plan that can change because you don't know how you are going to feel when you get to that point?

- *Yes, and again it's not something I want to dwell on but have a rough idea -I'm a very changeable person I might choose a song today and want a different one in 5 minutes time! But I think I'd want my family to know what I want it just takes the - families can bicker sometimes about the silliest things. You know what I mean and if they all know what you want it kind of takes the pressure away as well. Because we treat people differently even our own family. When you're a sister a parent a brother whatever it is our relationships with those people differ, you know what I mean? My mother was different to me than she was to her husband so I think it's important that you put the things you want personally your family will realise that.*

Would you want to know what your condition was if there was something?

- *Yes, I'd want to know so I could make decisions that are relevant to what's going on I think. Yeh, I definitely would I want to be treated like a human being. As you get older you know. You shouldn't be treated any less It's almost like people get treated like a child. Like they are a child. I think that is a bit of a failing in this culture.*

Explained hospital current approach being trialled - to encourage patients to start end of life care planning when diagnosed with a life limiting condition - do you think that's a useful approach?

- *Depends on the timescale if you ... It can only start earlier if they diagnose. We're not talking hereditary?*

Could be anything e.g. dementia. Would you find it completely off putting? You seem a bit conflicted?

- *I am conflicted. There is technology for genetic illnesses when they are looking to be able to predict illnesses you can get and stuff like that. And I might be going off at a tangent a bit But, because of the world we live in and the care that we pay into with the National Health Service. It's almost if you can afford to pay for your care you can skip cues and things like that. I'm kind of concerned that in the future we start looking at illnesses that could be happening they'll start to put your premiums up, so I worry about that.*
- *All these things are great and knowing about the services. But can cause a conflict it is a really sensitive time.*
- *Would have liked to have stayed with mum for 10 hours before they took her away, but other family members did not want it.*
- *Would have been useful to have hospice 24-hour phone line but have to take some responsibility for not knowing.*

Individual lessons:

1. Upon diagnosis arrange to meet to give full information and support person and family to make end of life care plan and note person's wishes about where they wish to die, mediation, treatment/intervention and DNR.
2. Recognise that families can disagree so take every opportunity to discuss options with dying person and record their wishes to avoid conflict between carers/family.
3. Treat older people as human beings not children.
4. Share care plan to all involved.
5. Avoid unnecessary treatment that prolongs life or disrupts remaining life unnecessarily against person's wishes. Do not give false hope by avoiding difficult conversations focussing on one aspect and not considering whole picture with patient.
6. Consider dying person's physical and support needs and limitations with regards to travel to appointments at short notice.
7. Do not record refusal on practical grounds as a missed appointment.
8. Consider how appropriate it is to delay an appointment for a week when someone has two weeks to live.
9. Schedule GP home visits as soon as possible following diagnosis.
10. Take action to improve the practice of District nurses to be:
 - Consistent, well trained, organised, compassionate and professional.

- Respectful in somebody's home.
 - Supportive and sympathetic to family and carers remembering that a sharp word or negative comment is particularly impactful to people who are tired and emotionally drained.
 - Competent to deliver pain relief and clear about procedure.
 - Mindful about asking the same questions over and over as this can be difficult for family.
 - Apologetic if they get it wrong, are stressed or over stretched/ rushed.
 - Never argue or undermine carer in front of dying person who has reached a stage where they can't respond but may be able to hear.
11. All practitioners to offer clear information to the dying person and their family about what to expect, how to look after a dying person, what support they can access, when to call for help and what to do when they die.
 12. Explain options after person dies an expected death at home so that family can adjust and don't feel rushed if they wish to retain the body for longer to say their goodbyes.
 13. If 111 is the correct place to call ensure that arrangements agreed, take place.
 14. It would be useful for people caring for people at the end of their lives at home to be told about the hospice 24-hour telephone line.
 15. Encourage people to make plans or to discuss their end of life at an early stage in illness or in life recognising that plans can be changed. This will:
 - Allow people to have more say about where they wish to die, their views on treatment and DNR.
 - Allow people to discuss their wishes with their families or carers.
 - Allow practitioners to gain an understanding of people's expectations and information or support needs.

Story 8 (Focus Groups feedback) Herefordshire.

- *My experience was really a bit like (story 7) but mother was like 16 years ago. We knew she had cancer because she had been unwell but not diagnosed and then she was blind as tumours had blocked both canals and both eyes completely dead and I nursed her at home. (I was a nurse.) But I have a serious deteriorating condition so by then I'd finished work because of it.*
- *The district nurse came out we didn't get on we crossed swords. We did cross swords she wouldn't come regularly.*

- *Mother used to get some whopping bad heads her head would swell and go pumping and red but from the neck down her body was completely cold. And this district nurse didn't believe at all and the doctors.... I had a community nurse that came out cos luckily, I knew a consultant cos, yes he was doing Alzheimer's as it is now then, but I knew him from when I was nursing previously. And he said you are falling through the trap and you need somebody because they weren't linked up then and he said I'll take you on board because there is dementia because of the tumour damage. So, he took me on which was a great help and sent out a community nurse.*
- *He didn't see quite the bad head he walked in on the aftermath when her head was cooling down. When her temperature was going up she sort of flipped because she didn't know what was happening because you couldn't control the pain and afterwards she'd sleep for about 48 hours. You couldn't wake her if you woke her she'd be sick and vomiting and in agony and you just left her and it was as if she was unconscious but not quite -a very, very deep sleep.*
- *And the doctor said you must call and luckily, he was on call and I phoned and I said mothers got a bad head - he only was around the corner before I had a chance to put down the phone he was with me. He said I haven't seen anything like this. He couldn't take her temperature under the arm because there was nothing and the temperature in her ear was normal, but the sweat was pumping out and her head was swollen and red and he said she had got - there was more tumours there than what they realised and so she was put on morphine. The other nurse came and said nobody have seen these heads that you keep saying about real narky. I said yes, they have. She said, who? I said the doctor have. She said well he haven't mentioned anything to me about it and so that was why I was surprised to hear (story 7) because I thought they had improved.*
- *Then she didn't come then for a few weeks. They kept giving her 6 months to live. That went on for three years. She'd scream out in agony let me go to peace land get me out of this agony. Smother me! I'd say sorry mother I'm not going to smother you I'd be in prison. I don't care I'd be out of this agony. And eventually they put her on patches and Oramorph and she understood. The doctor said you can't. And then I said at the end of it she started saying give me a sherry. And the doctor said don't give her a schooner give her a half a glass, and I said well I give her a half a tumbler. And he said give her the full tumbler it won't hurt her. So, get me out of this agony get me to peace land give me a sherry!*

- *And then one day the OT came and got me a hoist. She'd gone from 15 stone down to 4 and half stone when she died and she (district nurse) didn't see the OT there. She said what is this hoist doing here? I never gave permission for this hoist to be brought here. And the OT stepped out and said, no I did. Oh, didn't realise you were involved. (And the OT said) Well where have you been? (meaning the District nurse). Because they'd been looking in the folder to see when she'd been coming, and they'd noticed that she hadn't been at all. Well I'm here. (District nurse). So, the nurse said I'm not happy I'm getting the doctor here.*
- *The doctor came - the consultant and this is about 12 months before she died, and she was in one of these sleeps. And the doctor was here the consultant and me next to the bed and the dog was curled up on the bed because he was wonderful with her he was her eyes. And the consultant said if that was like that you'd be had up for cruelty nodding at the dog then mother then me (meaning the dog was like mother) I said I know, well what can I do? He said nothing - he said you know she could go in days? I said yes but she rallied, and it was 12 months almost to the day that she did pass so she almost made that last 6 months.*
- *They were very good the podiatry come to the house and the optician they said but you know she don't really need glasses because she can't see I said I know. cos every time we went to the eye hospital with the trainees they said can we look in your eyes I said but there is nothing there they said but the chances of seeing that again is very high, but she said there is nothing there. There were no nerves no nothing it was completely dead.*
- *Then 6 weeks before her speech - she couldn't say foal she said babby horse her speech had gone and different words had gone. She started using village names for people. I couldn't work out who (village name) was. And then it dawned on me it was her God daughter because she used to live in village name.*

How much information were you given about the effect of the tumours and what was likely to happen?

- *She won't be here in 6 months nothing else. It helped that I had a bit of background in nursing, so I had an idea of what was happening. Doctor and I did have a chat he said well when it was first discovered he said we both know she has got it. How do you want to what do you...? I said I'd like a scan, but I do realise she is too ill to go in one. For the full length she needed. She'd had one but this was 12 months earlier, but we knew a lot had spread and it was slow growing obviously. It was. She said I'm not going in that tunnel. She was too ill to. So, it was just left but like they said if she was in hospital or in hospice she wouldn't have lived that long but because she was home and I*

nursed her and I knew what to do it was just getting her through. Then one day it was bad, and my brother rang to say he'd had a foul my sister visited she said I hadn't told her about the foul I said I had. She couldn't remember 'twas a bad day.

- And then when she got up next morning I said we are up to see the babby horse. That was her last day up. She came home went to bed and she was in bed 6 weeks.*
- They sent the emergency duty team then - morning and night - to help me and they couldn't believe there wasn't a bed sore red mark or nothing on her.*
- Then I had a bit of an argument with the district nurse because I knew she would live till the Tuesday because it would have been fathers 80th birthday and her father died on my birthday and she always said why couldn't he live the extra half hour to die the next day. She always said that. Why couldn't he live the extra half hour? The district nurse said you know she won't live the weekend. I said she'll get to Tuesday. And she did. District nurse said you were right. Her last words were on the Sunday.*
- The District nurse said you do know if she does die not to call the doctor till 6 in the morning. And on Tuesday night my brother come I said she's only got about 2 hours left as she'd started to shut down from the feet up and the veins ...and 12.30 he said I'm up and off don't call me if anything happens. I had had day and night for a few days and I was starting to get a bit giddy, so I went to bed at about half past one / two and I woke up at 10 to 3 and she had just gone. So, I was there on my own not to phone my brother and not to phone the doctor. And then when I called the doctor. She said why you didn't call me? I said because I was told not to call you before 6 o'clock - she wasn't amused - she said you should have been told 2. I was told because it's an expected death I was told not to ring you.*
- I never had an apology from that district nurse.*
- That was 16 years ago that is why I was sad it is still happening.*

Speed of diagnosis. Could it have been spotted earlier?

- Yes, because I said to the doctor about it. Consultant said no, no, no I said the signs are there. And I sent my brother with my mother and he said mother and daughter don't get on that's why. I felt there was something more than what you are all saying you think it is. I said this needs picking up. With me taking her. I thought send my brother with her he might be able to do another track.*

The doctor said oh there is a problem there because mother and daughter don't get on.

- *When I first noticed it to when she died it was about 5 years before she died.*
- *Hard to know what is getting old and out of breath and what is a problem. And the older generation is a bit more frightened or just want to get on quietly.*

What would you like when you die?

- *I know I can't be at home because I live by myself. Full stop. But yes, I know I've got good carers. It's like last year I was so ill I'd been thinking about doing a DNR but luckily, I didn't otherwise I wouldn't be here they had to resuscitate me last year. And what I was impressed with a week later they sent a nurse to counsel me (not Hereford - out of county) about what I went through, and did I want help, and did I want you know to work it through and talk about it - not that I was aware of much about it - but I thought it was very good. Now I wouldn't have had that at Hereford but Yeh....*
- *I'm still a bit out on the DNR because of all that's wrong with me but Yeh I know I'd like at home but that's going to be impossible it'll have to be hospital or hospice or somewhere -not happy with it but that's the way....*
- *It's just they might do continuation at home as now, but it would just be that much easier because here would be 24 hour care around. So, there would be help at hand cos when I change I go very quick there isn't a lot of warning or anything. I could be fine now but in 2 hours' time I could be in hospital. I've had sepsis and be bad very quick Yeh, I've come to the conclusion it'll be hospital or hospice care or whatever.*

In the hospice what would you want, what would be important to you?

- *That somebody would be around they wouldn't be with me constantly, but somebody would be around just keeping an eye. And a friendly atmosphere hopefully in a side ward. Like what I did with mother what I did when the doctor came they said how peaceful. She'd never been a room that was so peaceful, but mother liked her music, like you do, so for last 6 weeks got a little portable CD player and I just played her music gently in the background. With the curtains a half inch open so the spirit could pass through -that was what I was taught. She said how peaceful I kept her music playing until the undertaker come.*

How much information would you want about your condition?

- *I'd want to know. But that's just ... I expect (story 9) is the same cos he'd know anyway!*

Explained hospital approach trialling -do you think that's a useful approach?

- *It's planting the seed letting it mature and it's up to you then...*
- *It's like my condition. The plan was in for that like years ago. I've had it like 30 years. I knew they said I'd be in a wheel chair by the age of 50 I said no I won't. So, they'd put the plan in from 50 and then the consultant said I had to move in to Hereford which I didn't like cos I'd get everything that I'd need. Yeh when I moved in I had everything I needed there and then it was all called on. But it's the same for long term illnesses and they just bring in the end of life into line with it.*

Individual lessons:

1. District nurse to:
 - Recognise and respect expertise and knowledge of family/carer.
 - Listen to carer concerns about events or episodes that dying person is experiencing when they or GP is not there and take steps to witness episodes and offer necessary medical care and support to person and carer.
 - In particular ensure that pain relief is promptly arranged.
 - Behave and communicate professionally and arrange and keep regular visits.
 - Recognise that they are entering somebody's home.
 - Apologise if mistakes are made.
2. Practitioners to communicate effectively to coordinate care.
3. GP to take carer's concerns seriously to diagnose patient as early as possible.
4. GP to check that carer is gaining the support they need and organise a change of personnel where personality conflicts occur.
5. GP to apologise if mistakes are made.
6. Recognise the support and health needs of the carer looking after a person who is dying over a long period at home.
7. Make information available to people who live alone with conditions that can develop rapidly so that they know what options they could expect for end of life care and if it would be possible to die at home.
8. After resuscitation e.g. during a crisis in hospital, offer to talk patient through this experience afterwards at home so that they can understand what happened and make decisions about future wishes.

Story 9 (Focus Groups feedback) Out of County.

- *When I had completed my medical training I went to see name in named Hospice and asked her if I could work with her she said you'll have to train as a GP first that's the training you'll need. So, I went off for another year or two and trained then she took me on and worked with named hospice for some time. And name knocked me into shape and she asked me if I'd help her by taking on named hospice in place name a long way from place name. So, I was installed as medical director in named hospice and I loved the nuns they were super.*

From what you saw what did you think was good practice and what did you think could be improved?

- *The early hospices were absolutely fantastic. Listening and tremendous skills in symptom control. And the willingness to face any question so when people asked me for euthanasia occasionally I would always say will you give me 4 days and see how you feel in 4 days' time and never did a patient ask for euthanasia again once they'd experienced good hospice care.*
- *Loving nurses, perfectly good nursing never ignored and the doctors bringing the body into a fit place to live.*
- *Suicidal - once have decent palliative care never once asked to die again.*
- *And so that's my experience.*

Anything could have been better?

- *What was going on in hospitals was often atrocious. Patients in severe pain, doctors who had no idea how to stop the problems. And often lying to the patients so that they thought that that would reassure them. Not finding out if patients want to know or not know.*

What would you like when you die?

- *Well if I die whizzbang in a car crash or heart attack then ok but if I'm diagnosed with a terminal condition then I would want to be at home with hospice care. That's all really. I think if I needed some hospital care to remove a tumour ok, but I would want to be home as quick as possible.*

So, you live in a rural area - how does your wife feel about that?

- *She agrees we worked together in a hospice.*

Have you made a plan?

- *Yes. In fact, I suspect I might have cancer of the colon. X-rays didn't show enough.*

Is there a part of you that does not want to know?

- *I just can't be bothered to go in again to hell with it let it kill me!*

Explained hospital approach trialling -do you think that's a useful approach?

- *I'd like it.*

Individual lessons:

1. Good quality hospice care, caring nurses, skilled nursing, never ignored and medication to manage pain bringing the body into a fit place to live.
2. Support people to develop end of life care plans and die at home if they wish.
3. Support patients to get home from hospitals as soon as possible after necessary operations during palliative care.

Story 10 (Focus Groups feedback) Herefordshire and out of county examples.

- *Someone going downhill rapidly social services were bought in rapidly. They promised this lady that they would be able to go in a home near Malvern. Wasn't until in ambulance was told would go to Hereford -north of Hereford. One in Malvern was 3 miles up the road. The one in Hereford had no buses. Cost £50 each time they visited - had to get a taxi. And the reason for doing it was because the one in Hereford was cheaper than the one in Malvern. More expensive for the family, more inconvenient, disturbed the end of life and everything. That was not on I'm sorry. I did make a formal complaint and social worker disappeared shortly afterwards, but I wouldn't want that to happen to anybody else.*
- *Diagram about End of Life care in Herefordshire shows nothing out of County.*
- *One friend went in shower, fell, wife couldn't pick him up. Friend and I picked up put to bed two days before he died.*
- *Mother in law kept falling. Ambulance took her in they said take her home. I said no, they said yes, I said no they said yes. I said would you give me 24 hours to find somewhere. Then she can move in sell her home and be settled.*

And I did find somewhere. First class where we never thought we'd find a place but that was where she died. The house was sold. She enjoyed her life to the end. That was another county.

- *Now I'm beginning to attend more funerals than weddings. Attend hospice but I've noticed like to come home before they die. St. Michaels is remarkably good around here I feel that most people want to go home, and St. Michaels helps to do that. But with GP services so stretched whether that will be a viable alternative...I don't know.*
- *The hospital and district nurses visit at home and my experience that works well.*
- *Mine a national company no statutory sick pay at all until I finished and started to complain. And then they offered me some statutory sick pay offered to pay it to me didn't pay it, so I then went through to customs and excise then they paid another £1k.*
- *When you are getting nothing and when you are fighting to get something that makes the situation difficult.*

Identified in timely way.

- *It was the same with me they could not identify because I couldn't. I went to GP who put me on antibiotics I rang up following morning she said you came in yesterday you can't come in today. Tried later same answer my wife came in later took one look at me took me to surgery in car. Receptionist said he's third on list he'll get around to him. My wife said I was a district nurse here I'm going to see him now. He said bring him in she said I can't. He came to car with nurse and oxygen took one look dialled 999 rushed to Worcester A&E Tuesday lunch time in 15 minutes. Incredibly fast saved me then and saved that night and then gradually went up.*

What could they have done to help you to identify your symptom earlier?

- *Need to be able to get an appointment with your doctor as soon as you can this is of paramount importance. Because you don't know if serious situation or not should be evident if person does not ring often should know if urgent appointment requested. Good triage needed.*
- *Annual check-ups did not pick up except high blood pressure. Had medication. I checked my own blood pressure. Wasn't happy. When I went they changed tablets but didn't flag up anything else. I think they could look more at this.*
- *Wasn't clear when should come again. That would help.*

What end of life care would you want?

- *Warden supported homes should be more available.*
- *I have started to write my wishes, but I was never told to. Just finished doing it. I have a box with it all in. You know you are going to go sometime. Not everyone wants to do this my wife does not like to talk about it.*
- *Happy at home. I'd want a pain free death at home. Support depends on condition.*
- *Years ago, children under ten not allowed in hospital better now because are allowed.*
- *I'd prefer hospice to care home. Can put your own stuff in room the people are so caring it is not true. Don't necessarily have to be there all the time. Can go home.*
- *Problem if go to wrong place and they can't handle condition and you get moved out. Someone I know was moved out as they could not handle her dementia. Went to home with separate dementia unit. It depends what disease you have got.*
- *Malvern have every form of care home possible.*
- *Need to ask if wife would want you to die at home important to talk to family.*
- *Give family choice they may be willing to look after you may be willing to.*

Individual lessons:

1. Social services to consider cost and travel distance for family when finding a care home for end of life care.
2. Include commonly used out of county care in Herefordshire End of Life diagram.
3. If more people can die at home, consider how emergency help could be offered e.g. help for elderly carers with falls and physical needs.
4. Consider solutions to give families time to arrange suitable residential or home care if necessary following hospital treatment.
5. Encourage good end of life care in care homes ensuring suitability for developing condition e.g. Dementia, so individual is not moved around unnecessarily during palliative care.
6. Encourage hospice at home.

7. Ensure GP services have sufficient resources to support people who wish to die at home and their families.
8. Support joint working between Hospice at home, GP surgeries, District and hospital nurse home visits.
9. Businesses to support people with life limiting conditions to have sick leave and pay when needed.
10. Improve triage to allow urgent appointments two days following at GP where necessary.
11. Increased warden supported homes.
12. Ensure that death at home is pain free.
13. Encourage people to record their end of life wishes recognising that some do not wish to.
14. Continue to allow families including children to visit person in palliative care in hospital.
15. Listen to person's wishes but encourage them to check family are able and willing to support death at home too.
16. GP's to advise patients clearly when they should come again to surgery regarding ongoing conditions e.g. high blood pressure.
17. Annual check-ups to be used to pick up heart conditions?
18. Diagram of Herefordshire End of Life care does not include out of county in diagram.

Story 11 (Focus Groups feedback) Herefordshire.

- *My wife's grandmother. Her husband had died and she had lived in a warden controlled bungalow. Had already had two strokes and had another stroke and was taken into Hereford. I didn't realise at the time that every time we went into see her. All there was by the side of the bed was a little cup of red jelly. She kept saying she was thirsty and the nurse was saying all you can give her is this. It was part of this Liverpool pathway thingy. None of the family could look after her.*

Group acknowledged that the Liverpool pathway is finished now. Someone themselves or family should agree to withdrawal of treatment.

- *I realise that this was 10 years ago, but I wonder if 9/10ths through a stroke say, incapacitated how you can make that decision if you have not written it down or spoken to families. How would they know?*

Stroke care was there any info about what that would mean? Did family know what to expect?

- *Bed ridden needed the kind of support of a care home. Warden supported minimal support. Needed more after stroke.*

- *First stroke warden supported bungalow second stroke debilitating needed constant care. Don't know if family knew about Liverpool pathway. Didn't tell me. Nurse put injection in drip few hours later was gone. Probably morphine.*
- *All certainly felt a peaceful release not struggling or in pain. May have been relief that they did not need to look after her.*

Explained new approach to talk to people much earlier about what their wishes might be.

- *Interesting as I was told my condition is life limiting and suggested I might like to start discussing my wishes. So, I have with my family.*
- *Re plans: Told would be good to make plans as life limiting condition (wife may be going too far with piano wire on stairs...), but doctor said this condition of next 5 years, may get worse condition but likely to go down then up then down so don't set in stone.*
- *What I thought was good was daughter's teachers as was slightly traumatised in hospital plugged into ECG with tubes everywhere. They talked to her at school about it which I thought was very good - her class teacher.*

Group looked at booklet re power of attorney and advanced care planning to tell people about what can do and advice to involve family.

- *Good idea. All agreed. Get on with living once have sorted.*
- *Is a problem re euthanasia won't change law unless people say.*

Ref sick leave employer attitudes...

- *For myself, after heart failure my firm has been absolutely superb. You take as long as you want, full pay offered for up to a year occupational health get in contact twice a month - come to me don't expect me to go to them. GP appointment once a week, consultant every two weeks can't fault it.*
- *Such a relief in a way when you think I'm on full pay for a year don't have to find out about benefits no worries. A private firm - 140 employees.*
- *If you had heart failure 2-3 months I would not be thinking about what my wife and daughter would be living on because I know my wife and daughter there's full pay until the end. And there is death in service payment with company and my own pension. Which is good takes that stress out of it.*
- *Shouldn't part of End of Life process be once you get terminal diagnosis quickly council say here you are this is what you and your family are entitled to. Given advice on that.*

Identified in timely way.

- *I don't see how, because I didn't recognise my own symptoms so how could they?*

What could they have done to help you to identify your symptom earlier?

- *Raise awareness? I suppose. Lots on TV. Are doing cancer programme if had a cough consult doctor, blood in your stools consult doctor blah blah great with cancer but there isn't much about other conditions. Stroke.*
- *I've had nothing but good support from surgery name since diagnosed but perhaps I should have made more fuss earlier, but I just thought its old age you silly bugger.*
- *At the point at which diagnosed as diabetic 4-5 years ago. Memory not good which is part of it. Diabetic care exemplary. Every 6 months nurse for diabetics checks done. Absolutely superb. Also see doctor 3 months do blood tests and medication. Also, to see me after heart issues and changed medication from hospital. Care I've had after is fine. Diabetic care leading up to it had heard of people but never thought I'd get it.*
- *Mother in-law bought me in carton of grapes and grapefruit juice nurse said not having that can strengthen drugs two or three times. Anyway, I ate all grapes nurse told me off. Thought it was good to eat 5 a day!*
- *Got no book of what good to eat etc. not back then.*
- *Cook own meals. I want you take a photo of every meal but did not have appointment for three months!! Couldn't take that many photos. Pasta slow release ok pasta no don't - conflicting information.*

What end of life care would you want?

- *Peaceful fall asleep I suppose.*
- *In care place (care home/ hospice) I wouldn't want my wife and daughter thinking spirit left in house.*
- *Pain, would you want relief? If you have that, can be dazed and not quite with it. What is the point? To be lucid and in pain you know what you are doing. Want control of pain, be able to control own pain and keep as clear a head as possible.*
- *I just feel, and this is personal, wouldn't want to be a burden to my wife and certainly for a young daughter, for her to see me suffering and going downhill, I mean that can't be a good experience for a child.*
- *Care home or hospice? Depends on length. Long-time care home. Difficult to decide if condition goes up and down. I'd want to know to put every affair in order and see everyone you want to. If terminal month to go, choose hospice.*
- *Carer at home, ok, if you can have choice. When I was in hospital there was an old guy moved from ward to ward. Family discussing around his bed which care home they were going to put him in. Any one will do, well, that's the cheapest. Myself and another patient looking at each other astonished. He didn't have any choice. I would want to have choice write it down beforehand.*

- *In a hospice have medical help on tap instant. At home or very rural might have to wait a long time.*
- *When I was released from hospital and went home it was a burden I think I was one who did all the cooking and I couldn't. My wife had to run around after me, sitting with my legs up, and little child running around. Tasks took a lot of time. Things have got better. But that's the point, if you are bedridden, and can't do anything for yourself, what pressure are you putting on the rest of the family, and are they prepared to take it? I think I would sooner take the choice away from them. And do it myself.*
- *Re planning at home. Quite well put in hospital didn't want someone helping discussion at home. Told will get better drop again better drop again will probably see you again in here just be prepared. If there is anything you really want while your wife is grieving trying to do what is right take it out of her hands make life easier by saying this is what you want e.g. hymns. Write it down. Maybe not down to undertaker, but what you want. That was the consultant name, his name was. Spent a good bit of time with me what he said made sense and we both agreed with that.*

Individual lessons:

1. Prioritise dying person's wishes about withdrawal of treatment over family.
2. Euthanasia is a subject that the public needs to debate.
3. At early stages of life limiting condition it is a good idea to raise the idea of planning for end of life by suggesting it would be a good idea to begin discussing your wishes with your family. Very useful to have consultant in hospital spend time with people and their family - explaining carefully and tactfully the sense of making plans and discussing openly what you want to happen as your condition progresses. This worked well.
4. The booklet on power of attorney and advanced care planning is a good resource that would help people to consider their wishes.
5. Support of employers with sick pay enables people to concentrate on their health and family without having to worry about money. Financial planning for end of life takes the worry out for person and family.
6. Council to provide quick advice as soon as you get a terminal diagnosis about what financial help is available for you and your family and how to apply for it.
7. Encourage people to seek help earlier for symptoms that can indicate being pre-diabetic and to improve healthy lifestyles.
8. Use television more to raise awareness of the danger of diabetes.
9. Consider offering support to families coping with traumatic hospital experiences especially children. Encourage schools to understand and offer counselling/ support/ pastoral care.
10. Offer patients different sorts of pain relief or control of pain relief so that they can remain in control and lucid if they can, and involved in choices of care and treatment.

11. Support patients that have conditions that go up and down that wish to die in a care home or hospice to decide when they need to consider moving from the family home.
12. Provide clear information about care home choices and costs so that person can decide their preferences and share with their families.
13. Advise patients about their condition and the likely medical needs that they will require and whether a home death is feasible. Including the risks of medical delay to reach a home in a rural outreach and the advantages of onsite availability of medical care and expertise, advantages of home care v hospital care v hospice v care/nursing home.

Story 12 (Focus Groups feedback) Experience - Out of County.

- *My son died earlier this year he had oesophageal cancer. Didn't want to be in a hospice they wanted him to go for some day care there maybe, but he wouldn't have that at all. So, he stayed home looked after by my daughter in law. He had a good experience mainly down to my daughter in law because she really did look after him. Also, the services that tripped in when it was needed.*
- *He had hospice at home care and then sort of social care people coming in to help with bathing, things like that, which I think they paid for.*
- *And then nurses that came in, because he, towards the end, had a syringe driver with morphine in and only district nurses can apply that and it all went well.*
- *Harrowing experience. It was in county name, but it went well. It went well a lot of pressure on family, but it is something they discussed.*
- *She was working but doctor gave her sick notes, so she was at home towards the end. He died in March. From January she didn't work. Prior to that worrying in day time front door unlocked because he couldn't always know who was at door. People did pop in. Nothing happened so it was ok, but I found it a worry. Her family lived in Loughborough they managed, not ideal. He was happy did not want to be in day centre.*

Did she have enough support?

- *She had support from family and 2.5 hrs away and 1.5 hrs away we felt guilty, did sometimes stay a weekend.*
- *For her, it hit her afterwards - had mental health issues because of the shock. Had sick notes after.*
- *Query compassionate leave from employer no card no telephone call nothing...*

Ref costs. Can have a carers' assessment but in 3 months is there time? Did anyone talk to your daughter about whether there was any help available with costs?

- *No, my son worked in civil service and had a post in (employment related field), so you would expect that they would but no it was awful. In actual fact I had said to son we'd like to go to MP about what was happening, but he said no he didn't want the stress. And I promised myself that once he died I would do something about it. But in the end, they paid but gave him wrong set of papers which were two years out of date had been with them 27 years and that threw him.*

Identified in timely way?

- *People at unit couldn't fault them. Don't see how could identify earlier.*

Information given to carers?

- *Yes, daughter in law given information.*
- *Always a cancer nurse could contact any time if concerned. Appeared with a wheelchair November hospital bed in December. Much better than ordinary bed. I don't think carers were overloaded. But was ok. Knew what to expect has 2 switched on sisters felt confident would ask. Does depend who you are as an individual*
- *Morphine recorded and carefully recorded. Any left in locked case.*
- *It's a hard job for carer (nurse or family). I never heard my daughter in law once complain and that is hard because we all have needs of our own. I am very proud of her.*
- *Hard the amount they talked together he and wife and difficult to talk to me but jolly good he did. He wanted humanist service and I have church background. I would have wanted to insist but he had been clear. Actually, it was beautiful. I couldn't fault it. Some of us thought that's what we'll have. Also gave a few minutes to think of him and what he meant and those of you who have religious beliefs a chance to pray.*
- *Later tree planting in autumn. He chose European Maple. Can't put roses can put bulbs I've put snowdrops.*
- *I know he was worried because he thought mum would want church funeral and it was not what he wanted.*
- *Able to make peace with finding time to say what you need to.*
- *Money considerations should be part of care plan. Incontinent pads had to buy in chemists not taking up bed in hospital feeding cups etc.*

Are you aware of a care plan?

- *I think he had a conversation with the cancer people told would be dead by Christmas. In September seems like they all knew what he wanted. Really wanted to be at home - planned his funeral - only wanted his wife with him at end.*

What end of life care would you want?

At home.

- *Not sure about paid carers as not good in press at the moment. It depends what age and if my family around which are not if happened now. But that is my preference. I know I don't want to go into a home. In the perfect world a warden supported home might be good. Well trained staff.*
- *So I'm just hoping that when I go hospice at home is good here.*

Is it about choice or knowing you are near the end of your life?

- *My mother hated going in a warden supported home as someone booked people in and out and she didn't like.*
- *If immobile I suppose it would have to be a home.*
- *If money no object - are some very nice places. Someone I know £1,300 a week a lot of money.*
- *One thing that would help because homes run for financial profit need to get something done about it. Are quality reports.*
- *Hospice perceived as being caring, Homes not perceived as being caring.*
- *I think they don't pay the staff enough in the care homes. To be non-critical it is their profit making if you only pay peanuts....*
- *Carers at home employed yourself - if can have that ideal carer.*
- *The thing is, if you write it down beforehand and you say you want to go in a particular home it depends what you need and what is available.*
- *Friend asked for no resuscitation he died at home. He was 88 and most care down to wife same age. By time carers came to help she had helped him already because carers took so long.*
- *Difficult when don't know which of couple will go first.*

Individual lessons:

1. **Encourage employers of staff on compassionate leave to touch base regularly and be considerate, caring (e.g. send card, flowers attend funeral where appropriate), supportive and helpful. Be clear about sick pay and signpost for help with benefits or mental health needs following death of loved one.**

2. Consider producing a pack that families and carers can give to their employers to explain how they can help and their employee before and after death of the person they care for.
3. Consider producing a pack for employers when an employee presents with a life limiting condition to explain how they can help and support their employee up to and when they must leave.
4. Hospice at home with social care works well when well-coordinated.
5. Consider how to fast track carers assessments when death is likely to be soon.
6. Offer families caring for people dying at home access to bereavement counselling, mental health support and time to recuperate before returning to work.
7. Support carers in taking care of their health needs during and after death of the person they care for.
8. Pay care workers more so that families can have more faith in the quality of their skills when caring for dying people at home or in a care home.
9. Look at reputation of care homes which are not perceived as being as caring as the hospice.
10. Support people to write care plans before hand when they are unaware of what care homes will be available and what condition will be the cause of their death or which one of a couple might go first especially if they have no children.
11. Consider needs of elderly carers dependent on very little care support including their health needs and likely knock-on effects of caring for somebody dying at home.
12. Consider supplying some resources such as incontinence pads that would be provided if person were dying in a hospice or in hospital as extra costs from a chemist adds to stress for families supporting somebody dying at home.

Story 13 (One to one meeting feedback) Herefordshire.

- *My husband was ill march last year died in October.*
- *Big problem was dementia. Had an appointment the year before with a consultant. Refused to see MRI scan. He thought he felt well. Had breathing tests and MRI scan. Pleased did not contact us but probably should.*
- *He had idiopathic pulmonary fibrosis.*
- *He became ill a lot had cold, a cough, didn't get better. Went to GP who referred back to consultant. 42 weeks wait. But got a lot worse suddenly and got a chest infection really ill I thought. Doctor did not talk about what to expect or end of life planning.*
- *Wife read NHS information Online which was horrifying. Husband did not look but knew he was dying because he was so ill.*

- Went to see respiratory nurse at surgery went to get help. Didn't say much - degenerative - said a steep learning curve. Lovely. Warned it's going to be hard. Didn't say what would need to do. But got appointment earlier with consultant.
- May bank holiday appointment with consultant. Fri and sat appointments. So ill that he collapsed. Called doc out and asked in the circumstances if should go to appointments - doctor said had no choice do need to get appointment gave him strong antibiotics. Got up 6 in morning had got family to help him get in car on each occasion but was very difficult.
- Consultant not nice focused on his dementia. Did not speak to him and he got angry that he was being ignored the doctor said I don't want any marital problems in this consulting room. Consultant showed them the scan from the year before and I could see how bad it was.
- Husband was very intelligent but didn't want to take in information. Consultant talked over him. Said he didn't want to see him again. Said not eligible for oxygen. Ignored her when she said if he does not get oxygen he'll be dead in a few weeks. Always good when sitting down so his oxygen levels seemed ok. But every time he moved around a little they dipped, and he'd collapse.
- The consultant said he would get respiratory nurse to ring in next few weeks. And it would be palliative care. He also said he could not arrange this until he came back from holiday.
- Things moved on because her husband was so ill. He collapsed again. 999 really good sorted him out 2 girls very good. They stayed till oxygen levels got back up. They said no point in going to hospital. And he wanted to stay at home. Girls said I'm afraid you are going to have to get pushy.
- She called 111 doctor who came following morning. Dr. Name. Husband was comfortable in bed. He had low blood pressure. Was taking high blood pressure pills. Doc stopped them. Doctor said I've seen a lot of this disease and gave a lot of information. Spent a lot of time and was very good. He said he would tell GP and on Monday told her to get her husband a home visit.
- I don't know what palliative care is.
- GP came out - duty doctor. He got him to take strong antibiotics that cleared up infection and got him out of bed.
- Called 111 Dr. Name gave reference to give if ill at weekend. He said they'd then contact him. Get back to me again.
- Sent ambulance again. Get home visit from surgery Dr. New name and they have been brilliant. She said he needs oxygen don't care what consultant says he had not written. (No evidence that it ever was sent).
- Oxygen was delivered same day. Delivery driver said I can't help you set it up and there was nobody to do so. So he did help set it up but didn't know prescription. Respiratory nurse at surgery she said she'd ring consultant's secretary to decipher notes. But he had not prescribed oxygen. So throughout she made it up herself.

- Once got oxygen and antibiotics husband could come downstairs. Was a bit better.
- Had a matron district nurse once a fortnight. No point in coming as nothing to do. She had their number. I had written to MP name. As was frightened. I thought I'd see if he could do something.
- Macmillan nurse every 3-4 weeks. I was struggling to get him showered and general care of him.
- Got daytime attendance allowance once a week for 2 hours caring and cleaning. Has been brilliant throughout but could not afford to employ her she did more than she should have and still around.
- Had a social worker. Dr. organised. A means tested assessment. Had a care company 17 days end of June into July. Told not to come. None of them could use oxygen. Personal assistant we already had worked for this agency but would not use her, would not let her, even followed her to find out if she was going there. All a bit strange. Very much on own. Asked social worker said could have personal assistant and that could be the one we already had.
- Took several months to sort paperwork and payments.
- Macmillan arranged respite week in St. Michael's, but he got distressed. And I had to take him home after one day.
- When you collect him tell him you need help, but personal assistant was on holiday. Make sure they send carers from hospice. He could not get down stairs he was so brave.
- When he was in the hospice they and he realised how ill he was. He said I've only got a few weeks I'm not staying there. Sent 2 nurses every night. Marie curie and Macmillan's and then care started from personal assistant so I could get out plus have my own X-ray. When people came he entertained them so didn't realise he was so ill.
- Dr. said weeks rather than days. Had proper care last 20 days.
- Only medication primorph.
- Lost so much weight. Was in pain once had been to hospice. Lost his referral which is why respiratory nurse never came.
- Rang hospital to get instructions re oxygen. Hospital said should not have it have you informed the fire brigade and insurance company? Worked out how to use it herself. Very dependent on me. Social worker focused on dementia not how ill.
- Should have got health funding.
- Feel didn't have quality time with him had to push to take medicine. Had to be his carer not his wife.
- Feel should have happened with consultant. What is palliative care and how to trigger? Had to spend all months fighting. Could not go out of house.
- Offered counselling hospice good.
- Hospice at home when he died offered to sit with him while I slept.
- Did not work when alive because he was calling for me. In the end in a lot of pain kids came he perked up they thought wasting their time.

- *Lot of pain in his tummy gave lots more morphine. Getting worse. Hospice said ring district nurse. Young lass came gave him morphine. Settled give ring if needed. Hour later conscious and in pain. While there he was sick she said was blood. She called emergency doctor. He came. Wanted to take into hospital I said no he respected his wishes. Hospice nurse came with GP with syringe driver. Was free of pain after but was in pain for quite a long time. She came at 10 he died 10.45*
- *Recommendations*

Individual lessons:

1. *Contact patient when scan shows a serious condition.*
2. *Practitioners to complete paperwork before they leave for annual leave and not to lose paperwork and do what have promised to do.*
3. *Improve coordination between GP and consultant.*
4. *Whoever orders Oxygen ensure that instruction is given to carer.*
5. *Ensure care companies can use all necessary equipment that has been set up.*
6. *Explain condition at as early a stage as possible so that patient and their family can make a care plan preparing for end of life. If patient is reluctant but couple are elderly, consider the needs of the partner as well as the patients so that they are not left unprepared.*
7. *Provide care support a lot earlier.*
8. *Enable people to sort funding quicker with less need for being pushy.*
9. *Explain what palliative care entails, what to expect and what to do to initiate support as soon as possible so person and carer can discuss their wishes.*
10. *Consider supporting lone carers by providing earlier night time support from St. Michael's hospice. people as it seemed a little late in the day in this case.*
11. *Lack of sleep personal support needed.*
12. *Avoid unnecessary pain and arrange syringe driver at the right time.*
13. *Recognise that it can be frightening for carer that has no experience of death and medical care.*

Story 14 (Telephone feedback) Herefordshire.

Elderly person cared for their husband who had a stroke for many years -had motor neuron disease looked after for 6 years and then their mother for a year alone.

Feel angry and very much neglected.

Carers' assessment gave no support. I was just offered to be paid to go to the gym for once a week. What I really needed was help with the housework. The cleaning ladies were erratic.

I was exhausted and alone. It has been a year and I'm still not well I seem to have picked up every infection going. I am finding it so hard to recover.

Mum got pneumonia and a blood clot and died.

Had problems with district nurses.

Mum had a bowel disorder, and nobody could tell me how to cope with explosive diarrhoea. Mum had been scrupulously clean but there was poo everywhere on curtains, walls, furniture. Whole house stank. Nurses did not know what could do about it.

Eventually I found a nappy pot I could use, and a disabled equipment place made suggestions. Sold me one. Then with the commode I used puppy training pads Chinese made with pheromones.

Individual lessons:

- 1. Greater consideration for people who have been carers over a long period or carers of successive people or relatives at home.**
- 2. Provide advice re gaining a fresh carers assessment as condition of cared for person worsens. Or ideally assess to take deterioration into account.**
- 3. Consideration of health of elderly carers including mental health.**
- 4. Practical solutions for handling difficult situations at home e.g. incontinence and explosive diarrhoea.**
- 5. Training for district nurse to give practical equipment advice to ease the lives of carers at home and to maintain a hygienic environment.**
- 6. Consider additional social care support for conditions that could cause hygiene of environment to decline and make life unpleasant for carer and dying person.**



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