

Frimley Health and Care



**HELP US SUPPORT YOU AND YOUR FAMILY IN YOUR
END OF LIFE JOURNEY TO MAKE IT A COMFORTABLE
EXPERIENCE**

Wednesday 5th September 2018

FEEDBACK

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Things That Really Helped

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| 1 | Listen to Families |
| 2 | Make time to ask the question – did you fully understand what happened today? |
| 3 | Say they are dying |
| 4. | Individual District Nurses were fantastic - continued family support after death |
| 5. | Give me time to do what I need to do before I die |
| 6. | If you know what they are dying of, tell us |
| 7. | Connections with other families going through the same thing 1) during death 2) after death |
| 8. | Having a telephone number I could remember (still needed out of hours) |
| 9. | Look good; feel better – Free skincare and make up workshops for people undergoing cancer treatment. |
| 10. | Practical Support was available |
| 11. | Having conversations early e.g. Advanced Care Plans/Frimley/CNSs/ GPs etc |
| 12. | Advanced Decisions |
| 13. | Pre-Death Wake! |

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Things I Wish I Had Known

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| 1 | People being supported to be 'ready to die' – acceptance support |
| 2. | Able to have the person dying at home |
| 3. | Good honest conversations – Hospice Care |
| 4. | How to get GPs involved in the conversations |
| 5. | Communities that could talk about death and dying – it should not be taboo (death cafes) |
| 6. | Support after death |
| 7. | Structure/steps of what's next |
| 8. | Out of hours support |
| 9. | Last weeks really hard – helps to know what to look for at each stage |
| 10. | How to plan before the person capacity to make a decision deteriorates |
| 11. | Conversations about hospice care and support they can give |
| 12. | Compassion is so needed – take time to talk |
| 13. | End of Life Services |
| 14. | DNACPR – decisions must be done with patients |
| 15. | Offer hospice care as a first |
| 16. | Right information at right time 1) How long have I got 2) How will I go? – need for honesty and openness |
| 17. | Young carers not having to fight to support the wishes and preferences of their relatives |
| 18. | Seek first to understand and then to be understood |
| 19. | We know the criteria for hospice care, but conversations must be had |
| 20. | More information about prognosis – what to expect so we are prepared |
| 21. | Don't fill the gaps (silence) in conversations |
| 22. | How to make a conversation about death more comfortable |
| 23. | DNAR |
| 24. | Difference in the old ways for support to new much better |
| 25 | Emotional support through the journey |
| 26. | HCP feel open to talking about what they want |
| 28. | Death is behind closed doors – it shouldn't be |

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| 29. | Be honest about any treatment options – die with dignity |
| 30. | Better cancer care but non cancer harder to do well e.g. dementia/COPD |
| 31. | Proactive will – Lasting Power of Attorney, ACP Funeral |
| 32. | How to have a conversation earlier with the person – accepting dying |
| 33. | If you can't fix it – be honest |
| 34. | Minimise the 'blunt language' - words chosen are important |
| 35. | What questions to ask doctors; or get doctors to understand; people don't know what questions to ask |
| 36. | Doctors don't know what to do if they can't fix you |
| 37. | How to have difficult conversations |
| 38. | Leaflet or information about death and planning ahead |
| 39. | Health literacy is very low – information along the journey |
| 40. | Guidance of what next/response to staying at home |
| 41. | Recognising end of life quality vs. quantity of life |
| 42. | I wish I had known that I could have taken her home to die |
| 43. | Have understanding how death happens in different ways to expect the unexpected (i.e. terminal agitation) |
| 44. | Didn't realise they are going to be alone so much with their dying person |
| 45. | Hospice = enabling death well; hospital = all about life, treating the living – hospitals need to do death better |
| 46. | Difficulties to ask questions of HCP/ASC about letters. Stop using jargon |
| 47. | DNR information and how to have that conversation with a loved one/family |
| 48. | Gaps in support when dying (CHC). Fast track family under stress. |
| 49. | To have information about "End of Life Plan" |

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1. How would you like end of life care to be when you or someone you know Finds out they are dying

Group 1 (Led by Rosie Fowler)

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| 1. | Need of facts – honest conversation, what is likely to happen and how long it will last |
| 2. | Personalised conversations lead by patient/ appropriate guardian |
| 3. | Need for confirmation of information (unknown is worst) |
| 4. | Having access to someone who is qualified to handle difficult conversations; i.e. letting people know what is happening in clear language which the patient and family members understand |
| 5. | Managing patients/families expectations |
| 6. | Supporting guidance i.e. a checklist for patients/families to follow |
| 7. | Advanced Care Planning |
| 8. | Power of Attorney – how to go about it - especially if family get stuck |
| 9. | COMMON THEME – CLEAR EMPATHIC COMMUNICATION WITH THE PATIENT AND FAMILY. SUPPORTING DOCUMENTS/ GUIDANCE. |

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Group 2 (Led by Cyane Sullivan)

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| 1 | Would like to be at home – for a decent conversation – comfortable |
| 2 | Be told by someone you can trust and feel comfortable with, who knows about my diagnosis and can answer my questions |
| 3 | Be told there and then in a conversation in language I can understand (honest & Genuine) proper medical terms not “poorly” |
| 4 | Use the words death and dying |
| 5 | If you can't fix me, tell me, either days, weeks, months or don't know. I need a timeframe to work to |
| 6 | Have these conversations as early as possible e.g. palliative care advanced Care Plan conversation |
| 7 | Ask if I want someone with me or not |
| 8 | Make sure the person dying is the focus of conversation even when they are supported by someone else. |
| 9 | To be clear what my options are |
| 10 | Having the option of an independent person in the room to take down the information (summary of the appointment) as even Family and friends may not be able to get all the information down and right at this stressful time |
| 11 | Don't “information overload” me, give bad news and have follow-up (face to face or telephone call). Give thinking time not leaflets |
| 12 | Provide an information journey – google self-scaring to be covered by perhaps a specialist nurse – try to make the information personal to each person |
| 13 | Relevant contact numbers in and out of hours, who to ring for what, Hospice, GP, Hospital etc. |
| 14 | A single point of access – 24/7 would be so much better to reduce stress of being pushed from pillar to post |
| 15 | Palliative care needs to be part of the local integrated care team (24/7 would be good) |
| 16 | COMMON THEME – CLEAR EMPATHIC COMMUNICATION WITH THE PATIENT AND FAMILY. PERSONALISED SUPPORTING INFORMATION AND CONTACTS |

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2. How would you like end of life care to be when you or someone you know is in their last month's/weeks or days of life

Group 1 (Led by Rosie Fowler)

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| 1 | An ease into hospice care at the end of life – should be patient led and conversations should be personal, bringing in humanity |
| 2. | Knowing what is available to patients/ the family if they choose to be cared for at home |
| 3. | Avoiding unnecessary hospital admissions and keeping patients at home. (IBIS, Intelligence Based Information System, enables the Ambulance Service to have up to date information about a patient's health and wishes.) |
| 4. | Respecting the wishes of patients who do not have capacity, and listening to their family members. Enabling families to speak on their behalf. |
| 5. | A skilled workforce which can balance the needs of the patient with families expectations and the patients best interests |
| 6. | GP interaction with family |
| 7. | Same person engaging with the family throughout the journey, prior to death and after dying. Giving the family familiarity and only having to tell the story once. |
| 8. | Support for the cared for if the person dying is a carer. Advanced planning and crisis planning for carers. |
| 9. | Support in the workplace, especially public sector, to support someone who is experiencing grief |
| COMMON THEME: PERSONLISED, PATIENT CENTERED CARE, TELLING THE STORY ONCE | |

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Group 2 (Led by Cyane Sullivan)

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| 1 | Want to still feel in control that decisions are mine |
| 2 | Sense of being normal – still me |
| 3 | One number to call 24/7 If I need to talk and understand how it all works as night time is different |
| 4 | Support me when I need it more than 8-8 and be responsive to my need |
| 5 | Respect my choice to be on my own or with someone when I die and my choice on advanced decisions or advanced Care Plan |
| 6 | Time to make choices - what I and my family have time to do |
| 7 | EoLC passport – at time of diagnosis, independent person or health professional to help think about Advanced Care Plan at the right time |
| 8 | To understand choices either way |
| 9 | Consistency of primary care contacts either GP or small team |
| 10 | Knowing all the signs of a person dying so there are no surprises |
| | COMMON THEME: PERSONLISED, PATIENT CENTERED CARE TO MAKE INFORMED CHOICES |

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3. How would you like End of Life Care to be when someone you know has died? What would better bereavement care look like?

Group 1 (Led by Rosie Fowler)

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| 1 | Information and support around arranging a funeral. Raising awareness of the costs. More support at registration of death/speaking to Frimley Park Hospital – bereavement office. Additional section in Advanced Care Planning booklet to include expectations for funerals. |
| 2. | Bereavement pack – check list – step by step guidelines – in the order that things need to happen. |
| 3. | Raise awareness of the “Tell Us Once” system and make this service prominent. “Tell Us Once” Lets people report a death to most government organisations in one go. (Cancellations of benefits/driving licence/records) |
| 4. | Templates of letters to be used when corresponding with organisations to cancel bank accounts, telephones etc. Ensure people are aware of the requirements for original death certificates |
| 5. | Having time to talk. Professional relationships – but, social interaction was/is important |
| 6. | Mental Health support for carers once the cared for has passed away. Carers are not prepared for what to expect after the death of the loved one, particularly family members who have been caring for a long time. Explanation of grief is needed and ongoing support. |
| 7. | Resource for the carers who have lost their caring role (what do they do next??) |
| | COMMON THEME – MORE SUPPORT AROUND BREAVEMENT AND WHAT TO DO NEXT – A BEREAVEMENT PACK WOULD BE USEFUL |

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Group 2 (Led by Cyane Sullivan)

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| 1 | Bereavement is different for everyone |
| 2 | Direct care after death is for about three months, I need a service available after three months |
| 3 | Working age bereaved people need an employer's policy to support the bereaved (E.g. calendar dates for anniversaries, designated person in the office for support) |
| 4 | Bereavement before death e.g. Dementia |
| 5 | Better information about bereavement care for all ages and to have the skills to be able to discuss with work, school or colleges etc. |
| | COMMON THEME – MORE SUPPORT AROUND BREAVEMENT FOR ALL AGES AND WHAT TO DO NEXT |