

User and Carer Input for End of Life Care Strategy.

Methodology

The End of Life Care Strategy board sent a questionnaire to NCPC. This was reviewed by the Service User Advisory Group, Policy Lead and Project Manager for User and Carer Involvement. Through feedback, a summarised version was formulated, which was approved by a member of the EOLC strategy board. This was sent by email to the following stakeholders with the option of people returning completed forms by mail or email.

NCPC Service User Advisory Group
NCPC policy groups
NCPC Ethics committee
NCPC Area and County Representatives
Royal College of Physicians patient carer network
Cancer Networks Network Development Program
Respond: Network for people with Learning Disabilities.

Recipients were asked to distribute the questionnaire to patients or carers with whom they had contact (including established patient/carers support networks). They were informed that the questionnaire could either be filled in individually or used to facilitate a group discussion. It was emphasised that we were looking for experience based responses, not opinions from people who were “one step removed” from the issues.

Responses

A total of 34 responses were received. It is unknown how many people the questionnaire was subsequently sent to, resulting in it being impossible to ascertain response rate. All respondents site personal experience of dealing with end of life issues but it unclear how many of these were in a professional capacity. It may be helpful to have a tick box on future questionnaires to the capacity of recipient to be recorded. General feedback to the questionnaire reflected that recipients felt that this is an extremely important topic and welcomed an opportunity to respond. Many people commented that the extremely short timescale prohibited meaningful consultation, due to the impossibility of organising patient focus groups. In some cases this meant that people were unable to respond to the questionnaire, for example the Respond group for people with learning disabilities. A number of recipients were annoyed and felt that it reflected a tokenistic attitude from the Department of Health regarding gaining user and carer input. Output from the Questionnaire is summarised below.

Initial Discussion about End of Life Care

What is the best way of approaching this and what problems might there be/have you experienced? How could this be improved?

Whether to have the discussion

The people involved (patients, carers and family members etc) may not wish to discuss this issue. This should be respected. It should also be carefully managed due to the potential ill effects, for example a family member not being prepared for their loved one's death, resulting in difficult bereavement experiences. It is reported that Jewish people do not want to acknowledge that they are approaching death.

Who to initiate or facilitate discussion:

It was agreed that if the patient's condition is suspected to be terminal, the health professional has responsibility for proactively indicating that this is the case. However, a number of suggestions as to who should conduct subsequent discussions about end of life care were made. These are listed below. However, the underlying thought appears to be that the person with whom the patient discusses end of life care should be someone with whom they have a comfortable and existing relationship.

- It does not matter who carries it out, but the health professional or key worker should be responsible for ensuring that the discussion takes place
- The health care professional
- Definitely not the health care professional, as this further strengthens the "nanny state" and fractures and disempowers existing social systems and networks.
- The patient
- Close family or friends

When to initiate discussion

There was strong support of the idea that end of life issues should be more openly discussed and accepted in society to reduce the "taboo" and to underline that death is a natural end to life. Suggestions about timing and methods of increasing awareness and discussion are listed below:

- In childhood either in the family or in school.
- With GP at age of 16 and regularly reviewed
- Compulsory "MOT" at age of 70, with penalties for non compliance.
- Media campaigns through leaflets and television programmes

In the context of terminal illness, where end of life issues are no longer academic, various thoughts were raised relating to timing of discussions.

- When the patient is ready to discuss it
- Whilst the patient is still lucid and able to contemplate such issues
- Whilst the choices are still practicable and the patient can benefit from decisions made.

- The discussion should evolve, rather than being a one off, isolated discussion so would occur during the entire course of illness.

Where to discuss end of life issues:

The environment is important. Particular factors are listed:

- Comfortable
- Clean
- Quiet
- Privacy
- In the location of the patient's choice, not purely for the convenience of health care professionals

How to discuss:

Those carrying out discussions should be trained to ensure that it is carried out in the following way.

- Respectfully
- In an organised manner
- Reassuringly
- Sensitively
- Giving dignity
- Optimum communication (including provision for language barriers and communication difficulties)
- Give time for discussion between those affected
- Awareness of existing dynamics and relationships between those affected
- Consideration and support of emotional needs resulting from discussions
- With confidence and without awkwardness
- Communicate that the reason for discussions is to facilitate a dignified and pain free death

Content of discussion:

It was emphasised that this would vary from person to person and that people should be treated as individuals. However, a number of suggestions are listed below:

- Prognosis
- Care options to ensure that end of life care requests are realistic
- Funeral arrangements
- Who to be contacted if nearing death
- Who to have contact with if experiencing severe symptoms of illness.
- Cultural factors
- Spiritual factors
- Where to go for extra support e.g. expert patient schemes, support for families of children with a terminal illness, bearing in mind that written information is not always visible or the preferred medium of communication.
- Personality type and coping mechanisms

- Practical issues e.g. care of family, pets etc

It was acknowledged that this can be an extremely difficult discussion for the health professional to carry out and suggested that the existence of a palliative care register or formal paperwork may act as a prompt or structure for discussions.

Are there any people who are likely to experience additional difficulties or challenges in this issue? If so, who are they and why? How could these issues be addressed?

It was agreed that there are people who are likely to experience additional difficulties and challenges. The following factors were suggested to have an influence:

- Different religious groups resulting in differing views about death
- Communication difficulties such as being hard of hearing, dysphasia
- Learning disabilities
- Mental health issues, including severe depression.
- Underprivileged
- Certain personality types may find it harder to discuss things than others
- Dementia
- Social isolation and living alone
- Cultural isolation
- Lack of good standard medical services
- The existence of dependants and requirement for appropriate legal arrangements
- Those with no comfort of faith
- Disconnection from the health service
- Excessive demands resulting in inability to focus on anything other than day to day living.
- Vulnerability
- Children
- Non malignant diseases
- Attitudes of all concerned to death (patient, health professional, family, carers etc) e.g. fear, previous childhood experience of bereavement, health professional's fear of "getting it wrong", false optimism
- Busy/inexperienced staff
- Those with no confidants

Potential effect on end of life discussions:

Very few people documented the potential outcome due to the above factors, but a few were mentioned:

- Secrecy about terminal nature of illness
- Denial of terminal nature of illness

- Feeling of being stigmatised
- Feeling that body is dysfunctional

What can we measure to ensure that this part of End of Life Care is carried out satisfactorily?

A number of outcomes were suggested. These are listed below:

- Positive reactions from patients and carers
- Calm and peaceful emotions from all involved
- Reduction in physical and emotional pain
- Specific variables resulting from national standards for End of Life Care Strategy
- Indication of whether end of life discussions have occurred
- Information about resolution of death
- Family's bereavement expectations, experience and outcomes.

The following methods of gaining feedback were suggested:

Informal feedback

- "Open door" policy for those involved to give feedback
- Asking patients and carers verbally
- Qualitative research
- Audit
- Patient satisfaction questionnaire
- Patient notes

Ways of facilitating measurement:

- Good communication skills
- Not just a "tick box" exercise
- If part of a national strategy, ensure that assessments are carried out regularly

Other applications of findings from measurement:

Use outcomes and findings as basis for bereavement support

Assessing the needs and preferences of people and their partner/carers

What is the best way of approaching this and what problems might there be/have you experienced? How could this be improved?

It is important that the needs of all affected people are taken into account and that dynamics between family members are managed. One person reports how there was friction between a patient's views and those of their family, leading to "competition" between them about how things were managed.

Areas of need to be considered

It was recognised that these needs will vary amongst individuals, but the following examples were cited.

- Different cultural needs
- Work needs
- Feeling ignored/misunderstood/unimportant
- Increased stress, anger and frustration
- Laundry
- Looking after children
- Food
- Continuation of present education + social events
- Personal preferences relating to how the patient is addressed by staff e.g. using nickname
- Care of pets

Are there any groups of people who are likely to experience additional difficulties/challenges with this issue? If so, who are they and why? How could these issues be addressed?

- Vulnerable people could be at a disadvantage
- Language barriers need to be overcome
- When a person has other existing health issues. One lady's husband was hemiplegic, but the nursing staff did not take special care of that issue

What can we measure to ensure that this part of End of Life Care was carried out satisfactorily?

Measuring the activities in relation to what is written on the care plan

Request feedback from the patient and family

Survey

Assess bereavement outcomes

Peer reviews after death, in which a carer takes part

Planning the Individual's Care

What is the best way of approaching this and what problems might there be/have you experienced? How could this be improved?

As a general rule, people felt that the patient should be listened to, especially if their choice of care is not what is deemed to be the most helpful (for example not wanting hand rails in the house or specialised disability aids).

Care plans

In general people were very positive about the idea of care plans. Some people felt that this should be made more profile through media campaigns and in particular through having pertinent storylines on popular soap operas. This would increase the amount of people wanting to take part in such planning.

Benefits:

- Record/Communication aid
 - Acts as a written advocate for patient's wishes
 - Would ensure continuity of care and consistency between agencies.
 - Is a way of keeping records regarding the whole process of care
 - Can be emailed
 - Can be updated as needs change
 - Especially helpful as a communication tool if the patient loses ability to speak or write
 - Acts as a legal document
- Assessment of needs
 - It would determine the degree of social care needed
 - Potential reduction in number of hospital admissions
 - Patient remains at the centre of their care, and can influence the plan.
 - Saves guesswork and speculation about need
 - Provides a framework for structured assessments of physical, psychological, emotional and social needs
 - Allows awareness of out of hours and emergency needed and would assist in co-ordination of care to fit in with the patient's wishes
 - Provides a defined framework between patient and health professionals
- Psychological Benefits
 - Provides reassurance and concern that needs are being provided for
 - Process of creating the care plan can be a means of preparation for the patient

- Allows the patient to feel in control at a time when things are out of control
- Nice to know that patient and healthcare professionals are working within defined framework to ensure a dignified death

Conditions

- Who is involved
 - It should involve all groups
 - A trained, qualified professional with understanding of available services
 - Those responsible for facilitation of plan creation should be involved throughout the patient journey
 - Should be planned and driven by patients themselves
 - Named key worker who is carefully matched with the patient e.g. having similar cultural background
- Process of creating plan
 - Allow enough time – should not be a rushed activity
 - Create plan at the patient's pace
 - The process is familiar to professionals but unfamiliar to patients, so should be handled with sensitivity
 - If the plan is emailed, follow up phone calls should be made.
 - All medical staff should be aware of the plan
 - Minimal bureaucracy
 - Must not be a “tick box” exercise but part of enduring dialogue
 - Uniform approach throughout NHS
 - Give examples of potential care options to act as a prompt for a patient
- Content
 - Nothing should be overlooked or forgotten
 - Include milestone targets
 - Information about car parking charges should be included
 - Create a form for patient to sign if they'd rather not get involved in setting up a plan – need to acknowledge it's not fault of the professional if the plan is not introduced by the patient.
 - Simple language – no jargon/acronyms
 - Any changes of previous decisions should be recorded
- Ongoing use
 - Have regular, pre-arranged reviews to ensure that changes in views are captured
 - People should be trained so that the plan can be implemented to a high standard
 - Ensure that it is carried out
 - There needs to be a protocol for how a care plan is delivered

- Potential issues
 - Dependent upon the mindset of the professionals involved
 - Some people may regard it with horror, especially if depressed.
 - There may be friction between the patient's requests and views of the family.
 - GPs do not always want to give up on treatment or investigations so planning is blocked
 - This could turn into a tokenistic effort, rather than being a real attempt to listen to a patient's concerns, especially if it is made a "QOF" target
 - It could raise expectations when resources are limited
 - Doesn't offer a guarantee
 - Difficulty if inflexible plan
 - Difficulty in non malignant diseases in that they may have a differing time course, so hard to plan.
 - Not everyone will feel empowered to answer questions or to ask the correct questions

Are there any groups of people who are likely to experience additional difficulties/challenges in this area? If so, who are they and why? How could these issues be addressed?

- People who have no close family
- Those with disabilities
- People whose first language is not English. Even a translator may not pick up the essence of requests.
- Those people with no one to speak for them.
- People with dementia
- Those who do not have good relationships with their family, and who may fear family conflict when filling in the plan
- Difficult if people are in denial of the situation
- People with learning disabilities
- People who are heavily sedated
- People with brain damage

What can we do to ensure that this part of the End of Life Care is carried out satisfactorily?

- A care plan can be monitored regularly which also ensures regular reassessment
- Request feedback from relatives after death of patient or anyone involved in plan/patient's life
- Patient and Carer Groups can monitor and feedback on the services
- Measure by seeing whether the requirements listed in the plan were carried out and to the correct standard.
- Patient satisfaction questionnaires

- Survey bereavement outcomes, complaints
- Audit patient notes
- Encourage carers to take part in peer review after death of patient.
- QOF Points for Gps – end of life issue discussed, preferred place of care/death discussed
- Put guidelines in place to make sure this happens, and measure when there is a straying from it.
- Audit the plans
- Regular recorded discussion against care plan and any subsequent changes help to measure it.
- Statistically quantified assessment of paper trail of care plans

Deciding where to live and receiving additional care or support

What is the best way of approaching this and what potential problems might there be/have you experienced? How could this be addressed?

General points:

Thought needs to be given about the timing for moving from one care environment to the next. Some people are eventually moved to the location of their choice, but only in the very last stages of life when it is too late for the patient to benefit.

- Coordination is essential
- Consideration should be given to the distance to place of care from family
- Difficult to place certain age groups e.g. difficult for children to be placed in a care home
- People are not always aware of what is available to them
- All doctors and nurses should receive more training in palliative care, thus improving end of life care in all settings
- Palliative care services should be supplied more from primary care settings.
- There is knowledge and good practice in community settings e.g. GSF
- Irrespective of care setting, prompt specialised help should be given.

Home care:

- Some people request to die at home but later change minds to manage pain, but also to withdraw from the world.
- In reality this can be more challenging than people anticipate, for example carer exhaustion. Night time nursing is in scant resources.
- It may take a while to get used to having other carers in the house.
- Need help being aware of entitlements to benefits and extra help.
- Feeling unsafe, insecure and frightened, dying alone and uncared for.
- Some people feel that a death taints the house and practical support is very limited

Hospices

Factors influencing choice:

- Not available to everyone
- Questions about why not
- Only available to those who have courage to face diagnosis
- Can provide for medical needs, giving peace of mind
- These are the best option when available
- May not be able to care for people with additional needs e.g. physical disability
- Concentrated on middle class, young, Caucasian and malignant disease
- Too far away from most rural communities

Care Homes

Factors influencing choice:

- Cost
- Standards
- Reputation of home
- Friendliness of staff
- Openness for visitors
- Cleanliness
- Regular staff not agency
- Encouragement to maintain independence
- They are not always able to provide adequate palliative care

Hospitals

Factors influencing choice:

- Very little specialist palliative care available
- Concern about mixed sex wards, noise at night, lack of privacy, Infection, distance for relatives to travel, rigid visiting times, conditions of death (will I have to die on a trolley), how will they know what's wrong with me if I can't speak.
- There should be no negative or worrying statements uttered in earshot of patients.
- Adequate mouth care needed
- Not a suitable place to die but many people do die in hospitals
- There should be a "dying" ward and when people have died; their bodies should be moved to special grieving room.
- Provides necessary medical care which can give peace of mind.
- Sometimes low standard of care including insensitivity and undignified way of treating dying person/dead person.
- Some GPs insist on keeping patients in hospital under investigation so that they have a suitable diagnosis to put on a death certificate

Are there any groups of people who are likely to experience additional difficulties /challenges in this area? How could these issues be addressed?

- Those that don't have enough information about what is available in terms of support and location of care.
- Those that don't have access to suitable/.preferred place of care
- Those with particular cultural requirements, learning difficulties and mental health issues may find it difficult to adapt to certain care settings due to cultural difference/language/food etc.

What can we measure to ensure that this part of the End of Life Care was carried out satisfactorily?

- Measurement of information given
- Possibly part of care plan - relationship between what is on care plan and what is carried out.

Ensuring Services are Integrated

What is the best way of approaching this and what problems might there be/have you experienced? How could this be improved?

When people report good care at End of Life, a common factor is integrated, proactive, joined up services.

Issues people have experienced

- Lack of cohesion between health and social services
- Poor communication between secondary and primary care about end of life issues
- Hospital teams don't realise patients are dying so don't plan
- Little or no co-ordination between hospitals (discharge procedures)
- Healthcare good but district nurse only attends to physical needs.
- Not enough monitoring of effects of medication
- Patient/family member/carers had to take "project manager" role - added anxiety and stress
- Budgetary issues affect care options available
- Varying services available depending on where you live
- The feeling of being a burden on the system (comment: would have been easier if I'd died because they wouldn't have to get me a wheelchair
- More of a problem at weekends)
- Even when good care is delivered, if uncoordinated it can lead to a constant stream of visitors and phone calls and e.g. 3 commodes being delivered
- Lack of coordination between acute care and community hospitals especially when there is an emergency admission
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What worked well/would help

People involved:

- Would be helped by having "key worker" or one agency responsible for each aspect of care. Works well in Rutland
- Older person should be assessed by an advocate to liaise and case manage - especially important if no family/friends.
- Service providers need training
- Experienced and empathic key worker
- Staff need communication skills and to take care about whose wishes they most closely listen to.

Content of discussions

- Should be told what benefits you are entitled to. If on benefits and get a change of income, need a machine to automatically update all other departments that are affected. Work should be done for those who are too ill to do it themselves

- Staff and patients need to know what's available to them - database would help. Voluntary services are aware of health services but not necessarily the other way round
- People need access to relevant information at the right time - could use email for this. A documented care plan containing a named contact would help
- Staff need time and resources to dedicate enough time to tasks
- Allowances should be made for patients who are experiencing emotional issues
- Agencies should meet with patient family as often as is required
- Staff morale can be low. Need to support staff more to help with motivation.

General comments

- The standard of care delivered is unlikely to change without significant reorganisation
- Good practice models should be developed and pilot schemes run. Invite ideas from public as well as professionals.
- Marie Curie delivering choice is a good option
- A palliative care co-ordination centre should be in place
- Care should be carried out in calm and relaxed environment

Are there any groups of people who are likely to experience additional difficulties/challenges with this issue? If so, who are they and why? How could these issues be addressed?

- Patient or staff for English is not their first language
- If you live in rural areas, services might be sparse - may affect "joined up" services
- Those who have no family or friends and no one to advocate for their needs
- People who are elderly
- People with Learning Disabilities
- People who don't know what they're entitled to.
- People with complex social and medical needs.
- People who are in denial about their condition and its terminal nature
- People who live alone

What can we measure to ensure that this part of End of Life Care was carried out satisfactorily?

- This is very difficult to measure
- It should be added to end of life to hospital targets somehow
- If it is part of a care plan, can be analysed according to the outcome in relation to items in the plan

- Record the number of complaints
- Yearly review of EOL care provided and assess deficiencies

Last days of life

What is the best way of approaching this and what problems might there be/have you experienced? How could this be improved?

Issues experienced

- Initially preferred place of care was home, but it wasn't physically practical due to extra health needs, and insufficient care from family and carers. Can be isolated. This can be especially problematic if children are involved.

Best ways of approaching/what helped

Framework

- Honest and open communication from outset

People involved

- Continuity of care - if key worker aware of issues from outset, can ask pertinent questions and facilitate best care possible. This can take away stress from all involved.
- Staff need time and resources to spend with family/patient/carer
- Staff sensitivity - e.g. reduction in number of consultant visits (with entourage). Bear in mind that the patient may still be able to hear even if in a coma/not conscious
- A manned helpline should be available for carers and patients for support if they are concerned

Activities and care that should be provided in last days of life

- Patients should be encouraged to write down wishes in advance (wish list or letter) and it should be made sure that these are followed through. This should also include names of people to be contacted if end of life is nigh. Including solicitor, children's carers, estate agent, pain killers, church visitor, furniture buyers, and pet carers.
- The wish for religious support should be established and careful attempts to avoid this should be made if requested. This includes respect for ritual, ceremony and silence if wanted
- All needs (emotional, physical, spiritual, practical) should be provided for in all settings
- There should be appropriate visiting times
- Patients need to be able to contact their families without exorbitant phone call costs
- Patient's voice must be heard above all others involved
- Need to manage patient's attitude/thoughts about diagnosis carefully. Especially difficult if the patient hasn't come to terms with it
- Need awareness of cultural issues
- Dignity should be maintained

- Flexible care arrangements - e.g. if appropriate, carer/family to change dressings etc
- Respect
- Organisation
- Reassurance
- Quiet room with dignity not open ward behind curtains
- People are happy to receive good care in a different context from the one they have requested.
- Good pain relief
- Nutrition plan
- Physical help e.g. commodes etc
- Proper support for carers - especially in eating well and getting sleep

Are there any groups of people who are likely to experience additional difficulties/challenges with this issue? If so, who are they and why? How could these issues be addressed?

- People with complicated family relationships and estrangements - family could end up addressing their own agendas, not that of patient.
- People in hospital because hospital staff don't have expertise/experience in dealing with end of life issues
- Elderly people
- Language barrier - even if interpreter, hard to accurately record essence of issue
- Those with whom the issues weren't addressed in a timely manner. Time runs out so their care is not provided at the correct point in their journey
- People who haven't come to terms with their diagnosis
- Those without access to the relevant care needed (post code lottery)
- Homeless people
- Age discrimination
- People who can't advocate their wishes

What can we measure to ensure that this part of End of Life Care was carried out satisfactorily?

- Audit staff involved.
- Survey members of public who have experience of EOL pathway
- Ask whoever can possibly be asked
- If experience was peaceful
- Assess against care plan, if wishes were carried out
- Rapidity of care delivered
- Targets?
- Issue of payment by results - what is the "result" of palliative care

Care after death

What is the best way of approaching this and what problems might there be/have you experienced? How could this be improved?

Potential issues

- Problems accessing fast death registration so those that wish to be buried within 24 hours cannot do so
- Care of the body should be timely and sensitive. People reported being on a ward where the body was left for several hours, resulting in a horrible smell and a general sense of unease. Others report that staff giggle whilst preparing the body, which is clearly a coping mechanism/shock reaction, but is most distressing to patients and carers
- Training of staff so that they can deal with body appropriately and with dignity
- Privacy for patients and carers should be ensured: One respondent said the following: My father died in hospital. I held his hand as the thin curtain separated us from children running around their father in the next bed with lots of noise
- The approach to end of life should be flexible approach within the parameters of the law

What would help

- Sensitivity in dealing with the body/place of death: Not everyone can face relative after death - prefer to remember happier times
- Family need time to say final goodbyes. Family need to know roughly how long patient may "last" so that they can do this
- Make sure wishes of patient are carried out - causes big problems with grieving otherwise
- Include wishes at this point in care plan
- Allow family choice about which agency is used
- Hospices good at dealing with death. They should share their experiences
- Special care of family including nice chaplain who gently talks through and helps with care at this point.
- Collection of equipment
- Provide contact numbers for and information about arranging funerals etc
- Ambulance and paramedic staff should be adequately instructed on non resuscitation

Are there any groups of people who are likely to experience additional difficulties/challenges with this issue? If so, who are they and why? How could these issues be addressed?

- Lack of cultural understanding and respect
- Those without relatives/close friends
- Those without accurate records/care plan explaining who to contact etc

What can we measure to ensure that this part of End of Life Care was carried out satisfactorily?

- Qualitative analysis - a trouble free phase
- Local focus groups involving relevant special communities involved.
- Guidance from national organisations

Bereavement Support

What is the best way of approaching this and what problems might there be/have you experienced? How could this be improved?

Bad experiences

Next to no support apart from care from neighbours and friends.

Good experiences

- Hospice bereavement services
- Excellent booklet from funeral services about bereavement.

What would help

- If bereavement support was ongoing - carers can feel abandoned after initial support has lessened. In addition, the spotlight is suddenly on them not the patient, resulting in the carer suddenly becoming aware of their own needs. Carers/families may need support in dealing with their own issues. A sense of abandonment can result from not only from person who has died but from medical services
- Short report for relatives stating what happened in last moments if relatives could not be there - advise of hospital procedures and assurance that they were carried out.
- National guidance and set of support information for those are bereaved, implemented locally
- Ensure that the death is dealt with in the best way possible. The way death happened will affect the bereavement support needs.
- Ensure that appropriate literature is available at the time of death, bearing in mind that this is not always what people need at that point
- Support groups/visits from people who had experienced similar experiences
- Ensure that staff are experienced and knowledgeable
- Sensitive provision of support to carers or family members: e.g. visiting them just as they're sorting out the funeral may not be most helpful.

Other thoughts

- Would rather hospices/hospitals put their resources into care before death than after if they are limited

Are there any groups of people who are likely to experience additional difficulties/challenges with this issue? If so, who are they and why? How could these issues be addressed?

- Those that don't have access to services e.g. hospice bereavement service not available to those who weren't supported by hospice
- Inequity for people with heart disease and lung disease
- People who have no family/support mechanisms

What can we measure to ensure that this part of End of Life Care was carried out satisfactorily?

- Surveys
- Patient discussion forums and focus groups
- Audit: Measure whether bereavement support continues

General questions

Do any stages of the care pathway create possible risks of discrimination for people who are not able to explain what they would like perhaps because they lack mental capacity (e.g. due to learning disability or dementia or are severely ill)

The overwhelming response to this was yes. Some thoughts:

Problems:

- Older people discriminated in relation to children
- Incorrect assumptions made about peoples' needs and preferences
- Lack of understanding of different cultures
- Alzheimer's
- Aphasia and other speech issues
- Very sudden death in younger people is difficult for professionals to handle
- Remember denial used as a coping mechanism

What needs to be done to ensure a person in this situation has their wishes understood or taken account of?

One general comment was that you can't ensure that wishes are taken care of. Staff can only do their best. However, the following would help:

- The Mental Capacity Act would take care of this but it risks becoming bureaucratic
- An advocate would help
- Involve relatives and carers
- Assistive technology
- Support for minority groups
- Lay and professional people to support with communication
- Penalties for non compliance: prosecution under age discrimination or human rights law to focus peoples' minds
- Initial assessment with health professional is vital to sensitively exploring what the patient is comfortable with. i.e. whether they want to engage in discussing this subject
- Lasting power of attorney should be drawn up well in advance
- Denial on behalf of patient/family should be addressed and dealt with appropriately
- Careful identification of problem and care in counselling
- Code of practice
- Health team need time to get to know the patient

In general, are you aware of any inequality or discrimination in the way that end of life care is currently provided?

- Where chosen accommodation is not available e.g. hospices not available
- Those with non malignant illnesses e.g. dementia
- In hospital where there is a lack of staff to be with people who do not have relatives or friends. Also a lack of privacy.
- Age discrimination – older people are ignored.
- Those whose first language is not English
- Some people with complex learning disability are sedated to calm them down. How can they make decisions?
- Where staff are over burdened ending up in them not being able to provide adequate care

What could we change to make the service fair so that everyone is able to benefit, whatever their background needs, views or life choices?

- Locally we are facilitating plans for frail/elderly people in care homes with some success but the same process to try and elicit wishes of young severely handicapped people is met with disapproval from carers.
- Encourage staff to do their best and keep learning.
- More information available
- Ensure that all involved adopt a nationally recognised pathway
- Budgetary changes – ensure that there is adequate training for staff. Release money from nursing care in the community
- Make care in the home more readily available
- Train carers in cultural practices surrounding end of life
- Give choices in all areas of treatment, including about how to receive it.
- Ensure that we all have understanding and can develop skills and knowledge to provide equally fair service to all diverse groups and individuals.
- Ensure no post code lottery
- Publish a set of guidelines/code of practice
- Educate GPs

How could we monitor this to make sure that the new service is being implemented fairly and continues to promote equality in the future?

- Surveys
- Spot checks
- Better data about services.
- More communication with agencies to ensure good practice is being observed
- Patient questionnaires
- Assessment from non service providers
- Quality assessment
- Measure against care plan – seek regular feedback
- Independent committee of people who have been through service and gain opinions
- Feedback opportunities for individuals, families and self help groups/charities working in this area
- Set clear standards and issue adequate guidance. Run a regular review based on these standards.
- Consult widely
- Yearly quality audit including patients, carers and health care professionals

Collated by Joanna Black, User and Carer Involvement Project Manager.
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