Wiltshire Involvement Network

health and social care

END OF LIFE CARE IN WILTSHIRE

A PUBLIC MEETING held on 19 November 2009

at the Civic Hall, Trowbridge

Introduction

This event was very well attended, primarily by members of the public but also others representing carers, communities, health & social care providers and the voluntary sector.

During the morning there were various speakers and DVD clips from real interviews with people who knew they were approaching the end of their lives.

The responses to the questions raised at the event were recorded and a typed version is attached. The workshops produced a wealth of diverse comments and participants were eager to express their views, ideas and concerns.

Feedback about the event was very positive. Many people expressed gratitude for the opportunity to participate in the discussion about this very sensitive subject. They described it as a very worthwhile and extremely useful experience.

Contents

WORKSHOP 1

Q. How do we encourage people to have discussions about the end of their lives with family and professionals?

Table 1

- Wills and Enduring Power of Attorney should trigger family discussion.
- Information should be available on GPs surgery screens, leaflets etc.
- Faith groups could help.
- At retirement a leaflet to be made available with pension information. Checklist nationally produced with end of life care wishes.

Table 2

- Have a national “Talk About It” week.
- Link with will making, power of attorney talks.
- Local information and advice with sources of help.
- All agencies to be clear on the pathway.

Table 3

- Greater candour from consultants, doctors and other health professionals regarding diagnosis.
- Fear of not knowing what will happen. No-one believes they are going to die. Sometimes it is more difficult for family and friends than it is for the patient. Who and when are the people who will be there to help.
- Difficult to make final plans until you know what you are dealing with. When a partner dies it may make it easier to discuss with family what your wishes are.
- Will making – you could add your wishes to your will. More should be done to get people to make a will and to include wishes. Ideal time to discuss with family.
- As you get older you would be more likely to discuss what you want. Making a plan is not a very good idea. Try to discuss wishes with family, try not to make it a serious issue. How do you begin? Documentation is an issue.
- Increase in dementia so need to have a conversation before its too late.
- Make a joke about it. Use other people’s experiences to bring up the subject.
- Have a “discussion week” to help people to know how to talk about your wishes.
- Help from GPs and hospitals – not just handing out a booklet.

- W.I. meetings could help with discussions and how to approach family and friends.
- W.I. Lite (for younger people) could start by bringing up the subject.

Table 4

- Professionals (carers, nurses, etc.) could have discussions.
- Sit down with family and tell them "There is a big envelope with everything in on the sideboard".
- Often people who are dying can cope but those around them find it difficult.
- Have spoken about wishes but husband/family do not like to discuss.
- Would be helpful if a form was devised for people to fill in.
- May be inappropriate to discuss things as children may not like what is put in place.
- Funeral organised and paid for in advance.
- Couples may talk independently but not to each other. Could professionals be the link?
- Children and younger people need to be encouraged to talk about death.
- Use humour e.g. "What would you like to happen with your ashes Dad as I don't want them sat on my mantelpiece – I won't know what to do with them".
- People need clarification about choices/options at end of life.
- Encourage people to look at their own mortality. Single parents could go to a solicitor to organise what will happen in the event of death.
- People are superstitious – if they talk about it, it may happen!
- Are professionals prepared to talk about death? Raising the issue in church could be openly criticised.
- Children were furious with parent who opted to refuse treatment.
- Most professionals very good but others appeared uncaring, disengaged.
- Some people like to cope from day to day, not plan in advance.
- People have different expectations from 50 years ago.
- Lady found a person's requests after someone else had organised the funeral.
- Take away some of the unknowns about death. Some cultures talk about death as part of the circle of life.
- Funeral is an important part of death. Important for people who are left behind.

Table 5

- Some professionals raise the subject. They talk about getting your house in order, where do you want to be, who with? People often prefer to discuss with a stranger, don't want to be a burden.

- A carer's opinion was that planning a funeral can make it easier for the family to discuss other end of life issues.
- End of Life needs to be looked at holistically with the whole family.
- A trained counsellor for CRUSE ran a course on dealing with own mortality. Many people found it impossible to imagine not being in existence. Each asked to fill out a forward planning sheet and then share it.
- Planning a funeral very important.
- Make instructions clear.
- Support needed for those involved in end of life care including professionals who are often neglected. Support stops immediately.
- Death still not openly discussed. Listening to people's fears and anxieties is particularly important.
- One person thought younger people are more open about discussing the subject.
- One professional's view is that young people at the end of their life are very willing to plan. It is very much an individual decision.
- Many different experiences. One person's grandparent died in the same room, a picture of her in the coffin was taken and sent to Canada.
- One person grew up with grandmother who died when she was 12. Was kept out of the way and not allowed to the funeral. Still thinks about that.
- A professional mentioned the death of a child and the school children were allowed to go in to see him. Many found this positive.
- Allow people to make choices by discussing options and recording chosen route.
- Be prepared for negative experiences, e.g. family disputes.
- Acknowledging spiritual side of death (whatever religious beliefs) very important, not just physical and medical support.
- Experience of carer from agency is that it can be difficult to explain needs and can be very time consuming.
- When to raise the issue of forward planning? Before illness? At retirement? In between treatment?

Table 6

- People with terminal conditions more likely to face the future and make plans for their end of life care. This usually brings the family together to join in the discussion.
- If children do not feel comfortable about this, write it down, as much information as possible about what might happen. How to deal with it, face the future and make the necessary plans.
- Children excluded from being involved in the process of death are deprived of their right to grieve.

- Memorials, planting a tree, bench in a special place. These can help to commemorate someone and provides a special place to visit for family and friends to remember the deceased.
- Sharing discussions with your friends. This could help to open the path, making it easier to broach the subject with family.
- Media involvement. TV programmes that broach this topic could also be an opportunity to open up the discussion with family members. Contact details about support groups are then provided.

Table 7

- Lead by example, instigate discussions about your own death with family, friends etc.
- Instigate discussion or ask for ideas from one you are caring for to make them more comfortable. “Are we all happy with the way things are progressing?”. Try and engage more family members in the conversation.
- Think about what is important to you; being pain free perhaps, comfortable and then try and apply this to your loved ones.
- Practicalities – how many bank accounts do I have. By thinking ahead, looking at practicalities can help make having an end of life care plan more of a priority.
- We all know we are going to die, making plans before you die also relieves the family from the burden of making more decisions after the death. Family may have to make decisions that suit them rather than the person who has died and may cause friction and anxiety.
- Fits in with cradle to grave idea. Birth plans are made via a ‘wish list’ and this should be done for the end of life stage. Again, it will be a ‘wish list’ and not always possible to fulfil but will be a great help.
- No-one knows when they are going to die and perhaps we are reluctant to think ahead and plan. We think we will live forever when capacity is lost and lose ability to be proactive. When proactive we can make choices and wishes such as dignity, respect, seamless care to keep family around.
- Information is not always available, the choices are not known and decisions are not what the person would have wanted if they had been informed.
- Sometimes GPs take people into hospital when not necessary, could be left at home to die.
- Some families do not want to make the decisions, it feels as though the natural order has been reversed when a child has to make decisions for their parent and they are not comfortable with this.
- Not everyone wants to be surrounded by people. For example, someone who wanted to die alone (they had no family) and he was able to. Carers were there three times a day and one visit they knew someone would discover him dead. This was right for him, although to

others may appear sad, but he died looking out at the view he had loved. This shows respect for people's choices.

- Leaflets or advertising can be a trigger for discussion. Do we need a strap line?
- We need to start at a younger age, accepting we live and we die. Realisation that people do die, need to engage in conversation.
- Age Concern forms for choices seen as a good idea. Give to parents and be proactive and fill one out ourselves.
- Open discussion is needed. Wootton Bassett returning soldiers' parade through town centre is bringing death conversation in younger people. Death is therefore high on the agenda.
- Sense of respect is lost. Respect even for hearse carrying body. We used to bow to coffins as they passed – now this is not done.
- People now living longer. It could be that children are dying before their parents and this brings its own difficulties, children could be elderly themselves.
- Need for openness between families. Sometimes being proactive in talking about death and practicalities. People may try and bring it up with carers/family and receive a reaction such as "you've got years ahead of you". People don't want to discuss your death with you but it can bring real relief.
- The form/wish list could be kept private to some degree like a will, e.g. for cremation or burial, don't need to know until person has passed away.
- Perhaps this could be encouraged by making it part of insurance application, that end of life care wish list is done. Dorothy House use a visual wish list/memory DVD.
- Could end of life care be addressed as early as in schools and address death at an early stage. They may experience death of grandparents or from some sudden deaths. As adults we don't feel able to talk to a child about death, we are not confident about discussing it with them. So, should we always allow children to explore death and not try and put them off discussing it. Children can then have permission to talk about death.
- Roadshows/W.I. meetings. Trying to bring the discussion of end of life care into an open forum. Perhaps alongside another related topic.
- Education and Information. We have all seen babies being born but we don't get to see a real death. TV dramas etc. do not give a real picture of how death can be.
- Person may feel real relief that discussion of their death wishes has been instigated. They may have been having difficulty in bringing up the subject themselves.
- Lack of respect about allowing a person to grieve. Prioritisation of grief – cannot say that because someone was old when they died they "had a good innings" that grief should be less severe or the reverse. People say that perhaps as someone was married for 40 years and lose their

partner, their loss is more significant than a loss after 10 years together. Grief should be prioritised and everyone's experience is different and individual and should be respected.

- Lack of training of hospital staff of options available for care. Age Concern has an instruction form to be extended to cover end of life care rather than just alter death wishes.

Table 8

- Wait and see what happens when I see my friend and tell her about this meeting! Give the information and see what the reaction is.
- Writing a will. A good introduction because it opens up the subject about planning for the future.
- A practical approach can help with the emotional side.
- Make a will and ensure your children know where the copies are and what is included.
- If it is known and you are preparing for a bereavement it can be easier to plan ahead.
- Guilt – is this fair to leave the decisions about end of life care to someone else, e.g. your family and friends.
- Sudden death leaves difficult choices especially when you can't do what the person wanted. "Am I doing the right thing?" It is a huge responsibility.
- Alternatives – should these also be discussed?
- When someone has died, sometimes you can then broach the topic with members of your family about their own death.
- What are the practical aspects for me and my family? I have always been on the outside. I want to save them the difficulty of the practicalities. I feel a duty so it's easier for them to have everything in place. While away on holiday family worried because they did not know where anything was. Perhaps it could be written down and left somewhere people can find it.
- The more information you can provide the better.
- 94 year old neighbour organised every aspect of her own funeral and her funeral was so personal. Music, speeches, everything. Makes it easier for people.
- Encourage but can't always make someone talk about their end of life wishes. You need to give them the opportunity.
- Build up a relationship so they will open up to you.
- Choosing the right person to have that discussion with, different professionals e.g. nurses, social workers.
- Person to "open the door" to discussion – "perhaps I should do something".
- I had not thought about talking to my children before but now I will.
- Culture – ripple effect of soap operas etc. where the myth is dispelled.

Table 9

- We need to know who says that the end is happening, does it happen when a diagnosis is made?
- Planning needs to be made maybe before a diagnosis. Early as possible. GP support is variable so for information like living will/advance directive will, the information should be available to all health professionals. GP is a useful tool to start the discussion with family etc. GPs have the “MOT” for certain age groups, may be part of this? The relationship of GP/patient is different today as they don’t know enough about families. This may be a barrier also communication may be an issue.
- The issue of donor cards ‘opting out’ method then all others donate, so should all GPs discuss death and dying unless people want to opt out?
- To take into consideration the people who do not access GPs. What about education in schools? Breaking down the taboo of death as a subject. Children may be being overloaded with information about inappropriate subjects. Would death be one of those which may harm/disturb children? But, then children may fantasise if they don’t know some facts. Children do experience death, either pets or family members or other children in school. Cushioning children too much may induce fear about death in the future as they have not experienced it.
- The earlier people talk about death in their life maybe more easier to deal with later.
- Medical knowledge – families who have members who have medical knowledge find the subject easier to discuss.
- Too much information/discussion for families may lead them to think that something is imminent or the patient has been told something is wrong/illness.
- The experience of ‘hospital bed death’ compared to seeing the same person at the chapel funeral home is totally different and people need to be prepared for this.
- Families are split so far apart for this fact to face discussion, it can’t happen over the ‘phone. Choice of language is also very important, eg passed away, died, etc.
- The Age Concern fridge box – should this contain information about wishes? Talisman/medical alert could this have the information about wishes etc. which may be recorded and found by family/medical staff when the time comes. Reassurance from the hospitals/medical professions that advance decisions will be respected and carried out. The most important thing is that wishes are communicated/held centrally to ensure all care providers know abut wishes/preferences.
- The ANDO – Allow A Natural Death Order instead of the DNR.
- The Planning for Your Future Care booklet should be circulated to GP surgeries etc.

Table 10

- Discuss how the family would deal with a situation similar to that experienced by friends or family. Easier to discuss with professionals, some have no family.
- Adjusting as circumstances change. Family step in when needed eg to arrange respite care on discharge from hospital. Difficult to discuss in advance and at time due to emotions. Involvement of health professionals helps eg to check able to cope to capacity at home.
- Raising awareness posters in GP surgeries/libraries.
- Consultant did not make clear mothers poor prognosis just told wouldn’t cope at home.
- Positive experience discussion with GP regarding appropriate place for her husband to die.
- Suggest some events eg in community centres, civic centres held by organisations such as Age Concern.
- May be easier for in-law to deal with than immediate family eg helping with visiting care homes.
- Discussion can follow from light hearted remarks.
- Fundamental discussions after attending a funeral – what you would want.
- Lack of information from hospital team regarding patient’s physical condition. “Message in a Bottle” not generally known. Needs to be publicised more. This is currently available from Warminster Lions bookshop, Independent Living Centre, Semington, Devizes Lions Club, Calne Health Centre.

Table 11

- A death in the family enables others to talk about how they would like to be treated at the end of their life.
- Having children makes people think about making a will.
- People want to care for their families but financially they can't, they have their own lives to lead and wouldn't be able to cope.
- Losing a loved one now is somewhat more intense than Victorian times for example, as you may have lost a brother/system whilst growing up.
- Other cultures are more open to death for example having your lost one in the family home for people to visit.
- A lot of people in their middle age, their first experience of someone dying is in a hospital.
- Children sense that something is wrong when somebody in their family is ill and its good to talk to them about it.
- Not wanting to ask family members what they would like in case you can't deliver their wishes.

Workshop 1 - Positive Experiences:

Table 1

- Help being provided by Neighbourhood Teams, with pain relief.

Table 2

- Neighbourhood Teams provide good support.
- Will making – makes this easier and makes it personal/positive inter-family communication.
- Discussing options – helps people make choices.
- Support for faith and faith groups – very important for some. Respecting wishes of the dying person – leads to peace of mind for people afterwards.
- Ability to talk to clinicians.

Table 3

- Will making – provides the opportunity to address issues openly.
- Use humour to make it easier.
- Use trigger points, e.g. bereavement in family, going to funerals, information/leaflets.

Table 4

- Good to communicate with your family about what you would want or do not want.
- A 'good' death is part of a 'good' life.

Table 5

- Allowing people to have choices by discussing options and then enabling them to happen.
- When you explore choices you must also **record** them.

Table 6

- Taking the experiences of this event home to help open up the discussion with the family of what you learn from the discussion and peoples experiences experienced in your group.
- Specific religious beliefs which prompt your need to plan for your end of life e.g. Jehovah's Witnesses, documenting you would not wish to receive a blood transfusion.

Table 7

- Being proactive and talking to mother-in-law about what she wanted and mother-in-law felt it was a great relief.
- Respecting wishes – a man who wanted to die completely alone was enabled to do this.

Table 8

- Planning your own funeral for a very personal occasion.

Table 9

- Comfort in having had discussions with parents.
- Write down wishes.
- Viewing dead person after death
- "Bottle in the Fridge", "living will", sign on GP screen.

Table 10

- Discussion with GP regarding appropriate place to die.

Table 11

- Other people dying within a family triggers people to talk about what they would like at the end of their lives.

Workshop 1 - Negative Experiences:

Table 1

- Where does dementia fit into End of Life Care? Strategy?
- Lack of respite care.

Table 2

- Not clear where dementia fits in.
- Lack of respite care.
- Care Services need to focus on whole family, not just the individual.
- Family arguments when patients wishes are not clear. Children are excluded from events they find difficult to understand and come to terms with in later life. This makes people afraid. Hospital staff not able to give enough time to meet all patient/family needs.
- Lack of information about the patient/family member makes planning difficult.

Table 3

- Use of euphemisms by health professionals (e.g. consultants, GPs and palliative care nurses) re **diagnosis** (need clarity to then accept help, information, care, equipment, benefits etc.).

Table 4

- Some people refuse to acknowledge that this is going to happen or is happening.
- Hospital focuses just on individual not the family unit.

Table 5

- Families arguing/discussing if patient wishes are not clear. This applies to care packages.
- Sometimes there are barriers, others may not understand spiritual needs.

Table 6

- The exclusion of children from dying relatives and funerals in the belief we are protecting them, which in turn deprives them from going through the natural grieving process. Children should be given the chance to say goodbye to the deceased.

Table 7

- Lack of respect.
- No chance to express grief.
- “Prioritisation” of grief
- People not being given options by hospital staff.

Table 8

- Lady’s plans were negated when she had to move. She gave up and died soon afterwards.

Table 9

- Hospital staff forbidding dying patient to see new grandchild.
- Adult children find it difficult to discuss, particularly in ‘non-medical’ families.

Table 10

- Hospital team did not give enough advice on patient’s condition for relations to put care facilities into place, e.g. not blunt enough.

Table 11

- Sudden death: when someone hasn’t made a will, you don’t know what to do and the press get too involved.

Workshop 1 - Actions:

Table 1

- Enclose a checklist of action that needs to be taken on End of Life Care, with pension information.
- Each case to be treated individually.
- To ensure everyone has a will and has arranged Enduring Power of Attorney.

Table 2

- Enclose checklist with pension forms, what help and advice is available from recognised places. Education and information needs to be available for all, especially children. Families should be able to gather information on time. Publicise “message in a bottle”.
- Wills - encourage people to have one and Enduring Power of Attorney.
- Have a “Talk About It” week – linked to will making, encourage planning.
- Make it part of life – integrate it into education system.
- Be an advocate and listen.
- Train voluntary sector workers to enable discussions.

Table 3

- Encourage **candour** about diagnosis e.g. “limited life”.
- “Talk About It” week. Link to will making/power of attorney.
- Talk to groups (as part of wider subjects). GPs to lead communication (with the surgery teams, hospice).
- Local information available with source of help, information and advice (+all agencies to be clear regarding pathways into help e.g. need to have referral from GP to trigger support from Neighbourhood Team).

Table 4

- A “Wish List” developed that people could fill in, make it part of packs given by organisations, or at local libraries.
- Include all members of the support network e.g. families etc. in decision- making about End of Life and what happens in death.
- Education and information for all, especially children. Take away the taboo!

Table 5

- Often difficult for people to talk to families but easier with professionals.
- Could those be more help facilitating discussions.
- Collect information over time, nurses build relationships and can gather information on visits but MUST record it.
- Very important to encourage people to begin to plan before the need to.

Table 6

- Time to discuss End of Life Care often arises from the death of a close family member.
- Should be part of “living”. Integrate into the education system e.g. projects that could open up the discussion (a lost pet for example).

Table 7

- Instruction form e.g. Age Concern’s (as amended to cover end of life).
- Promotion of end of life care by media and other agencies, e.g. schools.
- Be an advocate and **listen.**

Table 8

- Building a relationship to allow you to discuss end of life care.
- Training for voluntary sector workers in how to broach the subject and communicate.
- For younger people link information with planning for holidays e.g. travel insurance.

Table 9

- Central information electronically of patients wishes.
- ANDO (Allow a Natural Death Order) for paramedics.
- Greater circulation of ‘planning for future care’ and similar publications.
- “Bottle in Fridge” could be extended to include patients’ wishes.

Table 10

- More training of professionals in communication skills to enable end of life discussions.
- “Message in a Bottle” not widely known about. Needs more publicity.
- More events such as Age Concern and Community Services advertised in GP surgeries.

Table 11

- Talking in schools about death, incorporated within sex education?
- Do the local press understand the impact of a death? Meeting with them to help them understand how devastating it can be.
- Educating employers on how to treat employees when they return to work after a death and giving support to those who are caring and working.

Workshop 2

Q. How do we support people who want to die at home?

Table 1

- Take notice of peoples wishes.
- Education on end of life care in secondary schools.
- Pre-plan for supporting those to be cared for at home.
- Training for carers and partners of the dying.
- Talk more to all groups on end of life care.
- Media messages via the soap operas on TV and radio.
- Information should be available at all GP surgeries.
- A lot of information only available on website.

Table 2

- Easier with couples, not so easy living alone.
- Message In a Bottle in the ‘fridge.
- Make sure people know where they can get support for patients and family and finance.

Table 3

- Individual and patient need more support.
- On your own do we have flexibility of carers when they do arrive?
- Carers not turning up when expected.
- Practical support, availability - are the services in place? Neighbourhood Team – OT, Physio, Support Worker, Personal Care,

two visits per day depending on illness. Finance – can they afford it? Age Concern has a lady to help with problems. Finances help decide how and where you die.

- All people should be treated the same because of who they are, not how much they are worth.
- Financial assessment and benefit scheme – all should have free personal care, getting up, meals, putting to bed.
- District Nurse – dressing, equipment needed. Continuing health care if the end is near. This is paid for by the Health Services. Life Line – needs to be paid for – emergency support – Ambulance Service, alert doctor. What else can we do?
- All people can get help – healthcare or your own finance. All patients can have a social care assessment. Who will do shopping, food, cooking (meals on wheels no longer available).
- Volunteers. Training overseeing recruiting. Elderly people fall through the net if no close friends and family.
- Supporting people who look after their loved ones. Who helps if they have to go out?
- What happens in a recession? Who cares for you then? If help available more people would want to die at home. Some people don't want to be removed from their home.
- Certain hospitals cater for families with a relative that is dying. Family and friends there to cheer you up. Carers should be there to do all the other jobs. Unfortunately costs are not accessible 24 hours. Care is available but not done very often. Care nurses should have more support in order to give the service needed.
- Volunteers – shopping, cooking, housework. Training important.
- Plans. Discuss in the home with family and friends.
- Have a Carers Diary, times things happen etc.
- Care should not depend on volunteers. Statutory bodies should provide the care.
- Funds will be stretched in the future, how will we still provide the service?
- Package. Local community and health professionals – similar line as neighbourhood watch, to look out for elderly or people near end of life.

Table 4

- Individuals have different ideas about dying at home.
- Do not want to be a burden.
- People living alone may want company.
- People feel more comfortable about having someone who knows what they are doing.
- People frightened to be at home.
- May depend what I'm dying of!
- Depends what support mechanisms are in place.

- Sometimes lack of resources mean that "End of Life Care" doesn't work.
- Geographical differences apply. If you live close to hospital, hospice etc. you may get better care than rural areas.
- Professionals sometimes get requests about finding 24 hr care without notice.
- People need to be skilled in what they are doing, from GPs through to paid carers.
- Support services need to be "fit for purpose" e.g. brokered care package.
- Commercial farming out doesn't work!
- People need to know you have options, you don't have to go home.
- Residential homes will not keep patients at home if they get past a certain stage.
- Raising awareness in care/nursing residential homes. Carers/equipment can be brought in to keep people in their homes. Need more information.
- More investment.
- Improved training.
- More support for families.
- Recognise individual choices. Not everyone wants to die at home.
- Early intervention from professionals when people have a life-limiting illness. Minimum care standards for carers and qualifications, especially palliative care.
- Enhancing elderly care, raise importance within health care.
- Provide extra support to those who do not have families.
- De-medicalise dying.
- Remember people's dignity and respect.

Table 5

- People can change their views late on.
- Good communication with family essential
- Sometimes the practicalities of the need mean that people can't die at home, e.g. nursing and care package can't be in place soon enough.
- Need to be able to deliver on the practical support, including physical adaptation, even if it results in a person not going home there is still the expectation and this gives peace of mind.
- With families more dispersed, many people live alone without support.
- Experience is that many older people are now moving to live with their family. This may not be what they want but they may acknowledge the need not to be a burden.
- Communication and information are the most important.
- Practical implications – may need to turn the home into a mini hospital. This will not suit all families.

- Family members very fearful of having someone die at home. Marie Curie has a very good book about the process of dying and what to expect.
- Two different sets of pathways; terminal diagnosed disease with projected end and gradual decline with no specific pathway. No trigger for this discussion in those cases.
- Using retirement age as trigger.
- Screens in GP surgeries showing information.
- Gold Standard – every GP surgery has to have a register.
- A lot of different services able to support but is there enough information about what is available? No leaflets about neighbourhood teams. No Information about access to care.
- Access to care – referral from a number of agency professionals.

Table 6

- Discharge from hospital. There must be a dialogue between clinicians and the carer. Full assessment information on patient.
- Must be a DISCHARGE CAREPLAN and also co-operation between care agencies.
- Care needs should be set up in the home prior to discharge.
- Vital that local care agencies i.e. district nurses are fully informed of the patient immediately they return home.
- National holidays often cause delays in getting aid packages to patients in time. Often difficulties arise when applications are coming from different suppliers. Vital equipment is not being delivered at the same time. Needs a "joined-up" service.
- Essential to have co-ordination between agencies, clinical and care package providers.
- Need an "End of Life Co-ordinator/Manager".
- Acute Care Provider – should have an EOL Carer.
- Immediately someone is admitted to an acute centre this should trigger a preparation of a care package so that all the patient needs are catered for on discharge. Communication between all agencies is vital.
- Support staff should be properly trained.
- Care package for carers too!
- Carer needs reassurance that help will be on hand as and when needed.
- Support care agency providers should be regularly monitored.
- Support care agency training should have standards.

Table 7

- Society at large, we as individuals, PCTs, agencies etc. must be person centred, tailored to the person and what their wishes are.

- Experience of participant had of taking decision to keep mother at home but had no idea how long it would be, expected 2/3 years but it has been 5 years already but for him this is not a burden. Perhaps visit for mother and participation from a nurse to establish that all parties are happy and comfortable with the situation as it is, a review opportunity.
- This would provide opportunity for discussion, a support visit can open up channels for equipment etc., acting as a gate keeper and can get access to equipment and practical side of things, physical things.
- How are religious/spiritual needs met?
- Contact is very important, befriending can make a difference.
- Expectations of what we expect or what you would want can be forced upon the person you are caring for. Person may be quite happy to stay at home and not go out but for others this may seem very alien. Home is security for some and do not need or want to go beyond this territory.
- Some people do not live near loved ones so they cannot give the care they want to. Logistics/travelling can be very difficult. Care and support circumstances, finances and availability all play a part.
- What if wish list cannot be granted due to circumstances? They can be very anxious or upsetting experiences.
- The younger man in the DVD film came very low in the priority list. He was concerned that his end of life was as convenient as possible for his family and friends.
- To enable people to have the information they need when an end of life situation occurs.
- When people live far apart it can bring up difficulties as by the time you have arrived on the scene, some practical aspects will be taken in hand whether you like it or not. This can create interesting family dynamics – old ‘hurts’ resurface.
- What happens when some people don’t want to accept they are dying or that their relative is dying? Acknowledging the reality of the situation is vital. Hospice workers very experienced at helping everyone come to sort of acceptance of what is going on.
- Nurse gave description of however prepared a family may appear to be. Reality can cause fear and panic.
- It is important to trust professionals and accept guidance.
- Expectations of family of how death/end of life occurs can be difficult.
- Example of family expecting father-in-law to die in hospital, died in family living room as he wanted to sit in his chair and die.
- Importance and value of hospice beds acknowledged. Concerns raised about the lack of hospices beds available – wish lists may not be fulfilled due to lack of funding.

- Funding is an issue. Hospice and hospital beds are expensive but hospice care is invaluable. General consensus that more hospice beds are vital.
- ‘Hospice at Home’ provides excellent “security blanket” – a professional in the house provides excellent resource.
- In our daily lives we have no concept of what is normal for death, the experience of these people of what the signs and symptoms of the close of life are..
- Clergy have a role to play, can offer advice and share their knowledge. For some, clergy can be more comforting in passing on the bad news of imminent or actual death than a medical person. Patients can feel anger towards medical profession for not saving or prolonging life but feel more calm if clergy deliver the news. People often turn to spirituality at end of life.
- Must address the whole person, must be person centred – practical, nursing, spiritual, supporting, financial.
- Allowing family to be involved in end of life care, a positive experience in an inclusive situation where family are allowed to be included in helping in personal care.
- Unpredictability can be difficult for family members during changing health or mental illness.
- Stigma of asking for help – negative press surrounding social services has not helped. People too proud to ask for help.
- Pastoral care plays an important role.
- Information available everywhere e.g. supermarkets, media.

Table 8

- Make sure medical services are in place.
- Empathise.
- Keep all involved and informed about what is happening. Reiterate verbally, follow up in writing if necessary.
- Ensure emotional support for whole family.
- All agreed most people want to die at home.
- Relatives worry about responsibility and are concerned about others coping.
- Adequate respite for carers is essential.
- Spirituality - should vicar/priest be involved?
- Communication - carer needs to use listening skills. Comments can lead to affecting change.
- Identify what is the most important thing.
- Good deaths include family co-operating, good medical staff, peaceful.
- Can go to a solicitor when family can’t agree. Person can be caught in the middle of an argument, wishes hard to ascertain. Patients caught in feuds lose what it is really about. No-one should take sides.
- People with dementia may not be able to explain what they want.

- Discussion can be a positive experience.
- Does the loved one wish to be called if the person is dying? The responsibility is for the nurse to be with the patient.
- Regard it as a privilege to be with someone when they die.
- Home becomes a hospital, needs to be sensitively managed, may need beds, equipment and drugs.
- Some take it as an invasion.
- Families and patients can change their minds.
- Calming the situation can be key – peaceful as possible.
- Experience of death is clinical, people have died in hospital rather than home.
- Good planning essential but difficult with acute illness.
- People need help with bereavement. CRUSE have much information.
- Funeral Directors good at supporting family, organising the practicalities.
- GP would go out and certify the death and would speak to them about what happens next.
- Nurses/hospices do post-bereavement visits.
- People to be willing to pop in but may be frightened of saying the wrong thing.
- Carers can carry on duties not just cut off.
- Support from family, friends and continued support – carrying on with life.
- Provide books to read for those having a hard time.
- Local support group, befriender to take on continued support at crucial time.
- League of friends in the community. Would need training but as needed would help when families are so far apart.
- Unplanned visits useful because families may say they are ok but aren't.
- Pastoral care should be available.
- Quiet room away from children running around, or perhaps people need to have children running around as this is part of normal life. Dispel the fear
- At an early age, young children also need to be there and aware of what is happening.
- Appreciate that we have only got today and we must live life to the full.
- Important that people must broach the subject.
- Ask Undertaker to speak as part of training. Will help pave the way for the future.
- How many people know about woodland burials for example and where do you get the information? Wild flower seeds can be bought instead of having a headstone.
- Donating body for research by a medical school.

- Distressing for care staff if death has not been planned. Hard for staff to come to terms with.
- Undertaker is multi-skilled, can support people.

Table 9

- Care companies who provide staff must ensure that they are trained and able to communicate well with the patients and their families. Some staff do go over and above their job role to ensure good comfort and care.
- More time for home carers (staff) better training and value.
- The correct support from professionals will remove some of the fears.
- Sharing information between professionals as well, for example from hospital to GP. Without multi-disciplinary input, families may be unaware of needs etc.
- Care packages dependent on finances and funding may leave the self-funders “high and dry”. Continuing health care funding may bridge this gap.
- Do people who are self-funding have a named worker for palliative care without a social worker? How much support do people have without a social worker/professional involvement, how do they get into that network. GPs can be seen as gatekeeper to other services like district nurses etc.
- Without experience people are ignorant of where to find the help as sometimes it is not forthcoming from agencies.
- Helpline with a person who can help.
- The One Stop Shop for information. The social care help desk, although a good idea it does not seem to work for people who are trying to access it.
- The attempt is to bring together social and health to ensure partnership working and holistic assessment.
- The Hospice input although the tiny (2%) percentage of deaths occur there, they care for the carers, training them in practical skills etc. this should be rolled out to all people who want it.
- Looking at the after effects of a death, for families to cope with what to do next. Explanations of how and why things happened and ensure the family feels supported with practical and emotional information.
- Funeral Directors are also very helpful in their information after the event and the support for subjects that have to follow death.
- It is important that support during the illness/death continues after death to support families.
- Encourage life history story, celebrating the life.

Table 10

- Neighbourhood Team will do an assessment with GP. First go to GP who makes recommendations for hospice or care worker. Hospices thought of as a place to die rather than a place to live.
- Lack of knowledge of support that hospices can give to families as well as the patient.
- Communication of what various agencies can do and don't do. Who are they advertising to and who they are not getting to.
- Terminal patient told she was too well to go to day centres. Need for social support for people who are dying but nowhere near the usual age of people in care.
- Make the distinction between dying 'at home' or 'in a home'.

Table 11

- Although some people are able to die at home they might not want to because of others bad experiences.
- Necessary equipment is not always available for people who want to die at home.
- Paperwork should not be a barrier for emergency care.
- When a member of the family dies after they had been cared for at home, the equipment e.g. hospital bed has been left there for weeks which isn't a nice reminder for the carer. People do not always know who to contact for equipment to be removed.
- Whose job is it to empty a commode when somebody dies? Would the carer go back in after the death? The carer is not allowed in the building after the death.
- Patients can be inappropriately placed in order free up beds.
- Hospitals take advantage of the patients who are elderly because they can't speak up for themselves. They may move elderly patients to other organisations to free-up beds when they really need hospital care.
- What do you do when someone is of sound mind but they don't want support?
- Even if this leaves problems behind, should still respect their final wishes.
- The earlier a person is referred to the Neighbourhood Team the better, establishes good communication.

Workshop 2 - Positive Experiences:

Table 1

- Availability of appropriate equipment.

Table 2

- Appropriate equipment available.
- Good services exists and can be built on.
- Services are flexible and can meet different needs.
- Local communities can offer good support.
- Hospice at home is very good and so is all hospice support. Good co-operation between health/social care/voluntary sector & families.
- Undertakers are good!

Table 3

- Good support from Neighbourhood Teams very accessible BUT limited.
- Total support to all the family in local community hospitals.
- Dying at home – family there all the same.

Table 4

- Build on the good services that exist. Ensuring that Gold Standard goes across the board.
- Early referral to services once a person is diagnosed with a life-limiting illness.

Table 5

- Services and others to respond to individual needs.
- Families make sacrifices.
- There are currently a lot of different services available to support different needs/changing needs.

Table 6

- Local community support.
- Support from other carers in similar circumstances.
- Cancer service clinical staff personally telephoning carers to offer support and advice.

Table 7

- Being included as a family member.
- Positive support from clergy (spiritual support).
- Person centred approach
- Guidance of professionals.
- Hospice at home.

Table 8

- Planned, where families and health professionals are co-operating to create a calm, peaceful, pain-free death.
- Individual carers can provide excellent care.

- Input of MDT can be crucial – sharing of information needs to be individually tailored to patients and carers needs.
- Family Service Unit in Bath.
- Undertakers good!

Table 9

- Individual carers can provide excellent care.
- Input of MDT can be crucial.
- Sharing of information needs to be individually tailored to patients & Carers needs.
- Family Service Unit in Bath good.
- Undertakers good!

Table 10

- The help and support given by Dorothy House has been excellent.

Table 11

- A person who wanted to be nursed in his own bed, not hospital bed, worked fine with the other equipment.
- Student nurse has observed good quality of care.

Workshop 2 - Negative Experiences.

Table 1

- Is there sufficient money to implement the strategy to enable people to die at home?
- Not all carers CRB checked.

Table 2

- Carers need to be depended upon to turn up at the right time.
- Lack of resources, information and time.
- Appropriate care packages not always in place.
- Carers not given enough support.
- Negative press undermines confidence.
- Not always a good relationship with GP.
- Discharge planning not always up to scratch.

Table 3

- Carers needed at regular times, they must be dependable.
- Inequality of having to look at financial status to be able to access (free) help.
- Restricted visiting times for families.

Table 4

- Lack of resources, information and time means that people have bad experiences and inadequate care.

Table 5

- Appropriate care packages not being available.
- Limitation – not being able to deliver desired choice.

Table 6

- Insufficient attention given to care packages – not detailed enough.
- Not enough care and support given to the carer.
- Better co-ordination between supply agencies to ensure all equipment is available at the time of discharge.

Table 7

- Lack of guidance/information.
- Fear that expectations won't be met (e.g. dying in hospice).
- Negative press.

Table 8

- Circumstances where the person has not received the support they need.
- A planned peaceful death taken over by an emergency where the patient dies in an ambulance or in hospital.

Table 9

- Care providers not always able to supply fully fluent personnel and issues such as pay and conditions.
- Poor relationships with GPs.
- One-stop Shops not necessarily able to provide the answer.

Table 10

- Terminally ill patients has been told she is too young to go to a day centre, depriving her of social contact.

Table 11

- Bodily fluids after somebody has died, who would dispose of this? Seems to be a gap in the system.
- Hospitals sometimes don't realises what they are sending patients home to, no equipment, poor discharge.

Workshop 2 - Actions:

Table 1

- Government/Local Authority funding for Voluntary Organisations to produce information. Education for all.
- Preplanning for possible illness and death.
- The need for very good extensive support from professional services (health and social care).

Table 2

- Government/LA funding for voluntary sector to provide information, better communication for families to understand what it will be like for family member dying at home. Use plain English in all information and plans. Improve information from GPs.
- Strengthen links between health and social care. Improve respite care. Ensure all staff receive enough training. Social workers provide a great service but this needs to be strengthened. Provide end of life care training for carers – possibly provided by hospices?
- Encourage pre-planning for illness and death. Care plans need to be flexible. Early planning allows people to build full lives wherever they are. Planning for collection of equipment post death. Emphasis on listening and training.

Table 3

- More involvement of voluntary sector and local communities alongside Neighbourhood Teams (needs to be formalised). A flexible plan is **pivotal** to this and could include VCS/Community Services.
- More respite care/sitting services available.
- More volunteers to undertake practical help.

Table 4

- Early intervention/referral across the County to people who have been diagnosed with life limiting illness.
- Investment in appropriate services to meet needs.
- Improved training for professionals and NVQ 2 for all agency staff. Minimum qualifications.

Table 5

- Better co-ordination of all the people involved in developing care packages.
- Encourage people to think about where they will have to be physically so they have time to move close to family and plan/build a new life before they become too frail.
- Social Workers to be part of Neighbourhood Teams.

- Better communication with families about what it will be like if a family member dies at home.

Table 6

- Appoint an “End of Life Co-ordinator”.
- Better co-ordination between supply agencies.
- End of Life Care co-ordinator in acute providers to ensure all aspects of the care package is in place before patient returns home.

Table 7

- End of Life Plan which makes sense to all involved (plain language).
- Carry on with great service from Neighbourhood Teams and hospice at home and more hospice beds.
- Better information in GPs surgeries and even supermarkets and libraries. Better training for staff.

Table 8

- Build on community support.
- **Planned** availability of personnel and equipment in health and social care services.
- Good communication (**written down**) of the person’s wishes. Helps to ease family dynamics.

Table 9

- Hospices – offer short course to carers in moving/handling, nutrition, end of life, self care and post dying care.
- Care for family after death.
- Encourage patients to talk about their lives and experience.

Table 10

- Communication of what various agencies can do and what they cannot do. Improve information on systems available (things to do) for patients who are mobile but have no transport means available.
- Consensus of opinion was that hospices are a place to go to die. It was pointed out by a nurse that they are a place to LIVE. Perhaps the distinction of dying **at home** or dying **in a home** should be made.

Table 11

- Timely collection of equipment when somebody dies.
- Clarity of responsibility of who would move the person and equipment from upstairs to downstairs.
- Health professionals should listen to formal and informal carers.
- Doctors and paramedics in training should join inter-professional training done by all other professionals.

Appendix 1

END OF LIFE CARE IN WILTSHIRE

10.00am	Arrival & Registration
10.30am	Welcome
10.35am	Introduction & Context
11.15am	DVD Presentation followed by group discussion
12 noon	Comfort Break
12.15pm	Workshop 1 - How do we encourage people to have discussions about the end of their lives with family and professionals?
1pm	LUNCH
1.45pm	Feedback from Workshop 1
2pm	Workshop 2 – How do we support people who wish to die at home?
2.45pm	Tea/coffee
3pm	Feedback on Workshop 2
3.30pm	Summing up & Final Comments
3.45pm	END

Appendix 2

END OF LIFE CARE IN WILTSHIRE

List of Participating Organisations:

Abbey Care
Age Concern
Alzheimers Society
Bradford On Avon Health Centre
Care Providers Association
Carewatch Wessex
County Councillor
Dorothy House Hospice
Goughs Solicitors
Hounslow LINk
Local Midwife
Lovemead Group GP Practice
NHS Wiltshire
Prospect Hospice
Ridegeway Care
Ridgeway Community Association
Ridgeway Housing Association
Salisbury District Hospital
Sarsen Housing Association
Wiltshire Council Staff
Wiltshire & Swindon Users Network

Also present:

Members of the public (some currently receiving care)
Wiltshire Involvement Network Members
HAP UK staff
Enablers
Wiltshire Interfaith Group