

## End Of Life Care (EOLC) Patient Panel – East Berkshire CCGs

Thursday 22nd February 2018  
At Thames Hospice, Hatch Lane, Windsor

### Summary of the Discussions

#### Whole group session: If you were dying what would be important to you?

##### Information

- We would want the information necessary to make our own decisions
- We accept that not everyone would want the same level of information

##### Coordinated

- We would want our health care professionals to talk to each other
- We don't want to be asked the same questions over and over again

##### Services

- We want the services there when we need them
- We want choice; that choice may be different for each person

#### Small group sessions: What would better end of life care look like locally?

##### ***Coordination, information sharing and communication***

- Talk about death openly and earlier in the process and educate the public to talk and think about death.
- Co-ordinator / key worker for all – single point of contact to coordinate good quality care and ensure patients and families have access to the right services at the right time for them. Ability to choose the key worker.
- A joined-up service with shared information at the right level.
- One set of notes – an electronic set and a paper set for patients that is legible, clear and sequential. All information in one places and easily accessible to the patient.

- Contact list of important people to be kept informed of the patient's situation. This may include people who are not just NOK and people who would like to the opportunity to express their own preferences and be heard (inclusivity of the patient's network).
- Encourage legal provisions to be made beforehand and signpost to support
- Professionals being willing to have open and honest conversations about prognosis, but in a sensitive way. Practically ensure there is a suitable protected space available for these discussions. Communication style and content should be appropriate to the person's circumstances as their needs change. Where possible and wanted, enable patients and their families to feel positivity in the experience of dying and the dying process
- Personalisation – each person seen as an individual (with differing cultures, beliefs, spirituality and opinions); ask the person their individual needs and preferences (including the patient's consent to share information); allow time for the person to think, reflect and be heard.
- Enable the person to maintain control - provide details of what the patient should expect in terms of their deterioration and an understanding of the treatments to address this in a timely way (for example, constipation, care of skin, nutrition, hydration, psychological support – not just pain relief).
- Provision of information – for example, in leaflet form, so that patients and families understand what to expect. Request to ensure positive values are included, such as messages of peace and happiness.
- Professionals to share good practice and ideas.
- Explain terminology (for example, 'social care') and the responsibilities of different organisations in order for people to more easily navigate the system. Provide information on the services and support that are available at an early stage and reiterate the choices as the person's condition progresses.

### ***Nursing and care provision***

- Nursing care in home – care for your basic needs must be delivered in a way that is acceptable to patients and in a planned way so that patients know when care will next be given.
- EOLC takes longer to get right so give it more time
- Care in the home – strive to maintain dignity and respect of that person at all times

- Early provision of equipment to the home with an organised plan (provided at the point of delivery) of when and how/ by whom it will be removed or disposed of after death so that the family are aware of what to expect. Reuse as much equipment as possible.
- Equitable access to EOL care that is right for you – special consideration was given to the situation in which a person is on their own and has no family to support them
- Environment – be mindful that the person’s surroundings where they are being cared for may influence their state of mind; maintain a positive environment and atmosphere.
- Services that are free at the point of delivery. Better funding of, for example, palliative care services.
- Access to new technology and medications are vital to enable patients to experience a good death.
- Making available rooms or areas in hospitals for people who are dying.
- Having a choice for place of death – making that happen

### ***Carers / Families***

- At all stages for the patient where we shape services around their needs, there is a parallel journey for the carer/ families where support should be commissioned and offered in a planned and organised way – including during the EOL stages, pre-bereavement and post-bereavement.
- Identify pre-bereavement the need for practical support to be available after the person has died, such as support to care for children as a lone parent.
- Identify the need for carer respite and put provisions in place at an early stage so that this is provided proactively.
- Use of social media networks to bring patients and their families together to develop a community and combat loneliness and isolation.