End of life care and advance care planning in the Avon, Somerset and Wiltshire Cancer (ASWCS) network

Julian Abel

Consultant in Palliative Care

Weston super Mare

Chair, ASWCS palliative care strategy group

End of life strategy development

- Election Manifesto commitment May 2005
- Our Health, Our Care, Our Say January 2006
- Ministerial announcement of strategy June 2006
- Broad consultation with stakeholders
- Advisory board + 6 working groups (Care pathway, commissioning, measurement, workforce, care homes, analysis/funding
- Original intention had been to publish December 2007
- Linkage to Next Stage (Darzi) Review

End of Life Care Framework

- Public Profile
- Strategic Commissioning (PCTs and LAs)
- End of Life Care Pathway
    - Starting the conversation
    - Assessment and care planning
    - Coordination and register
    - Integrated service delivery
    - Review
    - Last days of life
    - Care after death
    - Support for carers
- Workforce development
- Measurement
- Funding

Local initiatives

- Avon, Somerset and Wiltshire Cancer Services network palliative care group
- Bristol, North Somerset, South Gloucester (BNSSG) cluster group
- Bath and North East Somerset (BANES) – End of life care group

Local Initiatives 2

- Wiltshire – end of life care group, neighbourhood teams – keeping patients at home and closing community hospitals
- Somerset Palliative Care Partnership
- Marie Curie Delivering Choice

Local Initiatives 3

- Bristol Health Services Plan – End of Life care group
- Nursing home education project, including advance care planning
- Advance care planning education
- Delivering Choice
- Project to address society issues

Local Initiatives 4

- Coordination with ambulance services
- GSF, LCP
- Joint cardiac, palliative care network meeting
- Just in case boxes. Links with Somerset Palliative Care Partnership which is linked to BNSSG
- Notes audit

Delivering Choice

- The Marie Curie Delivering Choice Programme projects provide excellent opportunities to test and implement new ways of delivering service in a range of different environments: urban and rural settings, areas of deprivation and contrasting prosperity, and ethnically diverse communities.
- Working in partnership with a range of local service providers - including the NHS, social services and the voluntary sector - each project aims to complete all three phases within a three year period.

Delivering Choice 2

- Phase 1 –understanding current state of services – thorough review lasting about 6 months
- Phase 2 – Designing new service models, lasting up to 6 months
- Phase 3 – implementation and evaluation

Advance Care Planning

- Advanced wishes
- Appointing someone to make decisions for you in the future
- Putting your affairs in order
- Making a will
- Writing an advance decision

Advanced wishes

- Where you think you would like to be cared for if you are dying (Hospital, nursing home, hospice, at home).
- Whether you would want to be told when you are close to death
- Who should talk to any children, or other close family
- Who should look after your pets

Advanced wishes 2

- How you want your final days to look and sound (flowers, pictures, photos, music, TV, radio etc)
- Is there anything that you would not want to happen to you?
- Who you would wish to visit you near the end

Lasting Power of Attorney

Mental Capacity Act (2005)

- Property and affairs LPA - such a person can make decisions about financial matters eg selling your house, or managing your bank account.
- A personal welfare LPA – such a person(s) can make decisions about your health and personal welfare eg where you should live, day-to-day care or having medical treatment.

Lasting Power of Attorney 2

- A personal welfare LPA will only take effect when you lack capacity to make decisions. With a property and affairs LPA the attorney can start managing the financial affairs as soon as the LPA is registered (when you may still have capacity) unless it is specifically stated that this should only happen after you lose capacity.

Putting your affairs in order

It is worth asking yourself, how easy is it for my next of kin to find all my important documents if I become ill, or die suddenly. How can I make it easier for them?

This will save your family having to search through piles of paper to find the information they need, at a time of great stress. The instructions could include:

- Details of you bank, building society, credit cards, pension, tax district and any other financial contacts.
- Telephone numbers and addresses of close (and distant) friends, family and colleagues.
- Where you keep documents eg passport, house deeds, insurance, life and other policies, mortgage and hire purchase agreements, birth and marriage certificates.

Writing a will

The Law Society recommends that a will should be drawn up with face-to-face advice from a specialist solicitor.

- Start by making a list of all your possessions and the people or charities you want to provide for, including any property you may wish to divide in a certain way. A will can name guardians for any dependent children and record your wish to leave money or property in trust for children or grandchildren.

Writing an Advance Decision (‘Living Will’)

You cannot make an advance decision to ask for medical treatment, or to have life ended. You can only say what types of treatment you would refuse.

The Mental Capacity Act (2005) addresses issues that can affect anyone unable to make some or all their own decisions and gives them increased legal rights. This has given advance decisions a legal status.

Living Will

- Must be in writing
- Must be signed by maker in presence of a witness
- Must be signed by a witness
- Must be a specific statement about treatment in a specific circumstance, even if life is at risk

Living Will 2

At the time you make an advance decision you must be:

- aged 18 or over
- mentally competent and not suffering from any kind of mental distress at the time it is drawn up
- must not have been influenced or harassed by anyone else
- must appear to be fully informed about the treatment options and their implication when the statement was written
- must not have modified the advance directive verbally or on writing since it was signed and dated

Living Will 3

- A doctor needs to be satisfied that an advance decision is both:
- **Valid**- ie- it has not been withdrawn, or overridden by appointing a Lasting Power of Attorney, relating to the treatment, or the patient acted in a way inconsistent with the advance decision.
- **Applicable-** It must be applicable to the treatment in question. It should clearly refer to the treatment in question and it should explain which circumstances the refusal refers to. If there have been changes in circumstances which there are reasonable grounds for believing would have affected a person's advance decision when they made it, then it may not be applicable.

Living Will 4

Some treatments that may be refused

- Resuscitation
- PEG feeding in MND
- Ventilatory support
- Antibiotics
- Stent insertion
- Nasogastric feeding

	Details:
Person I wish to be responsible for making my funeral arrangements	
My preferred funeral director is-	
My pre-paid funeral plan is with-	
I wish to be buried / cremated	
I wish my funeral service to be at:	
My wishes for music to be included in the service are:	
I would like the following hymns or readings included:	
I would like the following person(s) to conduct the service if possible:	
Other details and information you would like to record eg donations to named charity, flowers, people to be informed	

	Details	Place kept
Bank Name and account details		
Insurance policies		
Credit cards		
Pension		
Passport		
Birth/marriage certificates		
Mortgage		
Hire purchase agreements		
Will		
Other important documents/ contacts Eg Solicitor		