



Dying well: Quality end of life care

“Very useful – hope to see follow up events. We need to collaborate and build on today’s event.”



**Report of Community Services Scrutiny Committee
June 2011**



DELIVERING EXCELLENCE

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1. Purpose of Report

The Community Services Scrutiny Committee undertook an in depth study on the end of life care for adults. Most of us wish to die at 'home'¹ and the study focused on the steps being taken by health and social care and other agencies (including both formal & informal carers) to help achieve this.

The Committee was supported by a Project Team comprising:

- Councillors Salter (Chair), Robin (Vice Chair), Carr, Dr Caunce, Walker, Grimwade, Lewin, Stafford and Borton. Cllr Folkard and Cllr Horrigan MBE have been involved in this project (attending meetings on behalf of Cllr Carr);
- Fiona Abbott, project coordinator;
- Strategic Lead, Simon Leftley, Corporate Director Adult & Community Services;
- Sue East, Team Manager, OP Team, Adult & Community Services;
- Yvonne Campen, Assistant Director Transforming Community Services and Long Term Conditions, NHS SEE;
- Michelle Hill, Group Manager Strategy & Planning: Vulnerable Adults, Older People & Carers, Adult & Community Services;
- Rebekah Sayer, Legal & Democratic Services;
- Sherry Fuller – Facilitator, Adult & Community Services.

The project team met on 5 occasions and considered a wealth of evidence, some examples being the Liverpool Care Pathway for the dying patient; the End of Life project in Leigh; the End of Life Care Strategy. The project team also decided that the best way to gather evidence from stakeholders would be through holding a stakeholder event.

This event took place on 24th January 2011 and involved a broad range of stakeholders, including representatives from health (the PCT, Hospital, mental health trust), the ambulance service, voluntary sector, agencies working with older people, local authority (officers and elected Members).

The aim of the event was:

"In an informal but focussed atmosphere, (to) raise awareness, generate discussion about services, identify gaps and create ideas about the changes that would support people who wish to die at 'home'."

The outcomes from the event inform this final report and the recommendations. The project team also wanted all the delegates to be given the opportunity to see and comment on this report.

¹ Based on NHS SEE baseline review (detailed in the NHS SEE Strategic Plan - refresh) View 'home' as being somewhere other than being in an acute setting i.e. person could be in a care home, nursing home etc.

2. Stakeholder event

The Chairman, Councillor Mrs Salter welcomed delegates to the event² and set the scene for the day; summarising the national picture and talking about the importance of working together to give people the best support at the end of their life.

Two presentations followed. Yvonne Campen, from the local Primary Care Trust, talked about the End of Life Pilot Project, which has been running in Leigh-on-Sea and Thundersley. Details of the ongoing project are attached as **Annex 1** at the end of this report.

Chris Doorly (pictured), Chair of the Safeguarding Vulnerable Adults Board, talked about the importance of managing risk and protecting dignity at the end of life. Chris advocated that we need to adopt a culture of high expectation for our services.³



Working together

The remainder of the event was interactive; participants working together to talk about what good end of life care meant to them, and to share stories of real situations. Working in pairs, and then in small groups, people developed:

- visions for the future of services (page 5)
- the themes of good care (page 7)
- and actions that would lead the way to making those visions a reality (page 8)

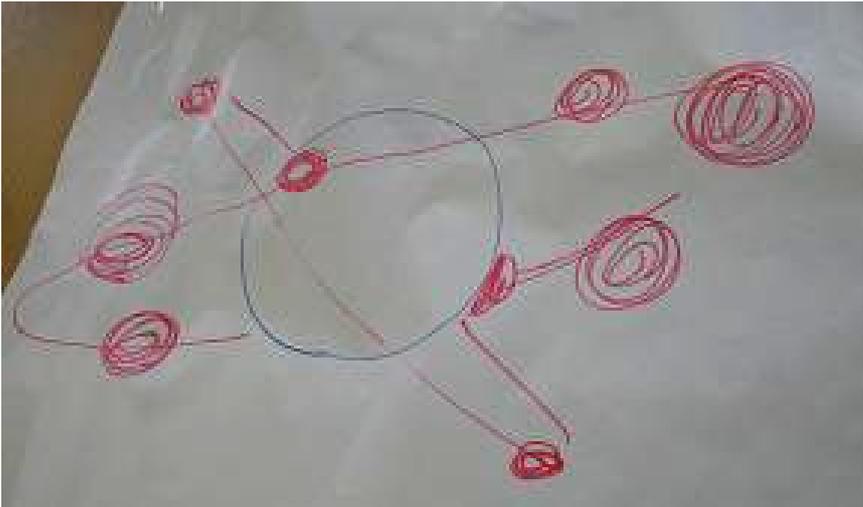
This way of co-creating a preferred future uses Appreciative Inquiry techniques. It's a whole systems approach which is effective in bringing together diverse groups of people to manufacture their own solutions.



² The agenda for the stakeholder event can be found at **Annex 2**.

³ Copies of the presentations / handouts are available on request.

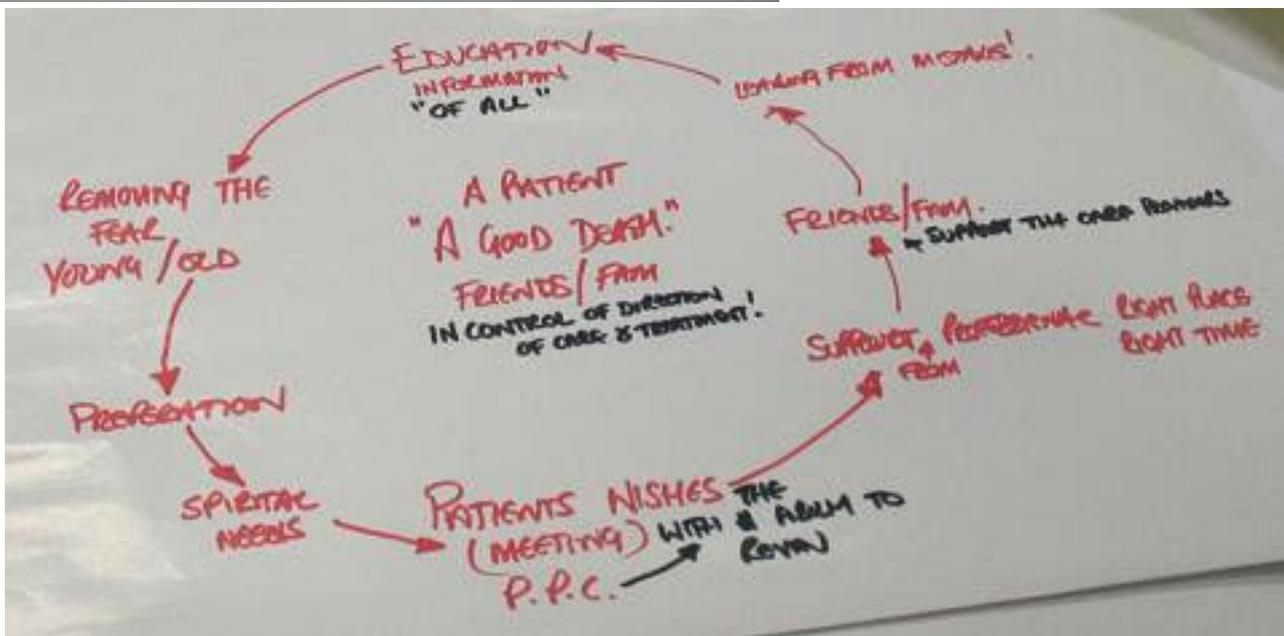
Visions for dying well



Patients are at the centre of the system. Everyone orbits around them working for the best for the patient, and in accordance with the patient's wishes.

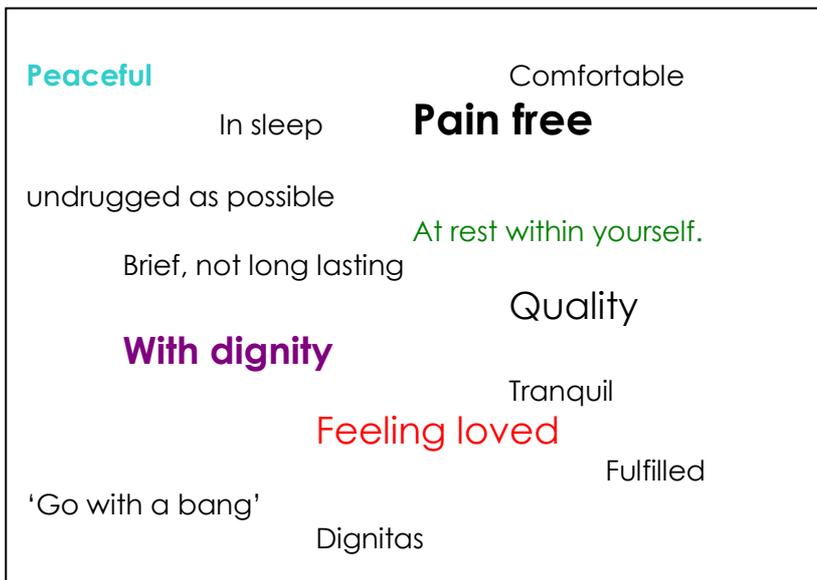
Patients and family are empowered to seek support and to get the right support at the right time.

Dying without fear: living through the end stages of life without anxiety about what will happen. Dying without pain, or with minimal pain.



Dying well
OUR COLLECTIVE VISION

DYING "HAPPY" IN THE PLACE OF MY CHOICE, HAVING BEEN HEARD AND SUPPORTED BY ANY SERVICES NEEDED, SURROUNDED BY MY FAMILY AND FRIENDS WHO KNOW AND UNDERSTAND MY WISHES AND ARE PREPARED FOR MY DEATH, CONFIDENT IN THE KNOWLEDGE THEY WILL RECEIVE THE CARE AND SUPPORT THEY NEED IN THE FUTURE.



Peacefully,
comfortably,
according to
my wishes,
in the place of
my choosing,
with the
people I want
around me.



Safe, comfortable
Controlled symptoms
'Warm' environment through planning and timely appropriate care.

Personalised care

- appropriate care
- appropriate time
- appropriate place
- (within available resources!)

Dying in a place of your **choice**, being **content** and having had the **opportunity to express own wishes** with the people you love/care about.
Physically and emotionally comfortable.
Being **listened to** and **your choices** respected.

At the event, people said that good end of life support would include:

Talking to people

- A culture shift in the way we talk about death as a society, and as professionals.
- Proactive conversations about the end of life. Help people understand the options available and how to make choices.
- Professionals need to be honest, clear and have compassion. Family should be supported to talk openly and ask questions.
- Ensure the person understands their prognosis and what to expect. Support acceptance of 'this is where we are now'.
- Hear what the dying person has to say.
- People need to be well informed about what to expect when a person dies. Particularly when death is planned to happen in the home.

Being prepared

- Don't make assumptions about what people might want to happen at the end of life.
- Support people to develop living wills.
- Good documentation that's easy for all professionals to access. For example, a "Preferred Priority of Care" (PPC) document that is clear to follow and to hand at the person's home.

Working together

- Involve family in practical issues. Families and loved ones should be involved in accordance with the dying person's, and the families', wishes.
- Share information between agencies.
- Join up information and offer simple access points. Share information systems, to make it easy to access client records, a pool of funds and referral/liaison points.
- There should be consistency in care provision (e.g. of the GP) and monitoring.

Signposting

- Make it easy for people to get the support they need - be they the person dying or a family member/carer. Help people to navigate around the system. When they need support, it needs to be timely, sensitive and appropriate.
- Assign a case manager. That person will then become familiar with the people and their experience - tailoring support to individual needs and being flexible.

Making things easier

- Good pain control is essential in ensuring comfort and dignity at the end of life.
- Risks should be balanced against quality of life and death.
- Symptom control - easy access to drugs and equipment
- Responsive services that act quickly.
- Consistency of care across all areas to enable dignity at death
- Access to 24hr face to face care, responsive in crisis (based on need not intervention).

Education

- Training for care home staff in end of life care. Including what is likely to happen when their client nears death.
- Bereavement training for care staff and others working with people at end of life.
- Professionals could visit schools to give talks. One attendee, a member of the clergy, said young children often ask about death and funerals when he visits schools about other matters.

What we could do to improve end of life care

<p>Talking to people</p>	<ul style="list-style-type: none"> • Use libraries (including the mobile library service) to disseminate information and employ the help of community organisations such as Southend Association of Voluntary Services, CRUSE, Macmillan Nurses. • Use family support officers from various agencies to maintain honest and open communication during end of life. Families could be assigned a Key Worker to help them during the end of life period. • Include people’s emotional and spiritual needs in conversations about dying and death. • Establish Support Groups in the community for end of life - a forum to talk about fears, ask questions, find information, and support one another. Professionals and religious institutions could liaise with these groups. • Champion compassion and dignity at death - for the deceased person and their loved ones. • Have a Night Owl helpline service to support the patient and family/carers with fears/practical issues during the night. (Seen as paramount to the successful management of dying at home).
<p>Being prepared</p>	<ul style="list-style-type: none"> • Talk to the patient openly about their plans and wishes - including the options around wills and living wills. • Develop a single page summary sheet of plans and wishes (to include single liaison point contact number) that stays with the patient and is easy for all professionals to access and use. Ensure the plan is reviewed and updated regularly as needs change. The summary could use a similar system to “Message in a Bottle”. • Clearly document decisions about Preferred Priorities for Care (PPC) (e.g. “Do Not Attempt Resuscitation” orders). • Carry out more research around end of life care. Consider findings from pilot projects and look at good practice elsewhere. • Think about carers: be prepared for and aware of how carers’ needs will change as the patient nears death. • Think about people with dementia: be aware of need to flag PPC at an earlier stage if patients have neurological degenerative disease. • Staff (from all agencies) should be ready to offer bereavement support and advice at the point of death, and direct people to information about funeral arrangements and ongoing support. • End of life register for people likely to be in the final year (or less) or life. • 24-hour unit to provide a rapid response when a person is dying. Such a unit could also deal with crises during the period leading up to death - avoiding admissions to hospital (which are unlikely to make a difference to the person’s

	<p>prognosis or quality of life) and supporting the person to die well at home, if this is their wish.</p> <ul style="list-style-type: none"> • A system for call handlers receiving 999 or out of hours calls to alert them to the fact this is a terminal patient and to advise on appropriate action (e.g. refer to response team).
Working together	<ul style="list-style-type: none"> • Set up a pool of (or bid for) funding to support specific projects and/or initiatives around end of life care. • Define the parameters of services and the links between them - find opportunities to work more closely together. • Ambulance services, other health professionals and care homes to work together to reduce hospital admissions during the end of life period. • Explore options for data sharing and joint IT systems; extranets, data sharing protocols, liaison points. • Further develop the Hospice at Home service and look into developing the role of Community Matrons. • Develop common standards and practices across professions and across types of condition e.g. long-term conditions and dementia.
Signposting	<ul style="list-style-type: none"> • Liaison points to navigate around the system; including funeral arrangements in line with the patient and family's spiritual needs. E.g. dedicated professionals, a helpline, an Internet service, or a combination of services. • End of Life Facilitator - for signposting and to support education, awareness raising and training. The facilitator could champion end of life care and play a key role in improving quality of services. • Develop an information pack about end of life support. Including key phone numbers, help lines, support organisations, religious organisations and funeral information. • Information about dying and death (and related support services) available in GP surgeries, shopping centres, community centres, religious institutions and other public places.
Making things easier	<ul style="list-style-type: none"> • Work with equipment providers and occupational therapists to find ways to make it easier for people to get the equipment they need towards the end of their life. • Appropriate treatments (e.g. syringe drivers etc) available in the community as well as hospitals. • Hospitals to enable family and carers to stay with the patient in private for as long as they wish after death.
Education	<ul style="list-style-type: none"> • Identify specific skills and competencies for care professionals and volunteers who support people during End of Life.

- Use the **NHS End of Life Care Programme** on-line training: <http://www.endoflifecareforadults.nhs.uk/education-and-training>
- The **National Council for Palliative Care** also provides End of Life training for professionals: <http://www.ncpc.org.uk/>
- Ensure professionals are familiar with the best practice model **Liverpool Care Pathway for the Dying Patient** and that this is implemented in care homes : <http://www.liv.ac.uk/mcpcil/liverpool-care-pathway/>
- Training about **spiritual assessment** and awareness for everyone involved in end of life support.
- Trainers from various professional agencies work together to create a **suite of training for end of life care** - tailored to the needs of the Southend caring community.
- Work with organisations such as CRUSE (bereavement care) to offer **bereavement training** for professionals and to develop awareness training for schools, communities and carers/families.
- Challenge death taboos in society by **talking courageously about the subject**. Visit schools and colleges to talk frankly and answer questions. Hold celebrations of death. Invite students to explore how various cultures view and approach death - e.g. how different religions view death and how other countries (such as Mexico) deal with death.
- **Community of Practice groups** - sharing good practice, stories, questions, concerns and seeking to continually improve experiences of dying.
- **Awareness training for GPs**: when to move from curative to palliative care.
- **Advanced learning for colleges and universities** (e.g. courses related to care, social work, nursing, spirituality): e.g. action learning sets/group work, modules linked to death and end of life care, post graduate courses/continuing professional development.
- Greater awareness for using the '**fast track**' tool under the NHS Continuing Care Framework to identify those who are 'rapidly deteriorating' and those who are anticipated to deteriorate before the next planned review (12 weeks).

3. Conclusions and what we can do next

There was enthusiasm about following up this event with further conversations; to keep momentum going. People enjoyed exploring options with colleagues from different services. The Scrutiny Committee will meet to decide the best next steps to carry forward the outcomes from this event and who has responsibility for making things happen.

“Excellent to network, share experiences and ideas which can be taken away and developed.”

4. Recommendations

The recommendations link to the agreed project plan and the proposed outcomes of the project:

- (a) To identify tools through training to equip staff to enable them to correctly direct patients, families and Carers.
- (b) use results from the scrutiny process to assist partners in developing good outcome indicators (including evaluation against 'Quality Markers & Measures') with the aim of increasing the numbers of patients to achieve their preferred place for care including enabling more people to be supported at home.
- (c) to make appropriate recommendations to the PCT, local authority, care providers, secondary care etc.

Recommendations:

- (a) That the **Health & Wellbeing Board** be asked to progress the following recommendations (to be incorporated wherever possible into existing workstreams) and report back to scrutiny in 12 months.

1	Facilitated conversations between the ambulance service and residential care homes about avoiding hospital admissions towards end of life.
2	To organise further engagement activities to collect stories and information from others (about EoL) primarily informal carers.
3	Establish 'design groups' of keen individuals, from diverse agencies (including carers), who could develop action plans for items raised in "what we could do..." These groups could look at themes, such as <i>Education</i> or <i>Working Together</i> , or could select topics that interest them - or that are clearly a priority.
4	To welcome the proposed roll out and continuation of the EoL project and to see the results of the review of the pilot. (See also the Annex to this report).
5	There need to be discussions with the Youth Council about engaging young people and educational establishments in conversations about death and dying (empowerment).
6	Event for the third sector to explore their role in supporting people to have good end of life care.
7	Engagement with GPs and the emerging Consortiums across Southend, to explore their input to the subject – possibly by hosting an evening event or by meeting with them during a scheduled training day.
8	Workshop for communication/public information leads from the various agencies to develop an appropriate End of Life information pack.
9	Diagnostic session: to map what services exist now, where they could join up and what else could be put in place.
10	There to be procedures in place to ensure people get the right equipment and support at the right time (e.g. air mattresses, syringe drivers etc)

- (b) To maintain impetus from the stakeholder event and the project, the Scrutiny Committee would like to see recommendations 1, 7, 8 and 9 being progressed at the earliest opportunity recognising that the Board will need to decide on its priorities and programme of work.

Annex 1

South East Essex PCT End of Life Project

Yvonne Campen's presentation at the stakeholder event on 24th January 2011 covered – the national context, the local context and provided details of the End of Life Pilot Project, which commenced in August 2010 covering Leigh and Thundersley areas.

National Context.

Changing face of death – 100 years ago and picture today.

End of life – what does it mean.

- Patients with a life limiting condition with a prognosis of 12 months or less
- End of Life Care
 - supports patients and families through the end stages of life.
 - Provides a holistic approach
 - Practical;
 - Spiritual;
 - Psychological;
 - Social
 - provides support to carers in bereavement

Provided information on the national strategy.

End of Life – patients and carers - what does it mean

- society does not talk openly about death and dying and this is true of professionals as well as the general population. As a result patients and carers may:
 - be frightened
 - find death and their personal wishes difficult to talk about
 - patients may receive treatment that they do not want if carers are unaware of their preferences
 - patients may not be aware of all the services that may have helped e.g. Hospice.
- the timing and honesty of end of life discussions are crucial
- patients may not get the opportunity to do all that they wanted (put their affairs in order, achieve a personal goal)

EoL – Local context and key issues and strategic vision

- we have an aging population
- currently 68% of deaths for cancer, heart and respiratory disease occur in hospital
- a local review suggested that:
 - 70-80% of those patients could have been supported to remain in home
 - 55% of people would prefer to die at home

- Only 19% of people currently achieve this
- End of life patients are admitted at least 3 times to A&E in the last days of life
- patients in the end stages are not always referred to services in a timely way
- as a result care is not always coordinated as it might be
- more people could be supported to remain at home and die in their preferred place of care
- NHS SEE made a pledge in its Strategic Plan 2009 – 2014 to 'improve the experiences for people at the end of their lives to enable more people to be cared for and die in their preferred place'.
- In order to achieve this we needed to;
 - improve training for professional on EOL care
 - commission rapid access to quality EOL services
 - ensure all providers apply EOL tools in the delivery of care
 - commission services that provide support for relatives and carers through the end stages of life and during bereavement
- in order to deliver developed the end of life pilot.

End of Life Pilot – *right care, right people, right place* - aims

- to test out new ways of working through the introduction of a case management for EOL care
- to improve information sharing of patient and carers choices for treatment, care and place of death
- to ensure that everyone approaching the end of their life are
 - appropriately identified
 - have their holistic needs assessed and their care planned and delivered in a coordinated way
 - enable to die in their preferred place of death
- who is involved:
 - Fairhavens
 - Macmillan
 - Southend Hospital
 - Hospice at Home
 - NHS SEE
 - Southend Unitary authority
 - Essex CC
 - Out of hours doctors
 - Essex Ambulance

Commenced August 2010 – concludes July 2011

- progress to date – patients and carers have access to:
 - Macmillan nurses 7 days a week
 - Carer respite through hospice at home
 - Single point of access
 - Choice and personalisation through case management approach

- Patients are identified as being in the end stages of their lives in a timely manner
- Improved communication for patients
- key challenges:
 - recruiting appropriately qualified staff
 - linking IT systems across organisations
 - identifying patients in the end stages of life
- what does good look like?
 - context – terminal illness diagnosed while on holiday
 - over 7 months the family came into contact with – 4 acute hospitals, 2 primary care trusts, 17 departments / services
 - what made it good – **good communication and coordination**
- how it was achieved:
 - professionals that listened and help us to achieve our aspirations
 - professionals that were honest and open with us
 - professionals at a local and tertiary centre that respected the skills and expertise of each other
 - 2 case managers at the tertiary and local level – 24 hr access
 - A GP who respected and supported the local community services to deliver care in a way that meet out needs

Which meant that:

'that as a family we could concentrate on making the end of life the best that it could be, safe in the knowledge that we has a skilled team around us that we could access 24 hours a day should we need it'

Annex 2

Stakeholder event – 24th January 2011 - programme

08.45 – 09.15	Registration & coffee	
09.15 – 09.25	Welcome & introductions - Councillor Lesley Salter, Chairman Community Services Scrutiny Committee, Event Facilitator - Sherry Fuller, Project lead - Fiona Abbott	
09.25 – 10.35	Setting the scene:	Councillor Lesley Salter
	Local context	
	Scene setting from Chris Doorly, Chair Vulnerable Adults Board	
	Stories about end of life - real situations for real people	
	Comments / reflections / Questions	
10.35 – 10.50	Comfort Break / refreshments	
<i>The following part of the event involves us working together in groups</i>		
10.50 – 11.20	Part 1: What does it look like?	
11.20 – 11.35	Part 2: Summary discussion	
11.35 – 11.50	Feedback from groups	
11.50 – 12.10	Part 3: Vision for Dying Well	
12.10 – 12.20	Share the visions	
12.20 – 12.40	Part 4: Next steps What do we need to do to make our visions real?	
12.40 – 12.55	Share thoughts on next steps and priorities	
13.00	Closing remarks	Councillor Lesley Salter
	Lunch & networking	

Before the event, delegates received the following information:

- Definitions – *palliative, end of life* and *supportive care*
- 'End of life ' story
- 'A good ending'
- Key points on End of Life Care Strategy
- Information on the scrutiny project
- Some helpful information.

At the event itself, the following information was circulated:

- Presentations given on Safeguarding Adults and the PCT – End of Life project
- SEPT
- Hospital team overview
- PCT
- Social Services

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