

AGENDA MANAGEMENT SHEET

Name of Committee

Cabinet

Date of Committee

28th May 2009

Report Title

**Review of End of Life Care in
Warwickshire - Final Report of the End of
Life Care Review**

Summary

The aim of this review was to consider the working arrangements between different services and how service providers contribute to meet national standards, which is provided in a combination of health and social care settings throughout the county. The review not only covered the care for people with cancer, but looked at the care for people with dementia and other life limiting illnesses such as obstructive pulmonary disease and heart disease.

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**Would the recommended
decision be contrary to the
Budget and Policy
Framework?**

No.

Background papers

None

CONSULTATION ALREADY UNDERTAKEN:-

Details to be specified

Other Committees

☐

Local Member(s)

☐

Other Elected Members

☒ Cllr Jerry Roodhouse,

Cabinet Member

☒ Cllrs Bob Stevens, Colin Hayfield

Chief Executive

☐

Legal

☒ Jane Pollard

Finance

☐

- | | | |
|--------------------------|-------------------------------------|--|
| Other Chief Officers | <input checked="" type="checkbox"/> | David Carter, Graeme Betts, Marion Davis |
| District Councils | <input type="checkbox"/> | |
| Health Authority | <input type="checkbox"/> | |
| Police | <input type="checkbox"/> | |
| Other Bodies/Individuals | <input type="checkbox"/> | |

FINAL DECISION Yes

SUGGESTED NEXT STEPS:

Details to be specified

- | | | |
|--|-------------------------------------|------------------------------|
| Further consideration by
this Committee | <input type="checkbox"/> | |
| To Council | <input type="checkbox"/> | |
| To Cabinet | <input type="checkbox"/> | |
| To an O & S Committee | <input checked="" type="checkbox"/> | Adult and Community Services |
| To an Area Committee | <input type="checkbox"/> | |
| Further Consultation | <input type="checkbox"/> | |

Agenda No

Cabinet – 28th May 2009.

Review of End of Life Care in Warwickshire Final Report of the End of Life Care Review

Report of Chair of Health Overview & Scrutiny Committee

Recommendations

That Cabinet:

1. Considers the report and endorses those recommendations that require acceptance and implementation from WCC

1. Introduction

- 1.1 End of life care in Warwickshire is provided in a combination of health and social care settings throughout the county, depending on access, either in the community, hospital, hospice or care home.
- 1.2 The panel invited representatives from the following services to support and contribute information and advice:
 - NHS – PCT & Acute Services
 - Local Authority – Adult Social Care and Children's Services
 - Voluntary Sector – Carers and Support Services
 - Independent Sector - Hospices
- 1.3 They considered the working arrangements between different services and how service providers contributed to meeting national standards, best practice and related national policy
- 1.4 The aim of this review was to look at the services and care being provided for patients/clients who have been diagnosed as being near the end of their lives in Warwickshire. Taking into account the following:
 - The services provided by the NHS, Local Authority (Social Care Arrangements), Voluntary Sector and Hospice Movement
 - How the service providers above work together
 - The support offered to users, carers and families

- To support 'Dignity in Care' campaign introduced by the Minister for Care Services Ivan Lewis in November 2006, which aims to place dignity and respect at the heart of caring for older people
 - To consider the needs of children and adolescents
- 1.5 The panel's objective was to gain a better understanding of palliative care provision and the resources available, the relationship between health and social care and what service providers do to meet the needs of those affected.

2. Recommendation

- 2.1 That Cabinet:
- Considers the report and endorses those recommendations that require acceptance and implementation from WCC

Cllr Jerry Roodhouse
Chair of Health Overview and
Scrutiny Committee

Shire Hall
Warwick

22 April 2009

Review of End of Life Care in Warwickshire

Final Report of the End of Life Care Panel

April 2009



Chairman's Foreword

Can I start by placing on record my thanks to every one who has been involved and contributed towards this 'End of Life Care' scrutiny review.

The review has sought to do two things the first was about informing the local and national debate about choice and the second around the issue dignity and the family what happens after the death.

The review whilst in progress has seen a national strategy launched and local initiatives taking place and we welcome these.

We have spoken to many people and taken evidence from numerous sources and believe that the recommendations if adopted will go towards achieving an improved end of life care for individuals and their loved ones within Warwickshire.

A handwritten signature in dark ink, appearing to read 'Jerry Roodhouse', written in a cursive style.

Cllr Jerry Roodhouse
Chair of Warwickshire Health Overview and Scrutiny Committee

Executive Summary

Index

1. Introduction	12
2. History of Palliative Care	12
3. Palliative Care Defined	13
4. Specialist Palliative Care Services	13
5. Scope	14
6. Aims and Objectives	15
7. Methodology	17
8. End of Life Care – National Picture	17
9. End of Life Care in Warwickshire	20
10. Hospices in Warwickshire	21
11. Hospitals	24
12. Social Care	28
13. Admiral Nurses & Carers	32
14. End of Life Care Stakeholder Event	33
15. Key Findings	37
16. Conclusion	42
17. Recommendations	47

Glossary of Terms

CCU	Coronary Care Unit
CSCI	Commission for Social Care Inspection
CHAAT/CHA	Continuing Healthcare Assessment/Criteria
CHD	Coronary Heart Disease
COPD	Chronic Obstructive Pulmonary Disease
CPR	Coronary Pulmonary Resuscitation
DNR	Do Not Resuscitate
EMI	Specialist Care Home e.g. Dementia, Parkinson's
GP	General Practitioner
ICU	Intensive Care Unit
LCP	Liverpool Care Pathway
MDT	Multidisciplinary Team
MI	Myocardial Infarction
NICE	National Institute for Health and Clinical Excellence
PCT	Primary Care Trust
SHA	Strategic Health Authority
SLA	Service Level Agreement
UHCW	University Hospitals Coventry and Warwickshire

Acknowledgements

The panel would like to thank all those below that helped contribute to the review of 'End of Life Care in Warwickshire':

Michelle Mello, Gerard Dillon and David Widdas – NHS Warwickshire (PCT)
Gill Young - Myton Hospice
Maureen Walker & Jane Tedstone – South Warwickshire General Hospitals NHS Trust
Simon Robson – Adult, Health & Communities Directorate, Warwickshire County Council
Liz Hancock – Mary Ann Hospice
Duncan Forbes - Shakespeare Hospice
Heather Norgrove, Nigel Kee, Carol Anne Taylor and Canon Edward Pogmore - George Eliot Hospital
Helen West, Trust Lead, Cancer Nurse, UHCW
Jodie and another– end of care nurse
Heather Goding - Macmillan Nurses
Rachel Marshallsay - Admiral Nurses
Dr John Bland

Executive Summary, Key Findings and Recommendations

Introduction

- 1 Early on in the review the End of Life Care Panel agreed to adopt the philosophy of the Admiral Nurses – We cannot add days to a life, but we can add life to each day.
- 2 The panel not only considered the care for people with cancer, but looked at the care for people with dementia and other life limiting illnesses such as obstructive pulmonary disease and heart disease.
- 3 The panel invited representatives from the following services to support and contribute information and advice:
 - NHS – PCT & Acute Services
 - Local Authority – Adult Social Care and Children's Services
 - Voluntary Sector – Carers and Support Services
 - Independent Sector - Hospices
- 4 They considered the working arrangements between different services and how service providers contributed to meeting national standards, best practice and related national policy.

End of Life Care in Warwickshire

- 5 End of life care in Warwickshire is provided in a combination of health and social care settings throughout the county, depending on access, either in the community, hospital, hospice or care home.
- 6 The county has three general hospitals based in Nuneaton, Warwick and Stratford and a tertiary hospital in Coventry.
- 7 There are four hospices based in Nuneaton, Rugby, Warwick and Stratford with a new hospice planned for Coventry in 2009. Myton Hospice in Warwick is currently the only facility that provides inpatient service with 24 beds, when Myton opens a new facility in Coventry it will have a total of 44 beds, which will serve all of Warwickshire and Coventry.
- 8 Each hospice provides 'Hospice at Home Service', which covers the whole of Warwickshire. NHS Warwickshire (PCT) also contract limited services from out of the county in Solihull and Lichfield.
- 9 Warwickshire has three community specialist teams (based at Mary Ann Evans Hospice, Myton Hospice in Warwick and Rugby) and two hospital teams (George Eliot Hospital and Warwick Hospital).
- 10 There are approximately 120 care homes in Warwickshire and around two thirds of these provide nursing care.

Aims and objectives of the Panel

11. The aim of this review was to look at the services and care being provided for patients/clients who have been diagnosed as being near the end of their lives in Warwickshire. Taking into account the following:
 - The services provided by the NHS, Local Authority (Social Care Arrangements), Voluntary Sector and Hospice Movement
 - How the service providers above work together
 - The support offered to users, carers and families
 - To support 'Dignity in Care' campaign introduced by the Minister for Care Services Ivan Lewis in November 2006, which aims to place dignity and respect at the heart of caring for older people
 - To consider the needs of children and adolescents
- 12 The objectives of the panel were to understand:
 - Palliative care provision, the resources available
 - The relationship between palliative care and health
 - What service providers do to meet the needs of those affected and how they work together
 - The transitional arrangements for children and adults
 - Differences in approach to ethnic minority groups
 - Access to services in line with social inclusion agenda
 - Dignity in Care 10 point plan
 - Arrangements for care of patients/clients including care pathways
 - Any financial constraints in providing end of life care
 - Post death provision for the bereaved
- 13 To suggest recommendations where there could be service improvement that would:
 - Improve patient & family experience & quality of care
 - Enable a good death 'Dignity in Care'
 - Provide choice of where to die
 - Provide a person centred approach
 - Ensure that services are more robust/flexible and more demographically based

Findings of the Panel

- 14 The quality of care provided in hospices seemed higher than that of hospitals.
- 15 Although changes were being made to treat those with other life limiting illnesses the majority of patients in hospices are those with cancer.

- 16 The quality of care appeared to be better in the south of the county.
- 17 There was an uneven distribution of resources for palliative care with funding going to the NHS.
- 18 Hospital staff that deal with patients, following an acute emergency, appeared to be more equipped to deal with end of life care.
- 19 There did not appear to be a uniform approach to the provision of end of life care services in a hospital setting, which meant the quality of care could be 'hit and miss'.
- 20 There were recognised difficulties of moving patients from hospitals to hospices at the weekends.
- 21 It was felt that there was a need for more beds in the community for medicine management/treatment as this would prevent patients from being admitted into an acute setting.
- 22 Identified that the 'Continuing Healthcare Assessment' (CHAAT) process was unclear, and procedural delays both in a hospital and social care setting caused difficulties when patients wanted to go home to die. This caused distress both for the patient and their families.
- 23 'Continuing Healthcare' or 'Respite Care' was also a problem for those with a disability, because they move in and out of entitlement to these services.
- 24 There appeared to be no real clarity for staff around areas of responsibility and pathway decisions.
- 25 It was considered important for all hospital and social care staff involved in end of life care had bereavement and end of life care training.
- 26 There was a real need for a strategic approach to workforce development/training in both the hospital and social care setting.
- 27 Staff missed having the locality meetings of all health and social care teams.
- 29 There is inequality of community provision in the north and south of the county.
- 30 When someone needs to go into hospital they can have concerns around how they get home again? Who will pay? Going home was dependent on the person's needs.
- 31 Admiral Nurses find their limited resources are causing problems in trying to support people with learning difficulties such as Down's

Syndrome, who have an increased risk of developing dementia in later life due to living longer.

- 32 Admiral Nurses currently located in the north of the county would like to provide a more equitable service extend their services into the south.
33. Carers highlighted the need for them to receive care as well as the relative.
- 34 Carers stressed the importance of doctors and healthcare professionals talking with the patients as individuals and they should be told about their illness and what to expect. Also healthcare professionals to recognise pastoral care is important to meet their spiritual needs.
- 35 Carers felt they needed more information on how to deal with a relative with dementia and they and their relatives needed to be empowered with someone to negotiate with NHS/Social Care on their behalf.
- 36 Carers wanted to have help with practical concerns such as having housing to suit their needs and benefit information.
- 37 Carers considered death should be more discussed openly, which could be beneficial for the relative and the family.
- 38 Problems were identified with the Continuing Care Framework in delivering end of life care there was a lack of continuity which affected the quality of service being delivered.
- 39 It was considered it was a priority to raise awareness that dementia was a terminal illness, which needed specialist end of life care services.
40. To care and cope with the demands to provide end of life care in settings it was considered important that all those providing this care, whether as a professional or family member, would benefit from having training in physical, emotional and social skills.
- 41 Communication skills were considered key to end of life care with an awareness of care pathways which is sensitive to patients and carers needs.
- 42 In delivering the right choice of end of life care it was considered essential that the patient and their families are asked what they want, what is available, it is delivered at the most appropriate time and regularly reviewed.
- 43 Services need to be joined up, seamless, easy to use, integrated to work across boundaries.

- 44 To improve end of life care within the community setting that the Gold Standards Framework to be used by all GP's.
- 45 The review identified there was still a need to raise awareness of cultural differences.
- 46 In looking at children's palliative care transition arrangements there was a need to sort out the legal issues and allow direct payments for continuing healthcare.
- 47 Identify the lead professionals to be able to start the planning process for transitional arrangements - possibly at 14 years.
- 48 To provide out of hours rapid response and the resources to manage crisis situations 24/7.

Recommendations

- 1 NHS Warwickshire to report to Health OSC on the resources being made available to provide end of life care by the new Out of Hours service in Warwickshire. To ensure that service needs of children are being met in a crisis.
- 2 NHS Warwickshire, Coventry & Warwickshire Partnership Trust, Acute Trusts and Adult Social Care to review how they can improve the Continuing Healthcare Assessment process and report back to Health OSC in September 2009.
- 3 NHS Warwickshire to raise awareness of the 'Gold Standard Framework' especially with GP's in Nuneaton/Bedworth and North Warwickshire via a number of forums such as the GP Consortium. This would help share best practice and would also take into account and act upon the support needs of carers.
- 4 For NHS Warwickshire, acute trusts and the hospice to agree protocols arrangements for inpatient admissions. To report to Health OSC in six months time the arrangements agreed.
- 5 NHS Warwickshire, Hospices, Acute Trusts and Social Care commissioners, with representatives from their workforce, to meet to discuss the provision of combined end of life care training and report back to Health OSC in six months time on how this would be implemented.
- 6 For Warwickshire County Council to consider an 'end of life care' common induction process for carers, plus in house training courses.
- 7 When looking at World Class Commissioning that NHS Warwickshire and Warwickshire County Council should ensure that end of life issues and dignity in care are taken into account within any commissioning process and that all contracts have this written into them.

- 8 For NHS Warwickshire, Hospices, Acute Trusts and Social Care to set up a forum to meet three times a year to review partnership working and communications between agencies. To report back to Health OSC in six months time on whether this has been implemented and progress being made.
- 9 George Eliot Hospital, South Warwickshire General Hospitals and UHCW Trust Boards to take a strategic role in ensuring that 'Liverpool Care Pathway' and 'Dignity in Care' are introduced into all acute settings and not just wards that normally are expected to provide end of life care.
- 10 In recognition that cultural differences in the approach to end of life care needs to be developed further that NHS Warwickshire and Warwickshire County Council to devise a guidance document about end of life care for all faith groups.
- 11 To help reduce inappropriate admissions to acute trusts and the possible savings that could be made that NHS Warwickshire to consider funding the 'Hospice at Home Service'.
- 12 Acute Trusts to provide bereavement cards with information for families such as the bereavement and befriending service.
- 13 The conclusions and recommendations of this report are used to inform other strategies such as dementia care and the report be given to Adult and Community Services OSC for comment.
- 14 To ensure equity of access NHS Warwickshire with Coventry and Warwickshire Partnership Trust consider commissioning an Admiral Nurses Service, in the south of the county for people with dementia and their carers.
- 15 For NHS Warwickshire, Acute Trusts and Adult Social Care consider the setting up of one point of contact for carers that could navigate, on their behalf, for the services they required. To report back to Health OSC in six months time on how this could be implemented and progress being made.
- 16 In recognition that information for families varies, according to the setting they find themselves in, that representatives from the acute trusts plus the residential care sector review the information available with a view to making it more consistent.
- 17 Care & residential homes to have designated staff providing end of life care and bereavement support for families, carers and staff. Families and carers to also receive written information about what to expect when a loved one is coming to the end of their life with bereavement support.

- 18 NHS Warwickshire and Warwickshire County Council to review transitional arrangements for children requiring end of life care to identify lead professionals which can take the planning process for transitional arrangements forward.
- 19 For George Eliot Hospital NHS Trust to conduct a feasibility study on whether they could provide end of life inpatient facilities at the hospital and report back their findings to Health OSC in six months time.
- 20 That end of life care is monitored as part of the CSCI assessment (from April 2009 Care Quality Commission) when visiting residential or nursing homes.
- 21 Copies of the report are sent to the Royal College of Physicians, Royal College of General Practitioners and Royal College of Nursing for them to be aware of the issues raised, such as the needs of patients, families and when providing end of life care as part of general training.
- 22 Copies of this report to be given to all stakeholders involved with this review and local MPs.
- 23 A copy of the report to be given to the National council for Palliative Care with special regard to the dying agenda.
- 24 NHS Warwickshire, Acute Trusts & Adult Social Care to report to Health OSC in six months time on what actions they will take when considering the conclusions and all of the above recommendations in regard to 'End of Life Care'. Also to provide information on how they plan to work together to provide a single approach to 'end of life care'.

Review of End of Life Care in Warwickshire

The Report of the End of Life Care Panel

1. Introduction

- 1.1 Early on in the review the End of Life Care Panel agreed to adopt the philosophy of the Admiral Nurses – We cannot add days to a life, but we can add life to each day.
- 1.2 The panel not only considered the care for people with cancer, but looked at the care for people with dementia and other life limiting illnesses such as obstructive pulmonary disease and heart disease.
- 1.3 The panel invited representatives from the following services to support and contribute information and advice:
 - NHS – PCT & Acute Services
 - Local Authority – Adult Social Care and Children's Services
 - Voluntary Sector – Carers and Support Services
 - Independent Sector - Hospices
- 1.4 They considered the working arrangements between different services and how service providers contributed to meeting national standards, best practice and related national policy.

2. History of Palliative Care

- 2.1 The word “hospice” originates from Roman times and throughout the early centuries the religious community ran establishments dedicated to the care of the sick and dying. These early hospices took a very holistic approach to care and focussed on the specific needs of the dying individual. Following religious suppression these places declined and it was not until the late 19th century that the old idea of hospice began to revive.¹
- 2.2 Much of the theory and structure of modern hospice care in the UK can be credited to Dame Cicely Saunders, who observed the need for the spiritual and psychological care of dying patients whilst working as a hospital nurse. Following qualification as a doctor in 1957, Saunders interviewed many terminally ill patients and coined the phrase “total pain” from her understanding that dying people have physical, spiritual, psychological and social pain that must be treated. She made the important clinical observation that “constant pain needs constant

¹ Robbin J, Moscrop J, (eds), 1995, “Caring for the dying patient and the family”, Chapman & Hall: London (3rd Edition), p246

control". These two features of pain relief and control are an essential part of modern hospice medicine.²

- 2.3 Using her wide experience in the field of caring for terminally ill patients, she opened St Christopher's Hospice in 1967 (the start of the modern hospice movement). These new hospices combined the accomplishments of modern medicine with the more traditional holistic approach.
- 2.4 Traditionally nurses were the main healthcare providers in the palliative care setting, this remains true today. However the role of doctors in palliative care has changed significantly over the last 40 years and in 1987 palliative care was recognised by the Royal College of Physicians as a speciality. Since then the number of consultants and doctors in palliative care training schemes has increased dramatically. Now doctors in the palliative care sector work as an integrated part of a multi-professional team.³

3. Palliative Care Defined

- 3.1 Palliative care embraces many parts of supportive care and has been defined by NICE as follows:

'Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments'.

- 3.2 Palliative care aims to:

- Affirm life and regard dying as a normal process
- Provide relief from pain and other distressing symptoms
- Integrate the psychological and spiritual aspects of patient care
- Offer a support system to help patients live as actively as possible until death
- Offer a support system to help the family cope during the patient's illness and their own bereavement

4. Specialist Palliative Care Services

- 4.1 These services are provided by specialist multidisciplinary palliative care teams and include:

² Milcevik N, 2002, "The Hospice Movement: History and Current Worldwide Situation". Archive of Oncology, volume10(1), p29-32

³ <http://www.rcplondon.ac.uk/specialty/Palliative.asp> , 2007

- Assessment, advice and care for patients and families in all care settings, including hospitals and care homes
 - Specialist in-patient facilities (in hospices or hospitals) for patients who benefit from the continuous support and care of specialist palliative care teams
 - Intensive co-ordinated home support for patients with complex needs who wish to stay at home. Which may include providing advice to a patient's own doctor and district nurse to enable them to stay at home, plus providing specialist palliative nursing, medical, social and emotional support in the patient's own home 'hospice at home'
 - Day care facilities that offer a range of opportunities for assessment and review of patients' needs and enable the provision of physical, psychological and social interventions
 - Advice and support to all the people involved in a patient's care
 - Bereavement support services which provide support for the people involved in a patient's care following the patient's death
 - Education and training in palliative care
- 4.2 The specialist teams should include palliative medicine consultants and palliative care nurse specialists together with a range of expertise provided by physiotherapists, dieticians, pharmacists, social workers and those able to give spiritual and psychological support.

5. Scope

- 5.1 The rationale for doing this particular scrutiny was that a recent peer review about end of life care in Warwickshire, plus local concerns had been raised about the quality of care being given. The panel decided to include dementia, because although it is generally seen as a long term condition, it was still a terminal illness, which would require the support of end of life care services.
- 5.2 NHS Warwickshire's baseline review of 'End of Life Care', indicated that the standard of provision of end of life care varied across the county and that the models of care should be compared against pathways being provided such as the Liverpool Care Pathway with a view to extend this into the community. The intention following this review would be to look at what joint working arrangements could be achieved with Coventry in providing end of life care.
- 5.3 This baseline review provided the panel with the following information:
- 80% of the population indicated they wanted to die in a community setting (outside of hospital)
 - Across the West Midlands an average of 56% of all deaths take place in an acute hospital, 20% at home, 20% in an elderly care home and 4% in hospices
 - In Warwickshire 66% of deaths occurred in acute hospital, 17% at home, 12% in elderly care homes and 5% in hospices (see table 1)

- The PCT spends around £9 million a year for patients dying in hospital and a further £6 million in the community – total cost of £15 million
- Better provision exists for those dying from cancer however the aim was to ensure all patients irrespective of illness would receive the same quality of care
- There was less community-based provision in the north of the county than the south
- Extend the 'Hospice at Home' service to enable hospice type provision/support to reach more people in the community

Recorded deaths from all causes	4702	
Number of recorded deaths	4268	
Expected number of deaths in hospital	564	(based on 11% of population wishing to die in hospital)
Observed number of deaths	2846	(66% of total number of deaths for time period)
Expected number of deaths at home	2873	(based on 56% of population wishing to die at home)
Observed number of deaths	721	(17% of total number of deaths for time period)
Expected number of deaths in a hospice	1334	(based on 26% of population wishing to die in hospice)
Observed number of deaths	255	(5% of total number of deaths for time period)

Table 1 – place of death for all non-sudden causes of death between 1/8/2006 – 31/7/2007⁴

5.4 Excluding accidental deaths there were approximately 3,000 deaths each year in Warwickshire, of these 355 were attributable to dementia and of these 142 occurred in hospital, 192 in care homes and 21 at home.

5.5 The panel were informed that the operating framework defined end of life care services as:

'services to support those with advanced, progressive, incurable illness to live well as possible until they die. These are services that enable the supportive and end of life care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes the management of pain and other symptoms and provision of psychological, social, spiritual and practical support. This is not confined to discreet specialist services but includes those services provided as an integral part of the practice of any health or social care professional in any setting.'

⁴ Baseline Review of End of Life Care in Warwickshire Initial Report – November 2007

6. Aims and Objectives

- 6.1 The aim of this review was to look at the services and care being provided for patients/clients who have been diagnosed as being near the end of their lives in Warwickshire. Taking into account the following:
- The services provided by the NHS, Local Authority (Social Care Arrangements), Voluntary Sector and Hospice Movement
 - How the service providers above work together
 - The support offered to users, carers and families
 - To support 'Dignity in Care' campaign introduced by the Minister for Care Services Ivan Lewis in November 2006, which aims to place dignity and respect at the heart of caring for older people
 - To consider the needs of children and adolescents
- 6.2 The outcome from this review was for the panel to:
1. Gain a better understanding of palliative care provision and the resources available
 2. Understand the relationship between palliative care and health
 3. Understand what service providers do to meet the needs of those affected and their families and how they work together
 4. Ensure that service providers provide a flexible, appropriate, clinically effective and accessible service in response to the needs of those affected and their families
 5. Understand the transitional arrangements from children to adult services to include the model of care for children and adults in hospices, hospitals and at home
 6. Understand the difference in approach that ethnic minority groups may take to 'End of Life Care'
 7. Take into account equity of access to services in line with the social inclusion agenda.
 8. Compare care in the north and south of the county to identify any inequity of provision
 9. Support 'Dignity in Care' 10 point plan
 10. Provide a detailed analysis of current services and arrangements for the care of patients/clients at the end of their lives – including care pathways
 11. Identify issues where there is financial challenge and suggest areas of sustainable funding where appropriate
 12. Look at post death provision for the bereaved
 13. Suggest recommendations where there could be service improvement to improve working arrangements between service providers which would:
 - Improve patient & family experience & quality of care
 - Enable a good death 'Dignity in Care'
 - Provide choice of where to die
 - Provide a person centred approach
 - Ensure that services are more robust/flexible and more demographically based

- 6.3 An indicator of success would be to increase equity of access and patient choice.
- 6.4 The key areas for consideration by the panel to review were the:
- a) Out of Hours access to advice, support and crisis management
 - b) Patient pathways for accessing palliative care such as the Liverpool Care Pathway
 - c) Training available for staff - NHS, Local Authority Services, voluntary/private sector organisations
 - d) Multidisciplinary Team (MDT) working & joint commissioning arrangements
 - e) Pain control and symptom management
 - f) 'Dignity in Care' 10 point plan
 - g) Psychological, spiritual and social support that could be culturally sensitive
 - h) Patient choice – the facilities available to stay at home or access services in the locality
 - i) Information for patients and their families
 - j) Support for carers and their access to respite
 - k) Individualised person centred care planning and support
 - l) Perceived role and impact of the single assessment process
 - m) Palliative care of children and adolescents
 - n) Financial arrangements – how funding is used
- 6.5 The panel decided not to do a separate review of children's services as this had already been reviewed by the Strategic Health Authority (SHA).

7. Methodology

- 7.1 The panel agreed it would use the following methodology to review end of life care:
- i. Initial research to find out what are the current issues relating to end of life care.
 - ii. Presentations from NHS Warwickshire (PCT), Public Health Director, Adult & Children's Services Warwickshire County Council and GPs about end of life care
 - iii. Visits to hospices, hospitals, adult social care and Admiral Nurses to discuss end of life care with staff and carers.
 - iv. A Stakeholder Event with representatives from hospices, acute trusts, Admiral Nursing, GPs, Adult & Children's Services - Warwickshire County Council, Local Involvement Networks (LINKs) and carers

8. End of Life Care – National Picture

- 8.1 The provision of end of life care services has become increasingly complex. People are living longer and the incidence of frailty and multiple conditions in older people is increasing requiring a combination of health and social care services whether in the community, hospitals, care homes or hospices. Care is also provided by informal carers such as family members, close friends or volunteers.
- 8.2 Most of end of life care is delivered by a large number and a wide variety of generalist staff such as doctors, nurses, allied health professionals and social workers. Specialist palliative care is an aspect of end of life care delivered by health care staff such as nurses, doctors and physiotherapists with specific training in the management of pain and other symptoms and the provision of psychological, social and spiritual support.
- 8.3 The majority of deaths occur in an acute hospital and do so following a period of chronic illness such as heart disease, cancer, respiratory disease, neurological disease or dementia. However, most people would want to be cared for and die in their own home, but the number of people who are able to do so, varies with age, geographical area and the type of illness they have.
- 8.4 Dignity in Care
- (1) Since January 2006 the Department of Health have taken a number of steps to take forward the Dignity in Care agenda at a national level.
 - (2) The provision of dignity in care means the kind of care, in any setting which supports and promotes, and does not undermine, a person's self respect regardless of any difference.
 - (3) The dignity challenge lays out the national expectations of what constitutes a service that respects dignity and is backed up by a series of dignity tests that can be used by providers, commissioners and people that use services to check on how they are performing. It focuses on ten different aspects – the things that matter most to people.
 - (4) High quality services that respect people's dignity should:
 1. Have zero tolerance of all forms of abuse
 2. Support people with the same respect you would want for yourself or a member of your family
 3. Treat each person as an individual by offering a personalised service
 4. Enable people to maintain the maximum level of independence, choice and control
 5. Listen and support people to express their needs and wants
 6. Respect people's right to privacy
 7. Ensure people feel able to complain without fear of retribution

8. Engage with family members and carers as partners
9. Assist people to maintain confidence and a positive self esteem
10. Act to alleviate people's loneliness and isolation

8.5 Liverpool Care Pathway

- (1) Over the past few years a major drive has been underway to ensure that all dying patients and their relatives and carers receive a high standard of care in the last few hours and days of their life. The Specialist Palliative Care Team at the Royal Liverpool and Broadgreen University Hospitals NHS Trust and Marie Curie Hospice, Liverpool developed the Liverpool Care Pathway (LCP) for the dying patient.
- (2) The LCP was recognised as a model of best practice in the NHS Beacon Programme (2001) and was then incorporated into the Cancer Services Collaborative project and the National End of Life Care Programme (2004-07). It was recommended in the NICE guidance on supportive and palliative care for patients with cancer (2004) as a mechanism for identifying and addressing the needs of dying patients, in 'Our Health, Our Care, Our Say' white paper as a tool to be rolled out across the country and again in the End of Life Care Strategy DH 2008.
- (3) Best practice in care of the dying should be seen as the norm not the exception, driven by patient and care expectations.
- (4) The aim of the LCP is to improve care of the dying in the last hours/days of life, by improving the knowledge related to dying and quality of care. The LCP provides a useful template to guide the delivery of care for the dying to compliment the skill and expertise of the practitioner. This would be by providing initial and ongoing assessments, with care after death looking at the physical, psychological, social and spiritual needs of patients, families and their carers.
- (5) The LCP framework is a continuous quality improvement framework for the care of the dying irrespective of diagnosis or place of death.
- (6) The LCP affirms the vision of transferring the model of excellence for the care of the dying from hospices into other healthcare settings.
- (7) The LCP provides guidance on key aspects of care including:
 - Symptom Control
 - Comfort measures
 - Anticipatory prescribing of medication
 - Discontinuation of inappropriate interventions
 - Psychological and spiritual care
 - Care of the family (both before and after death of the patient)

- (8) The implementation of the LCP in a new setting involves a number of key steps:

- Training of health and social care professionals
- Baseline reviews and analysis
- Implementation and reflective practice
- Benchmarking of care provision within a National Audit Process

9. End of Life Care in Warwickshire

- 9.1 End of life care in Warwickshire is provided in a combination of health and social care settings throughout the county, depending on access, either in the community, hospital, hospice or care home.
- 9.2 The county has three general hospitals based in Nuneaton, Warwick and Stratford and a tertiary hospital in Coventry.
- 9.3 There are four hospices based in Nuneaton, Rugby, Warwick and Stratford with a new hospice planned for Coventry in 2009. Myton Hospice in Warwick is currently the only facility that provides inpatient service with 24 beds, when Myton opens a new facility in Coventry it will have a total of 44 beds, which will serve all of Warwickshire and Coventry.
- 9.4 Each hospice provides 'Hospice at Home Service', which covers the whole of Warwickshire. NHS Warwickshire (PCT) also contract limited services from out of the county in Solihull and Lichfield.
- 9.5 Warwickshire has three community specialist teams (based at Mary Ann Evans Hospice, Myton Hospice in Warwick and Rugby) and two hospital teams (George Eliot Hospital and Warwick Hospital).
- 9.6 There are approximately 120 care homes in Warwickshire and around two thirds of these provide nursing care.
- 9.7 Public Health Perspective
- (1) The Public Health Director in Warwickshire provided the panel with information relating to Coronary Heart Disease (CHD), Cancer, Chronic Obstructive Pulmonary Disease (COPD), Stroke and Dementia. The format used to collect the data on the above diseases, apart from dementia, provided reliable trend data enable NHS Warwickshire and the Warwickshire County Council commissioners to plan future end of life care services in the county.
- (2) The data collected on CHD indicated that there would be a 14% increase in the prevalence of this disease from 2007 – 2029. Applying the age specific mortality rates in Warwickshire produced an estimated increase from deaths from 869 in 2007 to 1,408 in 2029.

- (3) However the mortality rates from CHD had fallen in recent years and if this decrease was projected to 2010 (it was inadvisable to project the figures beyond 2010) the mortality figure for that year could fall from 917 to 863. The projected number of admissions to hospital was set to rise by 40-45% between 2007 and 2029.
- (4) Healthy life expectancy (years of life lost and mortality rates) indicated there was a disparity between the north and south of the county. Not only was life expectancy lower in the north of the county, but the years of ill health was longer. The panel concluded that they would not look at the specific causes of death, but would look at the care given at end of life.

9.8 Transition Care Pathway, Children

- (1) Although the panel decided that the review would not focus on children's services they were made aware that there was a desire to sharpen the planning for transition from children's services into adult services, especially for those with life threatening illnesses who survived into adulthood. The aim was to secure equity of provision irrespective of illness. The transition care pathway had goals that could be audited but all bodies need to adopt this.

10. Hospices in Warwickshire

- 10.1 The panel visited two hospices in Warwickshire – Myton in Warwick and Mary Ann Evans in Nuneaton. The following is a summary of the information provided at these visits.

10.2 Myton Hospice, Warwick

- (1) Myton supports approximately 1700 patients and their families per year of which 620 are inpatients. It is currently the only inpatient service for Warwickshire with 24 beds. It also offers a day service which helps keep patients in their own home and reduces anxiety when they need to use the inpatient service. In 2009, the new hospice in Coventry the hospice will have a total of 44 beds, which should be sufficient to provide specialist palliative care for both Coventry and Warwickshire. To improve transitional arrangements for young adults Myton Hospice is currently working with Acorns to improve transitional arrangements for young adults by ensuring 2 inpatient rooms at the new hospice will be allocated for their use. At the moment young adults requiring respite care are admitted into older people's care homes, which is far from ideal.
- (2) The hospice tends to have short waiting list by ensuring there is only 75% bed occupancy at any one time. This enables them to offer a set date for admissions and also have the capacity to deal with emergency admissions.

- (3) Myton's main aim is to provide symptom management, psychological support, rehabilitation and respite care rather than a place to die. Less than 50% of hospice patients die in the hospice.
- (4) They receive referrals from hospitals, GPs and Macmillan Nurses. Myton recognise that cancer patients tend to have better access to the facility than those with other life limiting conditions. Action is being taken to address this and recently Myton with Warwick Hospital has been trialling end of life care to patients with heart failure.
- (5) They also offer a hospice at home service which supports approximately 20 patients a month.
- (6) The hospice offers families a high profile counselling service from admission to discharge. They offer a bereavement service and contact the families 8/10 weeks after the bereavement. There is also a bereavement service for children up to 18 years old.
- (7) They mainly communicate with the NHS about discharge arrangements, but recognise the need to work with social care services.
- (8) Myton receives 30% funding from the NHS and 70% from fund raising - for every £3 of funding from the PCT the patient gets £10 of care. The new Coventry Hospice will cost £7 million to build and furnish, which the hospice obtained through fund raising. NHS Warwickshire (PCT) will not be providing funding, but will be supporting the revenue costs at 25%.
- (9) The hospice regularly conducts an audit to find out what the patients and families' needs are, but recognise this is not good in measuring their feelings about the service.
- (10) Myton raised the following concerns with the panel that NHS services are not equitable in the north and the south of the county. District nurses can provide a 24 hour service in the north, but this is not available in the south.
- (11) The main problems the hospice encounter when providing end of life care were around finance, trying to deliver high class skills and to be able to provide a first class education, to work with the NHS but still be able to maintain autonomy.

10.3 Mary Ann Hospice, Nuneaton

- (1) Mary Ann Evans covers Nuneaton, Bedworth and North Warwickshire and can take up to 15 patients. It is a day hospice with no overnight facilities and works Mon – Fri, 10am - 4pm. They also provide a hospice at home service which offers care, support and respite 24/7 and enables 70% of its patients to die at home. However, the hospice believes the area would benefit from an 8-10 bed inpatient service, because there is not a cancer unit or palliative care unit in Nuneaton. It would enable more people to die at home rather than in hospital and reduce George Eliot Hospital's mortality rates which are larger than most other acute trusts in the West Midlands.
- (2) Patients are referred from every source such as hospital, GPs, Social Care, but they can also self refer. When they are referred to the hospice they are never discharged and can use the facilities as and when required. Currently GP's are not as actively involved as they would like, but hope that by recently employing their own doctor this may improve.
- (3) The hospice used to have funding from the Arden Cancer Network, but this is now provided by the NHS Warwickshire (PCT). Unfortunately they do encounter problems if this funding is not provided on time.
- (4) They consider that the Service Level Agreement (SLA) should cover palliative care for other long term conditions in addition to cancer, such as COPD, CHD (heart failure) and not just cancer.
- (5) They agreed with the principles outlined in George Eliot Hospital's Foundation Trust Consultation Document. The trust considered that 'End of Life Care' was a fundamental element of what they did and their strategies placed quality of life for the terminally ill at the centre of their care provision to ensure dignity and peace in an appropriate setting at the end.
- (6) The hospice is keen to work with the Hospital in providing end of life care, but felt it was vital that the following was acted upon to achieve this, by ensuring:
 - a. The LCP is fully implemented and used as soon as possible.
 - b. There is provision for Palliative Care Beds in North Warwickshire. These could be provided on the George Eliot Hospital site and would offer patients an opportunity to receive inpatient palliative care locally. The unit would ensure the patient's dignity and peace which is not always available in an acute setting and would also increase the palliative care skills of staff throughout the Hospital
 - c. There is 'Palliative Care Medical Leadership' by increasing the number of palliative care medical sessions at the Hospital. The palliative care unit would also act as an excellent lure to existing Palliative Care medical staff and as a training or placement opportunity for others.

10.4 MacMillan & Marie Curie

- (1) Mary Ann Evans has direct links with Macmillan and Marie Curie nurses who are community based.
- (2) Macmillan fund a nursing post for 3 years, after which the nurse is employed by the PCT. Macmillan nurses assess the patient's circumstances and provide them with information and support.
- (3) Marie Curie nurses are primarily based in Solihull and provide a nurse sitting service for areas in North Warwickshire nearest to Solihull. They also provide bereavement cards which has information such as the bereavement and befriending telephone service.
- (4) Both Macmillan and Marie Curie as part of a multidisciplinary team meet every week to discuss and evaluate the needs of their patients.

11. **Hospitals**

11.1 The panel visited the main local hospitals that provide end of life care services for residents in Warwickshire. The details below provide a summary of the information provided to the panel at these visits.

11.2 University Hospital Coventry and Warwickshire NHS Trust (UHCW)

- (1) At the time of the visit (May 2008) the end of life care facilitators at the UHCW had been in post for 6 weeks. They both have expertise in end of life care with specialist skills in oncology and haematology. The funding for these posts was provided by West Midlands Strategic Health Authority and the appointments were made by the UHCW.
- (2) Traditionally end of life care has concentrated on those with cancer, but the UHCW is keen to help those with end stage renal failure, respiratory conditions such as COPD and CHD (heart failure).
- (3) At the time of the visit a draft 'End of Life Care Pathway' had been devised for the UHCW. This document was based on the Liverpool Care Pathway (LDP) for the Dying Patient, but was adapted for UHCW. It looks at the supportive care programme for the last 18 months of life. Since the visit, from the summer 2008, this pathway has been in use within the renal unit to manage their supportive/palliative patients within Coventry.

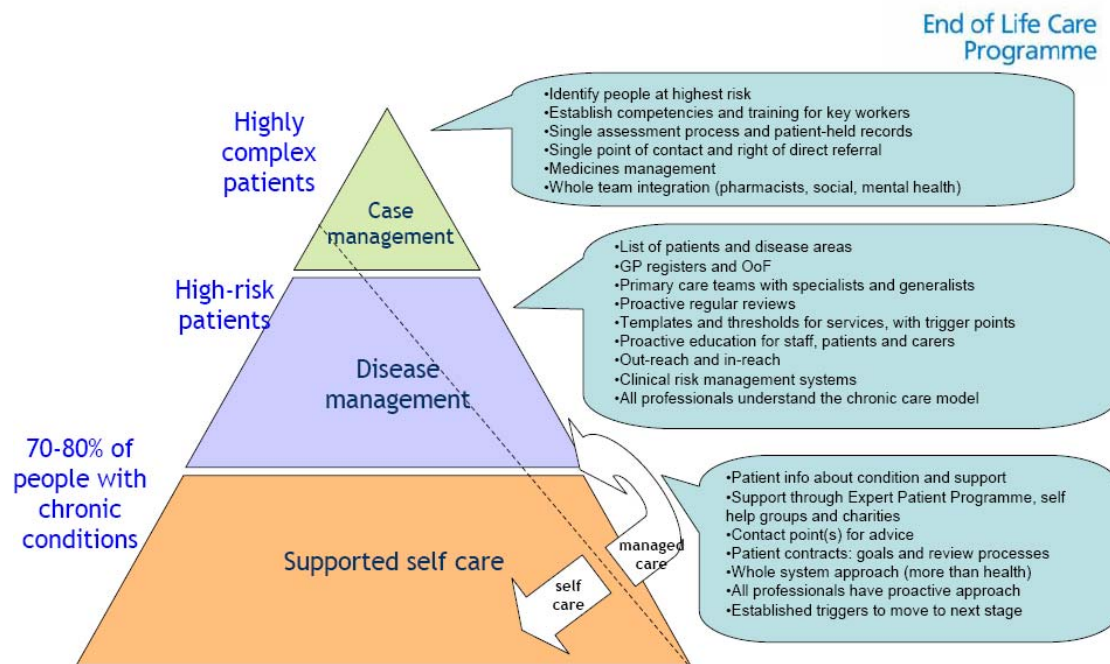


Chart 1

- (4) The acute trust provided the panel with information on how they provided healthcare to those with differing care needs throughout their end of life 6 – 12 months of life (see chart 1). The bottom half of the pyramid is where the patient is diagnosed with a life limiting condition, but can still self manage this with medication. The next stage in the pyramid is where they are being admitted to hospital frequently to manage their condition. The consultant highlights the need for a palliative care approach to their care which triggers input from a case manager (matron) to ensure they have support at home such as district nurses to reduce the need for admissions. The top 5% of the pyramid is where the patient deteriorates and requires a permanent case manager to ensure there is ongoing support in the community where more agencies may be involved. At the very top of the pyramid the patient usually has only 72 hours left to live and the End of Life Care Pathway based on the LCP for the dying patient is implemented. This pathway promotes best practice for the care of the dying. UHCW staff contact the end of life care facilitators to inform them the patient is being cared for on the pathway. Before they place a patient on the pathway they talk with the patient and their family to establish their preferred place of care. If the patient wants to be cared for at home during their last days of life the practitioners would initiate a fast track referral to Continuing Healthcare Assessment (CHAAT).
- (5) The UHCW is working with those that provide care in the community. They want to ensure that patients are discharged back to their home as soon as possible with the best possible care in the community.
- (6) The intention is that it should be a good death and the care offered to be consistent and standard set. The UHCW recognise that care may be inconsistent due to lack of end of life care training. More recently a

module has been developed to focus more on end of life care within nurse training at Coventry University and the facilitators intend to introduce training for staff that are interested. The panel thought this training should be mandatory for all staff.

- (7) There appears to be no overarching policy by the trust to adopt 'Dignity in Care' or the LCP across the trust, but the facilitators will be implementing the pathway in all wards. This was considered as beneficial for all in ensuring there is consistency in approach.
- (8) There are pressures on acute hospital beds, thought to be partly due to there not being enough nursing homes or community facilities. The facilitators considered there was still the need for community hospitals where they can provide non acute care to help patients with medicine management or treatment. They consider timely intervention like this would prevent patients needing to be admitted into an acute setting.
- (9) Hospices were traditionally linked with looking after cancer patients and this might have been due to how the assessment process was originally conducted. Myton Hospice and Marie Curie have started to admit patients with other life limiting illnesses such as COPD and CHD and these patients are already benefiting from the excellent end of life care that hospices can provide. The facilitators have found day care facilities very helpful for patients, but these need to be more readily available.
- (10) After death the patient's GP is informed and families are given information on how to register the death and contact bereavement services. However, unlike hospice services, once the family have left the hospital, hospital staff has no further involvement.
- (11) The facilitators were asked by the panel about what they think would help end of life care. Their response was to improve:
 - Communication between GP's, district nurses, families, and everyone who has to deal with end of life care. This would help reduce distress and guilt and help provide a 'good death'. They feel that as a nation we are not very good at talking or dealing with death, but it should be considered as a part of life.
 - The Continuing Healthcare Assessment ensures those in the last 72 hours of their life can receive a prompt assessment so their wishes can be met. At the time of the visit there were delays of longer than 72 hours if the assessment occurred at the wrong time of the week. Since the panel visit CHAT are now based at the UHCW and they can be called upon more readily to implement the assessment process. A new system has been put in place where patients can be discharged within half a day, but this can still take longer at weekends. This system works by:

- a) Nurses identifying patients that want to go home to die and send a fast track to CHAAT and let the facilitators know
- b) CHAAT/Facilitators working together to decide what each can do to speed up the process. The facilitators can also access equipment such as hospital beds and carers from family support
- c) Pharmacy processing end of life care drugs immediately to ensure rapid discharge,
- d) Ambulance Service picking up patients within 4 hours (dependent on 999 calls)

11.3 South Warwickshire General Hospitals NHS Trust - Warwick Hospital

- (1) The hospital has its own internal practices for end of life care, but as in UHCW and George Eliot Hospital the delivery of end of life care is not provided in the same way throughout the hospital. It is very dependent on whether the staff had been trained in delivering end of life care as part of their work.
- (2) At the time of the visit Warwick Hospital were working on paperwork for patient care, which will include a discharge pack. Staff are currently undertaking LCP courses and have been provided with a Continuing Healthcare Fast Track Tool, which is implemented within 1 week of someone dying.
- (3) There are not a sufficient number of beds to provide end of life care in the area, ideally there should be 16-19 beds. The trust has considered providing a palliative care ward, but feel it would be overwhelmed. There are sufficient resources in other areas, such as pain control, which work well and they can refer patients to Myton Hospice for symptom control.
- (4) The hospital offer good support to families, but there can be difficulties when end of life care when it relates to drug and alcohol misuse. They consider it would be helpful if social care could aid discussions with the family as they probably understand the family circumstances.
- (5) Continuing Healthcare is generally provided for those with life limiting illnesses including those with dementia or Alzheimer's. At the time of the visit continuing healthcare was considered poorly staffed, but the PCT had just employed two new staff.
- (6) As with other acute trusts imminent death is the criteria for having an continuing healthcare assessment, but again this can be a problem if this happens just after the weekly assessment panel. There are also problems if patients do not fit the criteria for social care, but the trust has involved Age Concern, through social services, to overcome this problem to obtain alternative forms of care.

- (7) Staff will take into account a patient's needs and will question the benefit of moving them home if near to death.
- (8) Warwick Hospital has used the local community hospitals for end of life care when there have been beds available. The hospital considers there is a wider role for community hospitals especially with the frail and older patients that are no longer motivated to take care of themselves as this could help free up acute beds. Although it would be helpful if there were more EMI nursing homes as well. They would like to use the community hospitals more for end of life care and could assist them by rotating existing nursing staff. It would be helpful if more community beds were funded locally.
- (9) The CCU in Warwick Hospital is a high dependency ward with 8 beds. There is a perception that patient should be treated even though they may want to end their life. The staff can find it difficult when facing end of life issues and need support and training. Warwick Hospital are initiating this training and there is procedure in place where they can be attend a debriefing session with colleagues and/or be referred to a clinical psychologist.
- (10) The ICU have contacted families later after a relative dies, but usually provide them with information at the time of death. Warwick Hospital is planning to put together a protocol with questions for families on bereavement services. There are lay chaplains at the hospital that provide the spiritual support, but cultural differences in approach to end of life care and death still need to be developed.

11.4 George Eliot Hospital

- (1) The panel visited the ICU and CCU at George Eliot Hospital. At the time of the visit the hospital was in the process of advertising for a Palliative Care Coordinator to implement the LCP.
- (2) Patients in the ICU at their end of life usually require ventilation and sedation as a consequence staff tend to have more involvement with the family rather than the patient.
- (3) Patients in ICU do not usually have cancer, but infections that overtake the body which closes down the main organs. The ward is mainly for adults but have on occasions they have had patients as young as 16.
- (4) The challenge for ICU is dealing with critically ill patients and getting them back to good health, but with those that are dying it is supporting the family e.g. deciding when not to do CPR (Coronary Pulmonary Resuscitation). Where they can they do involve patients with the decision on whether they should resuscitate them (DNR – do not resuscitate).
- (5) Visiting as a general rule is 8am-10pm but when a patient is dying on ICU these restrictions are lifted and relatives can stay, but

unfortunately this is not always provided on other wards The ICU can offer room facilities for families on a 24hour basis (these facilities are not available on other wards).

- (6) Hospice facilities are very limited which means patients with cancer are often treated on the general wards. Ideally would like to encourage patients to be able to go home, but there is a need for more community facilities to be able to do this.
- (7) The hospital chaplain is involved with the family following the bereavement. If the family has a negative experience which needs to be addressed the Patient Advisory Liaison Service (PALs) can provide support. They have conducted a cancer patient survey.
- (8) The hospital has one nurse involved in the network project to ensure end of life care at the trust is provided in a consistent manner.
- (9) The CCU considers the link between the hospice and hospital could be better and it would be helpful if there were palliative care facilities as the CCU's role is to get patients home or referred to a hospice and not to provide 'End of Life Care'.

12. Social Care

- 12.1 The panel held a meeting with Warwick social care staff at Shire Hall, Warwick and visited social care premises in Rugby.
- 12.2 The staff from Warwick explained that their aim is to help people to remain in their own homes by providing 'home care' or if that was not possible provide a place in a residential or nursing home. There is a risk that if they do not receive appropriate care at the right time they could be admitted into hospital, which causes its own problems. As a result there is a high risk that they may not return home and may have to accept emergency accommodation in a care home, which may not totally suitable for them or their family.
- 12.3 In the north of the county two social carers can be provided for patients 7am – 10pm, but in the south of county the social carers can provide 24 hour cover. To obtain this patients have to meet the CHA criteria but they can have problems if they have a disability as often they can move in and out of the entitlement for help.
- 12.4 Social Care use CHA criteria or respite care to provide 'End of Life Care'. They can bring in extra staff if required and have worked with families to share the care. Macmillan Nurses can also be used to provide support, which can include help for the staff and the families.
- 12.5 The main difference between residential or nursing homes is that nursing homes provide invasive treatments. Residential Homes work with GP's/District Nurses, families when providing end of life care and have access to specialist equipment. If the person becomes very ill

they can be referred to a nursing home, but this is dependent on availability.

- 12.6 End of Life Care is not routinely asked about or monitored as part of the CSCI assessment when visiting residential/nursing homes.
- 12.7 Social Care will be appointing a volunteer co-ordinator to not only access those willing to provide voluntary help, but to look at support relating end of life care such as shopping, reading, which sustains quality of life
- 12.8 Social Care are working towards the re-ablement process which recognises disability, but work with those with a disability to help them to learn new skills or revisit old skills.
- 12.9 There is not such a wide take up with ethnic minority groups. Warwickshire Social Care has information about equality and diversity on the County Council website. Some use Makaton - a form of sign language which is particularly helpful for those with dementia.
- 12.10 The panel asked the social care staff for suggestions that they think would improve end of life care and made the following suggestions:
 - a) Reduce length of time for reporting or obtaining a decision on whether someone is entitled to Continuing Healthcare.
 - b) To improve access to equipment or aids, six Occupational Therapists (OTs) are going to be appointed, which will hopefully speed up the assessment process, but there are still difficulties deciding who is responsible the OTs or NHS, which need to be addressed.
 - c) Increase demand for services is a problem, which will require additional funding to meet these needs.
 - d) Pooled Budgets which would help to reduce the time taken and a single budget/single team for 'End of Life Care'
 - e) Further training for health staff on how to complete assessment reports for patients. These are often not clear, which can delay appropriate care being offered to the detriment of the patient and their families.
 - f) NHS Warwickshire to focus more on improving Continuing Healthcare Criteria rather than commissioning.
 - g) Better co-ordination of care between NHS/Social Care and the development of joint strategies/joint working arrangements.
 - h) Acute Trusts to check discharge arrangements with NHS Warwickshire and Social Care when dealing with people that require end of life care. There is a tendency for the NHS to remove all their services when patients are referred to social care, but these should be referred to

continuing healthcare process before discharge to ensure they receive appropriate end of life care.

- i) Dementia training to be given to staff in residential homes to deal with those residents that develop dementia at a later date whilst in care.
- j) Less emphasis to be given to performance indicators with staff being valued and recognised for the care given to residents, which is just as important.
- k) GPs recognising their role in establishing care packages where visits may be necessary in preventing patients from being inappropriately admitted into hospital.
- l) Currently homes do not have family rooms, but a suggestion was made that Borough/District Councils sheltered accommodation could help families that need to travel a long distance to visit relatives that may be terminally ill.
- m) Age Concern does provide bereavement support where they come to the home to help relatives and sometimes the residents in the home, however an information package to take away would also be helpful.

12.11 Two members of the panel met with home care staff from Rugby and the following is a summary of their key concerns.

12.12 The staff made the panel aware that “Home care is survival – not about helping to live in dignity”.

12.13 With residential homes are becoming more like nursing homes with extra responsibilities. The staff considered they required more information about ‘end of life care’ to be able to support families properly.

12.14 The panel was made aware that there was a lack of consistent training for staff in end of life care and bereavement, which resulted in staff not feeling sufficiently skilled in offering the right support and care to families or to other members of staff.

12.15 There was a long discussion about concerns on who does what, is it the responsibility of nursing care or residential care, which was not helpful for the patients or their families. Considered there should be more clarity around responsibility and subsequent pathway decisions.

12.16 The Continuing Healthcare Assessment as in other areas encounter similar problems such as delays and time in being able to make an assessments and deciding whether the support required is personal (social care) or health. These factors can prevent those nearing the end of their life dying in the place of their choice. There was one case where this had caused acute distress for a family and the relative ended up dying in hospital rather than at home. The family did try to

appeal against the decision made, but withdrew from the process, because they did not want another battle at a very emotional time.

- 12.17 Staff from Rugby reflected that locality meetings that they used to hold benefited both health and social care teams as it enabled them to discuss and keep up to date with local issues and cases. These had slowly stopped when people move on.
- 12.18 Staff considered communication could be better as they were unclear on where they could access help, good literature and support.
- 12.19 Suggestions for taking 'end of life care forward were:
- Improve communications between key staff especially on the continuing healthcare assessment process
 - Staff need to become multi skilled especially if providing assistance at home
 - Staff training in end of life care and family bereavement
 - Pooled budgets and a joint strategy may help with discharge arrangements to ensure the same consistent care throughout the county instead of pockets of good practice.

13. Admiral Nurses & Carers

- 13.1 Admiral Nurses work with families that has a relative with Alzheimer's or Dementia and can provide emergency help if carers are finding it difficult to cope. They also provide bereavement help including mental health support after a relative has died.
- 13.2 The aim of this visit was to ask carers what worked well and not so well when dealing with GPs and setting in motion the Continuing Healthcare Assessments.
- 13.3 Carers considered dealing with the isolation, not having the freedom to be able to continue with their own hobbies and activities made life very difficult for them. They also found that families and friends tended to pull back from offering support when the relative became harder to deal with.
- 13.4 The carers appreciated day care services and the time they could have to themselves, but this was very dependent on what mood the relative was in and whether they were willing to stay.
- 13.5 Carers recognised that they eventually needed more help with caring for a relative which meant placing them into residential care. However, they found it difficult to recognise when it was appropriate to use residential care and thought it would have been helpful to have had this advice. When the relative eventually went into a nursing home although

these were very good (like a home from home) the carers still felt a sense of guilt of letting their relative down.

- 13.6 Carers found it difficult to express concerns on behalf of their relative. Doctors were not always very good at explaining to carers what was wrong, but found nurses were often able to better explain what these problems were.
- 13.7 Hospitals appeared to be much more impersonal possibly due to not having the time or necessarily expertise to look after patients with dementia. They felt that hospitals needed to be equipped more to help patients with eating, dealing with basic needs and those that tended to wander.
- 13.8 One carer through personal experience recognised that some of the tests to check for dementia did not always take into account that English may not be the relative's first language or cultural background. The provision of Aricept is reliant on these tests. This resulted in some discussion around the benefits and drawbacks of providing this treatment. Usually treatment is only provided for 18 months – 2 years and those with dementia tend to go downhill very quickly when taken off this treatment. At the time some carers felt they were not given enough information about what to expect, but thought they should have been fully informed of the consequences of having this treatment.
- 13.9 Carers considered that dementia needed to be reported as a cause of death to ensure service providers know the true extent of the problem. Often other causes, such as pneumonia, bronchitis were given as the cause of death.
- 13.10 They felt healthcare professionals should talk to those with dementia as individuals and not about why they are in hospital or the illness. Also that they should recognise that carers often are the experts on the needs of their relatives.
- 13.11 GPs needed to be more alert and recognise that relatives require information and help. Consider that there is inconsistency with information the doctors provide and they could use other health care professionals to help carers with support and advice.
- 13.12 Although carers fully supported the training being provided to new doctors at the University of Warwick in carers needs, they still considered there would be a continuing problem with those doctors that have not received this form of training.
- 13.13 The panel talked to the carers on their thoughts on the Continuing Healthcare Assessment process. One carer's experience of the assessment was very fraught and distressing. Their relative spent 5 weeks in Myton Hospice, then 5 weeks in a nursing home in Coventry. Problems occurred because the assessment was Coventry based, but their relative lived in Warwickshire. The NHS conducted the assessment, but the relative could not have social care support. The

carer had problems with the night sitting service, medication and the Out of Hours service. Found the whole process hopeless. The discussion highlighted there were cross boundary issues especially if the GP was based in Coventry or Staffordshire and the patient lived in Warwickshire.

14. End of Life Care Stakeholder Event

14.1 An event on 20th October 2008 brought together practitioners and carers together to openly discuss the 'End of Life Care Strategy', death and dying and how services could be improved in Warwickshire. The aim of the event was to ensure those receiving end of life care, their carers and their families had a good end of life care service – 'a good death' whether in hospice, hospital or at home by:

- Ensuring service providers provide a flexible, appropriate, clinically effective and accessible service in response to the needs of those affected and their families and have the training to meet those needs.
- Suggesting recommendations where there could be service improvement and improved working arrangements between service providers
- Identifying issues where there is financial challenge and suggest areas of sustainable funding where appropriate.
- Identifying what was needed to improve patient choice, on where they wanted to die
- Identifying what support and training needs are required, for those that provide end of life care, to make the above possible

14.2 Presentations provided delegates with the following information:

- 'End of Life Care' provision in its different settings
- The relationship between health, social care and other providers
- What all service providers do to meet the needs of those affected and their families

14.3 The intention of the 'End of Life Care Strategy' is that it will cover all 'end of life' settings and conditions such as Chronic Obstructive Pulmonary Disease, Multiple Sclerosis, Coronary Heart Disease and Dementia. It will build on the experience of hospices, specialist palliative care services and existing end of life care programmes, including other innovative service models such as Marie Curie 'Delivering Choice Programme'. Measuring its success should result in more people:

- a) Talking about death and dying,
- b) Feeling comfortable when talking to the dying or bereaved
- c) Visiting care homes or hospice
- d) Seeing a dead body
- e) Participating in the rituals relating to death
- f) Being aware of sources of advice and support

- 14.4 One of the challenges identified by the 'End of Life Care Strategy' was identifying what the workforce that provide 'end of life care' are good at and what they don't know. The strategy also needed to make the links with other strategies such as dementia care.
- 14.5 Most people would choose to die at home, but 58% die in hospital, 5% in a hospice. Only 18% of people manage to die at home with a further 16% in care homes, which highlighted the mismatch between where people wanted to die and their actual place of death. Hospitals receive 54% of complaints related to end of life care and recognise that they need to act right.
- 14.6 Evidence indicated that only a third of people in Britain discussed death and dying with anyone, which often resulted in a more painful bereavement for families. They are often left with a sense of failure in not knowing whether they provided the right care and adhered to the wishes of the one they loved. Essential that the public become more comfortable about talking about death and dying to ensure their and their relatives' needs are being met.
- 14.7 Delegates were informed that there were six steps to the end of life care pathway, from a need for discussion as end of life approaches through to care after death. This highlights that care does not stop at the point when someone dies. This end of life care pathway would be used in various care settings, for all 'end of life' conditions, but this would require workforce development to ensure it can be implemented successfully. Funding of £289 million will be made available for specialist palliative care, but it was important that commissioners made it a priority.
- 14.8 The National Council for Palliative Care will be monitoring the success, progress and challenges in all key areas of the 'End of Life Care Strategy'.
- 14.9 NHS Warwickshire (PCT) supported the national findings that although people preferred to die at home the majority actually died in an acute hospital. They considered it important that the control was given back to the patient. The PCT's priorities for the future would be to improve access and equity of care and develop a range of services in community settings to support choice and care closer to home. They wanted all stakeholders to be involved in the evaluation, planning and development of all of end of life care services and that the end of life services would be co-ordinated and seamless, with clear integrated pathways with patients at the centre.

NHS Warwickshire's (PCT) vision was that:

'All people in Warwickshire at end of life will be supported and cared for, feel safe and listened to and will be enabled to die with dignity and respect. The population of Warwickshire will have the opportunity to

access, a comprehensive high quality, equitable range of end of life care services, which are person and family focused, promoting choice, symptom control, respite and psychological, social and spiritual support, sensitive to individual needs and wishes, which are delivered in a timely, integrated and co-ordinated manner’.

- 14.10 Marie Curie Nursing Service informed delegates that they provide practical care to patients in their own homes with respite and emotional support for carers. Their aim was to double the number of people being able to spend their final days at home by providing a patient centred 24 hour service that serves local needs. Their model of delivery uses a whole systems approach and whole patient pathway. This approach is commended by the ‘End of Life Care Strategy’ and has pushed palliative care up the political agenda. They consider working in partnership using the whole systems approach achieves a better end of life care.
- 14.11 To identify barriers and understand local need Marie Curie intends to work with local partners to design new service models such as rapid response service, palliative care co-ordination service, discharge community link nurse, dedicated transport – palliative care ambulance and integrated health and social care service. These services will be offered to NHS Warwickshire in 2009/10.
- 14.12 The University Hospitals Coventry & Warwickshire (UHCW) and Myton Hospice made delegates aware that they were keen to work together to improve the patient experience. They considered working collaboratively with all partners such as pharmacy, ambulance, community services, families and carers is key to enabling patient’s to have real choice on their place of care, where they wanted to die and also to be able to change their choice if they so wished.
- 14.13 In the last 48/72 hours of care the UHCW and hospice use an end of life care pathway, which promotes communication about planned care with relatives and carers. Rapid response is essential to ensure rapid discharge home. It is an integrated care pathway for all life limiting illness and its aim is to reduce variations in the patient’s experience of care. They consider that 24/7 district nursing service leads to better care at home.
- 14.14 Both Myton Hospice and University Hospital Coventry & Warwickshire also work together on education and competencies and have increased training related to end of life care. They provide courses for all levels of care staff and it is now part of the nurses’ curriculum.
- 14.15 The supportive care pathway is similar to the end of life care pathway. It is a working document which prompts discussion with both patients in their last year of life and their carers around their choice of care. The intention of this pathway is to prevent inappropriate interventions,

provide comfort measures, psychological and spiritual care, anticipate what medication would be required in the future and document the preferred place of care. The pathway also recognises that patients will dip in and out of hospital in their last year of life. It identifies potential issues for Out of Hours and if death is expected or imminent. Having the Supportive Care Pathway in place should make sure there are measures in place to reduce inappropriate admissions into hospital at end of life.

- 14.16 The Arden Cancer Network provided delegates with information on user involvement, not only in Warwickshire, but the other areas the network covered such as Coventry, Worcestershire & Redditch including Bromsgrove.
- 14.17 User involvement was considered not only important in shaping services, but also played a part in influencing the future of cancer services. The network had good links with South Warwickshire Carers Association and done some positive work through the development of the North Warwickshire Young Persons User Group (16 – 24 year olds), which enabled support to be provided to young people touched by cancer, as a family member or friend. They had also been involved with updating a Macmillan publication 'Hello and how are you?' to make it more appropriate for young people.
- 14.18 The presentations finished with 'What Carers Need' and described how people became carers, their experiences, the support networks available their expectations, emotional impact, the response of carers to end of life and what would make a difference.
- 14.19 A carer gave a presentation on what it was like to care for his wife who suffered from Huntingdon's disease. He found the care and support offered by those representing the various services excellent, 'second to none', and as individuals they were wonderful. However, when trying to co-ordinate the packages being offered by adult social care to services provided by health, as his wife became worse, he started to encountered problems. There was no overlap between the two and losing the entitlement to home care made it difficult. He found it hard to know which service to contact when he needed help - was it adult social care or health? As a carer he thought it would have been easier if there had been a single point of contact - someone who would know which service to contact on the carers behalf. He explained trying to obtain the right service or equipment was a stressful experience, but despite this he found looking after the woman he loved a privilege.
- 14.20 Five workshops were held in the afternoon to discuss:
1. Continuing healthcare & the assessment process. This was to ascertain why the Continuing Healthcare Framework is causing problems in providing 'End of Life Care and what needs to be done to address these problems locally and nationally?

2. Dementia and palliative care. To see what can be done to help dementia be recognised as a life ending, what type of care is required and what support do carers and families need?
3. Training for end of life care. To look at who provides end of life care, what training do they need, what level of competency, who will pay and where would they receive this training?
4. Patient choice. How do healthcare professionals deliver choice, what are the barriers, what service provision is required to meet the needs of patients and who will provide these services?
5. Children's palliative care, transitional arrangements. To look at the problems that have been encountered, how can these be resolved, what is needed to make this happen?

15. Key Findings

- 15.1 The panel found the visits to the hospices, hospitals, social care and carers a very useful experience and wish to warmly congratulate all those involved in providing end of life care. The following is a summary of the key findings of the panel following the visits to hospices, hospitals, social care, Admiral Nurses and carers.
- 15.2 The quality of care provided in hospices seemed higher than that of hospitals. Both hospices offered a valuable service for the patients and their relatives and provide respite care, medicine management, rehabilitation and psychological services. They also offer a hospice at home service, which support people in their own home. Surprisingly less than 50% die in the hospice, although there is still a perception that people go to the hospice to die.
- 15.3 The majority of patients the hospice tend to support are those with cancer and traditionally there are not many referrals of patients with other life limiting illnesses. It is recognised that all those requiring end of life care would benefit from the services of the hospice and Myton Hospice with Warwick Hospital are currently conducting a pilot study to provide a day service to patients with heart failure. The panel support the hospices' move to provide care to those with other life limiting illnesses such as CHD or COPD.
- 15.4 Quality of care appeared to be better in the south of the county in part due to there being inpatient facilities at Myton Hospice in Warwick. Mary Ann Evans believed the lack of inpatient beds was the main challenge for them, but the new hospice in Coventry should significantly improve end of life care for the north of the county. On the plus side the day hospice was considered very important in providing support, it helped patients to remain in their own home and was also beneficial if the patient subsequently needs to be admitted.
- 15.5 There was an uneven distribution of resources for palliative care with funding going to the NHS, but hospices were mostly dependent on voluntary contributions. However both Myton Hospice and Mary Ann Evans Hospice found NHS funding also a challenge, because they

wanted to retain the autonomy to provide the high class training and education to be able to deliver excellent end of life care services.

- 15.6 Other challenges for Mary Ann Hospice was implementing the Liverpool Care Pathway and making improvements in palliative care training. They consider that medical sessions at the hospital could lure more medics into palliative care.
- 15.7 Hospital staff that deal with patients, following an acute emergency, appeared to be more equipped to deal with end of life care. The staff tended to have more involvement with the family and could provide relatives with support - rooms to enable them remain in the hospital, extended visiting and access to bereavement support via the hospital chaplain. They also had a good support network in place to help them in moments of stress.
- 15.8 There did not appear to be a uniform approach in hospitals to the provision of end of life care services, which meant the quality of care could be 'hit and miss'. Staff on other wards, such as the coronary care unit, appeared not to be so well prepared or supported. It was considered partly due to the type of illness that these patients have, where they may have several admissions over a longer period of time, with periods of recovery, which can result in staff not being prepared for end of life when it comes. Equally, families are very dependent on a member of staff's experience or training in end of life care, which if limited it can lead to distress and difficulties in dealing with the death of a loved one. The discussions highlighted that there was an inconsistency in approach where patients on one ward may receive much better treatment than in another ward.
- 15.9 There were recognised difficulties when moving patients from hospitals to hospices at the weekends, but there was also not sufficient number of beds or day facilities available in hospices to be able to refer patients that would benefit from this form of care. They thought this was in part due to hospices traditionally being associated with those that have cancer and possibly assessments mainly being carried out by Macmillan nurses. It was generally accepted that other patients with life-limiting conditions could benefit from the care and treatment that could be offered by hospice staff.
- 15.10 Community hospitals are used for patients who still required some medical care. The staff felt that there was a need for more beds in the community for medicine management/treatment as this would prevent patients from being admitted into an acute setting.
- 15.11 Patient choice was considered important, but the challenge for the hospitals was arranging the 'Continuing Healthcare Assessment Process' - CHAAT which could allow patients to be discharged to die at home if they so wished. These are arranged in the final stages of a patient's life, but can take up to a week if the patient falls outside of the

assessment period and is not helpful when it is only acted in the final 72 hours of a patient's life.

- 15.12 Social Care staff use the 'Continuing Healthcare' criteria or 'Respite Care' to provide 'end of life care', but there can be problems for people with a disability, because they can move in and out of entitlement to obtaining the right type of care when trying to meet this criteria.
- 15.13 The continuing care package was again identified as an area of concern in social care where inconsistency and poor communication between staff, caused patients and families distress with resulting difficulties for staff. The assessment process appears unclear in relation to 'end of life care' and what support is available – is it 'personal' or 'nursing'? There were also procedural delays and duplication of paperwork, which could result in it taking a week for the panel to make a decision.
- 15.14 Social Care staff found it difficult to decide who was responsible for providing different levels of care should it be the nursing staff or residential care staff? There appeared to be no real clarity around areas of responsibility and pathway decisions.
- 15.16 The review identified that bereavement and end of life care training would be beneficial all staff working in hospitals or social care that were involved in end of life care, to enable them to be properly equipped to work in often highly emotional situations. The staff in both these care settings wanted to be able to support families and know how to gain extra support.
- 15.17 There was a real need for a strategic approach to workforce development/training in both the hospital and social care setting.
- 15.18 There were also problems with residential homes becoming more nursing homes and the ensuing extra responsibility.
- 15.19 The social care staff missed having the locality meetings of all health and social care teams considered it was a real opportunity for them to discuss cases and keep up to date with local issues.
- 15.20 There were issues around providing care in the community with inequality of provision in the north and south of the county.
- 15.21 The aim of adult social care was to keep people in their own home by providing home care or care in a residential/nursing home but access to a residential home was dependent on availability. Warwick Social Care Team hope to use volunteers to help people to stay at home, but this will be subject to the volunteers having a CRB check.
- 15.22 The panel were made aware that issues can arise when if someone needs to go into hospital such as how do they get home? Who will pay? Going home was dependent on the person's needs.

- 15.23 Admiral Nurses find their limited resources can cause problems in trying to support people with learning difficulties such as Down's Syndrome, who have an increased risk of developing dementia in later life. Admiral Nurses would also like to provide a more equitable service in the county and extend their services to the south of the county.
- 15.24 Discussions with carers highlighted the need for them to receive care as well as the relative.
- 15.25 Carers stressed the importance of doctors and healthcare professionals talking with the patients as individuals and not to just look at their end of life, but recognise there is a beginning. Carers thought that their relatives should be told about their illness and what to expect so they can prepare for what they want in the future such as a living will. Also healthcare professionals to recognise pastoral care is important to meet their spiritual needs.
- 15.26 Carers wanted more information on how to deal with a relative with dementia. They also felt that they and their relatives needed to be empowered and have someone to negotiate with NHS/Social Care on their behalf.
- 15.27 Carers wanted to have help with practical concerns such as having the option to be able to rent a 2 bedroom home instead of a one bedroom. Living with someone who has dementia can be very disruptive at night and it is helpful if the carer has somewhere to rest. Also they wanted more information about allowances to offset a possible reduction in finances.
- 15.28 Finally carers considered death should be more openly discussed which would be both beneficial for the relative and their family.
- 15.29 The stakeholder event highlighted the Continuing Care Framework was a problem when funding is awarded to deliver end of life care and an existing service stops. The assessment should be able to take into account patients and relatives needs, but there was a lack of continuity with the quality of service being very dependent on where people live. This was probably a joint commissioning issue that needs to be resolved.
- 15.30 It was considered a priority that dementia was recognised as a terminal illness, which needed specialist end of life care services. Training and education of healthcare professionals would help raise awareness, with this information being made readily available to the general public including families, employers and schools. It was also important for carers and families looking after those with dementia to have a single point of contact or navigator and they also have access to consistent, equitable community support.

- 15.31 To be able to care and cope with the demands of providing end of life the event highlighted that family members and healthcare professionals would benefit from having training in physical, emotional and social skills. There was training to look after those with cancer, but appeared to be insufficient training with other life limiting illnesses. The training needs would be dependent on the care being offered but would require a set of competencies to ensure a good general level of care and support from both staff and carers. With the lack of resources available for training within the NHS it was suggested that a bid be made to the SHA to obtain funding from money being made available by DH for end of life care.
- 15.32 Communication skills were considered key to end of life care and an awareness of care pathways, which is sensitive to patients and carers needs.
- 15.33 To deliver patient choice the public needed to be asked what they wanted, what choices were available and these to be offered at the most appropriate time. However, it was essential that the choices made should be right for the patient and their family and regularly reviewed.
- 15.39 End of life care services offered needed to be joined up, seamless easy to use, able to work across boundaries – integrated and equitable so no matter where people live to reduce postcode lottery. As with dementia it was suggested that the patient/family would benefit from having a key worker/single point of access to liaise with all services.
- 15.41 All GP's in Warwickshire should be encouraged to use the Gold Standards Framework in providing end of life care. It was suggested that this framework should be considered for use in care homes.
- 15.42 It was recognised there were not always the resources available to provide an infinitive range of services, but care should not be about saving money but using the resources wisely.
- 15.43 In providing end of life care there was a need to improve knowledge and raise awareness of cultural differences. Also to change the perception that hospices are places to die.
- 15.44 When looking after children's palliative care transition arrangements the key findings were to sort out the legal issues, allow direct payments for continuing healthcare, identify the lead professionals to be able to start the planning process for transitional arrangements, provide out of hours rapid response and the resources to manage crisis situations 24/7 and provide training for key workers.

16. Conclusion

- 16.1 The panel reviewed all the key priorities as set out in the scope and reached the following conclusions.

- 16.2 The panel were interested in how patients and their carers access out of hours advice, support and obtain help in a crisis. When dealing with children and young adult in a crisis situation the panel were made aware that extra resources should be made available so the out of hours service can provide a rapid response twenty four hours a day, seven days a week (**see recommendation 17.1**).
- 16.3 The panel recognised that when looking at all care settings the continuing healthcare criteria assessment process (CHAAT) needs to have more flexibility to ensure patients and families have 'good' of end of life experience, which would allow them the choice to die at home if they so wish. In some cases the final arrangements for the last 72 hours of a patient's life can take up to a week if the patient misses an assessment meeting, which is not helpful and can cause extreme stress for both the family and the patient. A suggestion was made that electronic referrals and providing joint training of hospice, NHS and social care staff could improve the fast track process. The review also highlighted the need to provide a general easily understandable guide to the structures in place to provide Continuing Healthcare Assessments (**see recommendation 17.2**).
- 16.4 The review highlighted the role of GPs in establishing care packages where they needed to conduct a home visit to ensure patients are not inappropriately admitted into hospital. The panel consider that NHS Warwickshire should either raise awareness with GPs the importance of establishing care packages or make arrangements with the out of hours service to provide this facility, which should help reduce costs in having inappropriate admissions.
- 16.5 The panel considered it was important to set a gold standard for end of life care in the community similar to the 'Liverpool End of Life Care Pathway' process. The 'Gold Standard Framework' provides a plan for the last year of life and in particular the last 72 hours. The stakeholder event highlighted the importance of choice being available at the right time and these should be the right ones for the patient and their families. It was also important that the services provided should be joined up and seamless and be able to work across boundaries. The panel consider that all GPs should be encouraged to adopt the Gold Standards Framework in providing end of life care (**see recommendation 17.3**).
- 16.6 Concerns were raised when the new hospice facilities become available in Coventry that acute trusts may place undue pressure on the hospice to take patients that require end of life care so they can free up acute beds. The aim of the hospice is to have 75% occupancy so they have the capacity to deal with those requiring urgent care immediately. It was suggested that there should be protocol arrangements to agree access to hospice services (**see recommendation 17.4**).

- 16.7 The panel found there was an inconsistency in the treatment of 'end of life care'. Patients and their families receive different levels of care, dependent on where the patient is treated and whether the staff had any training in providing end of life care. The panel consider that all NHS and social care staff, likely to be involved in end of life care, should receive training including bereavement support and counselling. The panel were also made aware that training should also be given to key workers that provide help with transitional arrangements for children and young adults (**see recommendation 17.5**).
- 16.8 The training and qualification being offered to care workers could bridge the gap between present level of skill and those of nurses. The panel would like to suggest that the County Council may want to consider providing an 'end of life care' common induction process for carers, plus in house training courses, which could include private care providers (**see recommendation 17.6**).
- 16.9 The panel consider that Coventry PCT and NHS Warwickshire as joint commissioners should both look at end of life care together especially when the UHCW have to deal with different discharge arrangements. The development of the strategic county wide plan should involve both PCTs working together with the acute trusts, adult social care and hospices (**see recommendation 17.7**).
- 16.10 The review identified that there needed to be better co-ordination of care between NHS and Social Care. For example when a consultant agrees to discharge a patient NHS Warwickshire and Adult Social Care are not necessarily consulted, which means they are not able to provide the appropriate level of end of life care. At times there is no clarity about who does what, whether some care activity is the responsibility of nursing or social care. The panel considered it essential that all those involved in end of life care work in partnership improve communication, hold regular meetings of health and social care teams to be able to provide a seamless service (**see recommendation 17.8**).
- 16.11 The panel were content that both the hospices and hospitals offered an exceptionally good level of pain control and symptom management for those nearing the end of their life.
- 16.12 Hospice facilities at the George Eliot Hospital are limited so patients with cancer are sometimes treated on general wards, which is far from ideal. There is no overarching policy for the acute trusts to adopt pathways such as 'Dignity in Care' or the 'Liverpool Care Pathway' for all wards. The panel were made aware that general nursing training does not necessarily cover end of life care'. However, the panel considered this should be mandatory for all staff to ensure a consistent level of care (**see recommendation 17.9**).
- 16.13 The panel recognise that hospices offer a good level of psychological, spiritual and social support with facilities at the hospices for all faiths.

Facilities are also available at all acute trusts with access to lay chaplains, but recognise that cultural differences in the approach to end of life care need to be developed further (**see recommendation 17.10**).

- 16.14 The review has highlighted that there is not equity of access to end of life care services. In the north of the county more people die in hospital due to lack of inpatient community based facilities. The panel were made aware the need for more hospice day facilities and beds, so that more patients with end of life conditions can benefit from the specialist care, especially respite care. There was a possible role for community hospitals for some end of life care, which would help free up acute beds. However, there is a perception that people go to a hospice to die, which is not their role so there is a need for balance against what the patient wants and expects and the resources available. The hospice at home service may be the way forward in meeting expectations within the resources available (**see recommendation 17.11**).
- 16.15 The panel found that providing information to families in hospitals, such as dealing with bereavement, varied according to whether the ward was used to provide end of life care. They consider it would be helpful if the acute trusts adopt a consistent approach (**see recommendation 17.12**).
- 16.16 The stakeholder event highlighted the need to raise awareness of dementia with healthcare professionals. This information could also be made available to schools, employers and families (**see recommendation 17.13**).
- 16.17 The panel were impressed with the services provided by Admiral Nursing, but were made aware that there were only two nurses and they were located in the north of the county. With the likely increase in the number of people with dementia and to ensure equity of access the panel consider it was important that this service should be extended into the south of the county (**see recommendation 17.14**).
- 16.17 The event also highlighted the need for a single point of contact for carers to access support and information (**see recommendation 17.15**).
- 16.18 Warwick Hospital provides a good level of support for families, but there can be problems if end of life care relates to drug and alcohol misuse. Consider it would be helpful if social care could aid discussions with the family.
- 16.19 Carers sometimes found it difficult to convey the wishes of their relative and doctors were not always good at explaining what was wrong and the information given was inconsistent. There was a tendency for healthcare professionals not to see the patient as an individual, but as the illness. The panel consider that there should be more training of

healthcare and social care professionals in not only dealing with a patient's end of life care, but ensuring they meet the needs of carers as well. Also there should be a review of the information given to carers (**see recommendations 17.5, 17.16 and 17.17**).

- 16.20 It was recognised by the panel that the best personalisation of end of life care was provided in the hospice setting and that due to pressure with acute beds that the NHS appears to be less personalised. This was also the experience conveyed by carers. With the appointment of end of life care coordinators/facilitators the panel consider that this should improve.
- 16.23 Recognise that there will be two rooms made available at the new Myton Hospice in Coventry for young adults. However, the review highlighted that legal issues needed to be resolved to allow direct payments for continuing healthcare, the planning for transitional arrangements needed to start earlier, but it requires lead professionals to be identified to start this process (**see recommendation 17.18**).
- 16.24 People in the south are able to access inpatient services at Myton Hospice, Warwick more readily than in the north, but people in the north do have better access to carers and district nurses. This is currently the only facility for the whole of Warwickshire but a new hospice is due to open in Coventry in 2009, where it is hoped that this will improve. However the review identified that there is a need for localised services in the north of the county and not just Coventry. To address the gaps in service in north Warwickshire it was considered helpful if night shifts had more flexibility, with planned day and twilight shifts.
- 16.26 It was suggested that inpatient facilities could be provided using one of the empty wards at George Eliot Hospital. This could also provide training or placement opportunities for staff and increase the level of palliative skills throughout the hospital (**see recommendation 17.19**).
- 16.27 The panel also believe that social care need to consider what is required from them that would enable people to remain in their own homes it is not about survival, but living in dignity. A finding from the review indicated that end of life care is not routinely monitored as part of CSCI assessment (**see recommendation 17.20**).
- 16.28 The panel considered to raise awareness of end of life care in Warwickshire which could inform the national perspective that copies of they suggest the report should be made available to all those involved in the review, MPs, Royal College of Physicians, Royal College of General Practitioners, Royal College of Nursing and the National Council for Palliative Care (**see recommendations 17.21, 17.22 and 17.23**).
- 16.29 The panel recognise that end of life care services is provided in a variety of setting by many agencies involved and family members. The

review highlighted the complexity in providing this care and the need for partners to work together to ensure a good end of life for everyone (see recommendation 17.24).

17 Recommendations

The panel made the following recommendations:

- 17.1 NHS Warwickshire to report to Health OSC on the resources being made available to provide end of life care by the new Out of Hours service in Warwickshire. To ensure that service needs of children are being met in a crisis.
- 17.2 NHS Warwickshire, Coventry & Warwickshire Partnership Trust, Acute Trusts and Adult Social Care to review how they can improve the Continuing Healthcare Assessment process and report back to Health OSC in September 2009.
- 17.3 NHS Warwickshire to raise awareness of the 'Gold Standard Framework' especially with GP's in Nuneaton/Bedworth and North Warwickshire via a number of forums such as the GP Consortium. This would help share best practice and would also take into account and act upon the support needs of carers.
- 17.4 For NHS Warwickshire, acute trusts and the hospice to agree protocols arrangements for inpatient admissions. To report to Health OSC in six months time the arrangements agreed.
- 17.5 NHS Warwickshire, Hospices, Acute Trusts and Social Care commissioners, with representatives from their workforce, to meet to discuss the provision of combined end of life care training and report back to Health OSC in six months time on how this would be implemented.
- 17.6 For Warwickshire County Council to consider an 'end of life care' common induction process for carers, plus in house training courses.
- 17.7 When looking at World Class Commissioning that NHS Warwickshire and Warwickshire County Council should ensure that end of life issues and dignity in care are taken into account within any commissioning process and that all contracts have this written into them.
- 17.8 For NHS Warwickshire, Hospices, Acute Trusts and Social Care to set up a forum to meet three times a year to review partnership working and communications between agencies. To report back to Health OSC in six months time on whether this has been implemented and progress being made.
- 17.9 George Eliot Hospital, South Warwickshire General Hospitals and UHCW Trust Boards to take a strategic role in ensuring that 'Liverpool Care Pathway' and 'Dignity in Care' are introduced into all acute

settings and not just wards that normally are expected to provide end of life care.

- 17.10 In recognition that cultural differences in the approach to end of life care needs to be developed further that NHS Warwickshire and Warwickshire County Council to devise a guidance document about end of life care for all faith groups.
- 17.11 To help reduce inappropriate admissions to acute trusts and the possible savings that could be made that NHS Warwickshire to consider funding the 'Hospice at Home Service'.
- 17.12 Acute Trusts to provide bereavement cards with information for families such as the bereavement and befriending service.
- 17.13 The conclusions and recommendations of this report are used to inform other strategies such as dementia care and the report be given to Adult and Community Services OSC for comment.
- 17.14 To ensure equity of access NHS Warwickshire with Coventry and Warwickshire Partnership Trust consider commissioning an Admiral Nurses Service, in the south of the county for people with dementia and their carers.
- 17.15 For NHS Warwickshire, Acute Trusts and Adult Social Care consider the setting up of one point of contact for carers that could navigate, on their behalf, for the services they required. To report back to Health OSC in six months time on how this could be implemented and progress being made.
- 17.16 In recognition that information for families varies, according to the setting they find themselves in, that representatives from the acute trusts plus the residential care sector review the information available with a view to making it more consistent.
- 17.17 Care & residential homes to have designated staff providing end of life care and bereavement support for families, carers and staff. Families and carers to also receive written information about what to expect when a loved one is coming to the end of their life with bereavement support.
- 17.18 NHS Warwickshire and Warwickshire County Council to review transitional arrangements for children requiring end of life care to identify lead professionals which can take the planning process for transitional arrangements forward.
- 17.19 For George Eliot Hospital NHS Trust to conduct a feasibility study on whether they could provide end of life inpatient facilities at the hospital and report back their findings to Health OSC in six months time.

- 17.20 That end of life care is monitored as part of the CSCI assessment (from April 2009 Care Quality Commission) when visiting residential or nursing homes.
- 17.21 Copies of the report are sent to the Royal College of Physicians, Royal College of General Practitioners and Royal College of Nursing for them to be aware of the issues raised, such as the needs of patients, families and when providing end of life care as part of general training.
- 17.22 Copies of this report to be given to all stakeholders involved with this review and local MPs.
- 17.23 A copy of the report to be given to the National Council for Palliative Care with special regard to the dying agenda.
- 17.24 NHS Warwickshire, Acute Trusts & Adult Social Care to report to Health OSC in six months time on what actions they will take when considering the conclusions and all of the above recommendations in regard to 'End of Life Care'. Also to provide information on how they plan to work together to provide a single approach to 'end of life care'.