

**RUH End of Life Care Annual Report
April 2014 – March 2015**

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1. Introduction

There has been significant focus over the last year at the Royal United Hospitals Bath NHS Foundation Trust (RUH), to support the delivery of high quality, timely, effective, individualised services for patients with end of life care needs, support for their families and support for staff to provide these services. This service improvement work continues, to support staff in providing compassionate, holistic, patient centred care. Much of this is in line with the priorities set out in Leadership Alliance for Care of Dying People publication in 2014 'One Chance to get it Right' (2014):

1. The possibility that a person may die within the next few days or hours is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them
3. The dying person, and those identified as important to them, are involved in the decisions about treatment and care to the extent that the dying person wants
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion.

Caring for people nearing the end of life is one of the most important things we do in hospital. In the last year the Trust supported 1558 patients that died. This figure includes all deaths. This report gives an overview of the end of life care service improvement work at the RUH that supported the local and national priorities, over the last year.

2. End of Life Care Working Group

The working group has met quarterly, with representation from:

- Executive Lead (Chair) – Director of Nursing
- Lead nurse palliative care/end of life
- Senior palliative care nurse/end of life care facilitator
- Senior palliative care nurse specialist
- Matron oncology
- Head of Patient Experience
- Senior chaplain
- Medical and nursing representative from medicine and surgery
- Consultant in Palliative Medicine, RUH and Dorothy House (Vice Chair)
- Paediatric Nurse
- Heart Failure Nurse Specialist
- Patient /family representative
- Dorothy House nurse specialist/lead

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- Deliver education and guidance to support the development of a generalist workforce competent in palliative care.

In 2014/15 the SPC operated Monday to Friday 09.00-17.00. Out of Hours clinical advice was provided through the Dorothy House 24/7 advice line.

In team includes:

- Lead nurse palliative care/ end of life (1wte)
- Consultant in palliative medicine/ associate specialist sessions (5PAs) supported by Dorothy House Hospice, on an Honorary Contract
- Specialist palliative care nurses (3wte)
- Palliative Occupational Therapist (0.4wte)
- Admin (0.69wte)

The SPC team participated in annual peer review and developed an operational policy and an annual report for SPC services. Along with the end of life care working group, the SPC team supports the work set out in the RUH end of life care work plan.

5. End of Life Care Work Plan

The work plan aligns to the themes within the national End of Life Care Strategy (2008), NICE Quality Standards for End of Life Care (2011) and Leadership Alliance for Care of Dying People 'One Chance to get it Right (2014) priorities for care of the dying person.'

Work Stream 1 - Discussions as the end of life approaches	
Key achievements	<p>Promoted early identification of patients with 'prognosis uncertain' and 'end of life care needs,' through The Conversation Project (see CQUIN section). 6 wards have been supported to embed the principles of The Conversation Project and 3 wards have been supported with implementation.</p> <p>Advance care planning resources reviewed and updated on the internet and intranet.</p> <p>RUH engaged with the Wiltshire Clinical Commissioning Group (CCG) review of the Electronic Palliative Care Coordination System (EPaCCS) end of life care register and options appraisal for future electronic information sharing.</p> <p>Developed links with dementia coordinators and successful bid to South West Strategic Clinical Network (SWSCN) for a funded project in 2015/16 to support development of The Conversation Project Dementia and Frailty.</p>
Areas to be progressed	<p>Extending The Conversation Project to more wards in the RUH.</p> <p>Maintaining engagement with the CCGs to ensure the Electronic Palliative Care Coordination System (EPaCCS) and electronic registers support information sharing across settings.</p> <p>Developing advance care planning resources for frailty and dementia as part of the South West Strategic Clinical Network project.</p>

Work Stream 2 - Regular re-assessment and care planning

Key achievements	<p>Promoted assessment and care planning for patients with 'prognosis uncertain' and 'end of life care needs,' through The Conversation Project (see CQUIN section). 6 wards have been supported to embed the principles of The Conversation Project and 3 wards have been supported with implementation.</p> <p>Recognition of Treatment Escalation Plan or Do Not Attempt Resuscitation (DNAR) documentation when patients admitted from community. Promotion of RUH Ceiling of Treatment to record the outcome of significant conversations with patients.</p>
Areas to be progressed	<p>Extending The Conversation Project to more wards in the RUH.</p> <p>Continue to engage with CCGs and local stakeholders to work towards an integrated approach to support information sharing in relation to Treatment Escalation Plans, Do Not Attempt Resuscitation and Ceiling of Treatment.</p>

Work Stream 3 - Co-ordination and experience of care

Key achievements	<p>Promoted coordination of care for patients with 'prognosis uncertain' and 'end of life care needs,' through The Conversation Project (see CQUIN section). 6 wards have been supported to embed the principles of The Conversation Project and 3 wards have been supported with implementation.</p> <p>Implemented a new process for take home medication to include Just in Case Medications and developed guidance for staff, patients and families.</p> <p>Commenced St James's Project in partnership with Dorothy House – reviewing process for rapid discharge home for patients who are dying and who wish to be at home, and developing processes to support timely, safe discharge home at the end of life.</p> <p>End of life care information resources for patients and families reviewed and updated.</p>
Areas to be progressed	<p>To complete the St James's Project and implement processes to support timely, safe discharge or transfer of care for patients in the dying phase, to their preferred place.</p> <p>To review access to specialist palliative care services 7 days/week, evidence need for access to 7 day service and identify opportunities for supporting development of 7 day service for the RUH.</p>

Work Stream 4 - Delivery of high quality care of the dying in acute hospitals.

Key achievements	<p>Priorities for Care documentation implemented to support holistic assessment and patient centred care in the last hours/days of life. Baseline audit completed before implementation of the new documentation.</p>
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	<p>The RUH completed the National Care of the Dying Audit for Hospitals in 2013. Learning from the audit informed work plan for end of life care in 2014//15.</p> <p>Commenced review of Trust guidance on reducing inappropriate transfers of patients at the end of life.</p> <p>Reviewed resources for families – additional beds purchased for families to use when staying overnight and comfort care box contents updated.</p> <p>New process implemented to support free parking for families of patients in the last days/hours of life.</p>
Areas to be progressed	<p>Audit patient outcomes following implementation of the Priorities for Care documentation. Evaluate the effectiveness of the documentation in supporting holistic patient centred care.</p> <p>Complete the review of guidance to reduce inappropriate transfers of patients at the end of life.</p> <p>Undertake a review quiet rooms and facilities for families on the wards.</p>

Work stream 5 – Care after death

Key achievements	<p>Patient Affairs moved to Bath and Wessex House and changed of name to Bereavement Office.</p> <p>Guidance on care after death included within Priorities for Care documentation.</p> <p>Bereavement Feedback Initiative implemented, offering the bereaved family/carer the opportunity to provide feedback on the care provided at the RUH. Feedback shared monthly with ward managers, matrons, appropriate leads and head of patient experience. Themes and learning from feedback use to support training in end of life care.</p> <p>Bereavement booklet reviewed and consultation completed.</p>
Areas to be progressed	<p>Implement new bereavement booklet.</p> <p>Review the Last Offices policy.</p>

Work Stream 6 – Education for end of life care

Key achievements	<p>Closer working with the Education Department to include end of life care as part of the induction programme. End of life care included in the 'Patient at risk' day for registered nurses, Health Care Assistants (HCA) and therapists.</p> <p>Regular study days for the Ambassadors for end of life care, to support mentorship, reflective learning and sharing of best practice.</p> <p>Working in partnership with Dorothy House Education Department to support opportunities for learning for staff across different settings. Provision of</p>
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	<p>Compassion in Care training for HCAs and admin staff.</p> <p>Carer's story and experience of the end of life care provided to her mother at the RUH shared with Trust Board July 2014. Story now used in training and on-going education in end of life care.</p> <p>Promotion of end of life care across the Trust with Dying Matters Awareness week May 2014. Presentation of end of life care service improvement at the RUH at national conference 'Making Connections' Bristol March 2015.</p>
Areas to be progressed	<p>To develop e learning resources to supported ongoing access to information and learning in end of life care.</p> <p>To continue to use patient experience, carer experience and stories to support on-going learning in end of life care.</p>

Work Stream 7 – End of life care strategy

Key achievements	<p>South West Strategic Clinical Network review for One Chance to Get it Right completed.</p> <p>Work plan for 2014/15 aligned to National Strategy for End of Life Care, NICE Quality Standards for End of Life Care and Care Quality Commission (CQC) Essential Standards for Quality and Safety. Learning from the national End of Life Care Audit 2013/14 informed the work plan for 2014/15.</p> <p>RUH representation on Wiltshire CCG End of Life Care Programme Board, BaNES End of Life Care Steering Group and Serona End of Life Care Operational Group.</p>
Areas to be progressed	To develop an end of life care strategy for the RUH.

6. CQUINs

The CQUINs for 2014/15 built on the CQUINs for end of life care in 2013/14 to improve identification of patients and communication in end of life care through 'The Conversation Project' and in enabling patient's families/carers to feedback on their experiences of end of life care support at the RUH, through the 'Feedback Initiative.'

4.1 The Conversation project (CQUIN 6.1)

Indicator

Ensure that 'The Conversation project' continues to be embedded and then sustained on Pulteney, Haygarth, Respiratory, ASU, ACE and Waterhouse. Implement and develop 'The Conversation Project' on 3 other key wards: MAU, Combe and William Budd.

Rational

- Earlier identification of patients approaching the end of life.

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- Ensuring that clinicians have conversations with these patients and their families about the uncertainties of their future.
- Documenting any conversations about the end of life ensuring these are visible to all health and social care professionals involved.
- Ensuring that there is a clear medical plan in the notes, that this is revisited regularly, and that family/carers are involved.
- Relaying all relevant discussions and decisions made to appropriate professionals in any transfer of care.
- Supporting education healthcare staff delivering good end of life care.

Milestones

'The Conversation Project' being undertaken all specified wards and a quarterly update report submitted.

Key achievements

The CQUIN was met. The Conversation Project has continued to support patients nearing the end of life and their families to have the opportunity to talk about their care wishes, their uncertainties and concerns as part of advance care planning (ACP), to help inform care planning. The project has supported earlier identification of patients with end of life care needs within the acute setting. The project also supported communication and information sharing of discussions and decisions made across care settings, to support care of support out of hospital.

The Conversation Project continued to be embedded on 6 wards (Respiratory, ASU, ACE, Haygarth, Pulteney and Waterhouse) and was been implemented on a further 3 wards (MAU, William Budd and Combe). The palliative care team have attended weekly MDT/white board meetings on each ward.

A quarterly report was submitted using data from a monthly audit of patient records. 147 sets of patient records audited between 01/04/14 – 31/03/15. Of the records audited:

- 51% (75) of patients died during admission
- 49% (72) were discharged from hospital. Of these 31% (22) were discharged home, 43% (31) to nursing home, 6% (4) to residential care home, 12% (9) to community hospital, 4% (3) to Dorothy House Hospice and 4% (3) not known.

The audit showed that quality outcomes measures continued to be supported through the Conversation Project, but that there is a need to improve transfer of information on discharge.

	Outcome for Conversation Project standards	milestone
1	Evidence in the MDT records that recovery uncertain, approaching end of life or likely to die in the next few days	99%
2	Evidence of discussion with the patient and or recorded that patient did not have capacity	55% and 45%

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3	Evidence of discussion with the patient's family/carer	98%
4	Clear documented plan in MDT records	96%
5	Ceiling of Treatment form or DNAR completed	96%
6	Evidence of information on advance care planning shared with Primary Care Team for those patients discharged	69%

Areas to be progressed

The palliative care team will continue to support the wards using the Conversation Project, attending white board/MDT meetings to promote identification of patients, advance care planning discussions, recording of conversations in MDT records and communication on advance care planning on transfer of care.

The palliative care team will continue to audit patient records to monitor patient outcomes in end of life care and share learning from the audits to inform practice on the wards.

The palliative care team will continue to promote and share information on the Conversation Project on induction for new staff, ongoing training and educational sessions in end of life care.

4.2 The Bereavement Feedback Initiative (CQUIN 6.2)

Indicator

Ensure that patient carers and families have the opportunity to feedback on their and the patient's palliative care experience, and that this feedback is used to drive improvements.

Rational

To improve patients, carer and family experience of end of life care. Allowing the RUH to capture and learn from both positive and negative feedback, whilst supporting carers and families in addressing and issues around a patient's death in an informal supportive environment.

Milestones

Establish feedback system and contact process protocols and agree this with the commissioners in July Clinical Outcomes and Quality Assurance Group (CO&QA), and agree applicable improvement goals for Quarter 2-4, in July. Go live with feedback mechanisms, and submit quarterly report to CO&QA group on feedback rates, trends and themes. Evidence action plans for identified issues from October.

Key Achievements

The CQUIN was met. A process and guidance for the Bereavement Feedback Initiative was developed and implemented from November 2014. The bereaved family/carer is now offered a letter of condolence and information on

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how to provide feedback when attending the Bereavement Office. Feedback can be given through the RUH website bereavement questionnaire, through Patient Advice and Liaison Service (PALS) or telephone contact with a representative from the palliative care team.

A process was established for collating data from Meridian, returned paper questionnaires and information from telephone contacts. A monthly report with quantitative and qualitative measures from the feedback was developed. There were only 11 responses in total for November 2014 to March 2015. It is recognised that this represents a small sample of those families that were bereaved during this timeframe, however information was shared monthly with ward managers and matrons. A monthly report was produced for the Head of Patient and User Experience and information shared with Quality Board. Learning from the feedback has been used to support ongoing training and service improvement in end of life care.

The feedback is detailed in the following table:

	Outcome for bereaved family/ carer	Milestone
1	Do you feel the needs of your relative or friend were met in the last few days or hours of their life?	83%
2	Were you informed about what was happening to your relative or friend?	83%
3	Were you given the information at an appropriate time?	79%
4	Was the information given to you in a way you could understand?	86%
5	Did you feel involved in the decisions that were made about your relative or friend?	86%
6	Do you feel we supported you before your relative or friend died?	86%
	Did you feel we supported you after your relative or friend died?	75%

Themes from the free text feedback, included:

- Compassion: Compassionate communication with the family by ward staff, respect for family privacy, reassurance that the ward staff cared.
- Dignity: Patient and family treated with great sensitivity and concern. Privacy and dignity when patient moved to a side room.
- Communication: Family felt that there was a lack of communication from senior nursing staff and the medical team.

Overall, the bereaved families felt that their family members received good care at the RUH. Families appreciated that staff were trying to do their best, when they are very busy. Families stated that small things made a big

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difference – kindness, cups of tea, somewhere to stay. Dying in hospital rather than at home was not an issue for this sample.

Areas to be progressed

The Bereavement Feedback Initiative will continue in 2015/16 – through Meridian, postal questionnaire or telephone feedback with representative from the palliative care team. Information on how to provide feedback will be included within the new Trust Bereavement Booklet and on the End of Life Care website pages. If the response rate continues to remain low the process for gaining feedback will be reviewed.

Information from the feedback received will continue to be shared with ward managers and matrons, and will inform on-going learning in end of life care.

Information and guidance for ward managers will be developed on the use of bereavement cards/letters.

7. The National Care of the Dying Audit

The Trust participated in the National Care of the Dying Audit for Hospitals, in 2013/14. This was a retrospective audit completed in July 2013 of 130 sets of medical notes, of patients who had died in May 2013 and a post bereavement audit with bereaved relatives. 131 Trusts participated. The national care of the dying audit site report was published May 2014. The findings from the audit were presented to the End of Life Care Working Group 9th July 2014. An action plan was developed in response to the audit findings and incorporated into the work plan for the End of Life Care Working Group from October 2014. Key performance indicators from the national audit in 2013, identified as requiring improvement are set out in the table below. The table also includes actions taken to support improvement with these key performance indicators.

Standard	Action taken
Clinical Indicators requiring improvement	
Assessment of the spiritual needs of the patient and their nominated relatives or friends	Spiritual needs of patient included in palliative care training. Spiritual needs included in Priorities for Care documentation for the care of the dying patient.
A review of interventions during the dying phase	Included in Priorities for Care documentation for the care of the dying patient.
A review of the patient's nutritional requirements	Included in Priorities for Care documentation for the care of the dying patient.

Standard	Action taken
A review of the patient's hydration requirements	Included in Priorities for Care documentation for the care of the dying patient.
Percentage of patients whose wishes and preferences for their preferred place of death were documented within the last episode of care	Included in Priorities for Care documentation for the care of the dying patient.
Discussions regarding the plan of care for the dying phase held with patients who were capable of participating in such discussions	Included in Priorities for Care documentation for the care of the dying patient. Included in The Conversation Project principles.
Discussions with the patient regarding a plan of care for the dying phase included general treatment options for symptom control	Included in Priorities for Care documentation for the care of the dying patient.
Discussions with the relative/friend or IMCA regarding a plan of care for the dying phase included specific information for the following symptoms Pain Agitation Nausea Noisy breathing Dyspnoea	Included in Priorities for Care documentation for the care of the dying patient.
Discussions regarding the senior doctor's decision about Cardiopulmonary Resuscitation (CPR) were held with the relative/friend or IMCA.	Included in Ceiling of Treatment document. Review of decisions included in Priorities for Care documentation for the care of the dying patient.
Organisational Indicators requiring improvement	
A leaflet explaining the grieving process for relatives and friends	Included within review of bereavement booklet.
A formal process exists within trust clinical or quality governance structure for discussing and reporting on care of the dying (April 2012-31 March 2013)	End of Life Care Working Group reports annually to Trust Management Board, Trust Quality Board and Trust Board.
Formal decision-making process for diagnosing dying	Included in Priorities for Care documentation for the care of the dying patient.
Guidelines for the assessment and delivery of mouth care	Included in Priorities for Care documentation for the care of the dying patient.
Guidelines for referral to pastoral care/chaplaincy team	Included in Priorities for Care documentation for the care of the dying patient.

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Standard	Action taken
Policy for the deactivation of implantable cardioverter defibrillators (ICD's)	Plan in place to develop in 2015/16
Policy for providing relatives/friends regarding the verification and certification of the patient's death	Included within review of bereavement booklet and information provided.

8. Priorities for Care Documentation

Following the Liverpool Care Pathway (LCP) review 'More Care Less Pathway' (2013) there was a national requirement to stop use of the LCP by July 2014. The RUH had not implemented the LCP, but had developed a Trust Integrated Care Pathway for care of the dying patient. In light of the national review, this pathway ceased to be used nationally from July 2014. Recommendations made in the publication of 'One Chance to Get it Right' (2014) and the National Care of the Dying Audit (see section 7) were used to inform the development of Priorities for Care guidance for clinicians at the RUH from July 2014 to January 2015. During this period new RUH Priorities for Care documentation to support the care of the dying patient and their family were developed and piloted on Midford and Combe wards.

Before implementation of the Priorities for Care documentation across the Trust, a baseline audit was completed in November 2014. This retrospective audit of 35 medical records included expected death and excluded sudden or unexpected deaths. Key findings from the baseline audit include:

	Priorities for Care outcomes	milestone	comments
1	Evidence that that clinicians have recognised that a patient is dying.	79%	62% evidence of consultant or specialist registrar decision
2	Evidence that conversations have been had or attempted with patient or evidence that patient is confused or lacks capacity to be involved in conversations	45% and 42%	42% evidence that patient was confused or too unwell to be involved in conversations
3	Evidence that conversations have been had or attempted with family/next of kin	97%	
4	Evidence of clear plan in medical records regarding goals of care including	85%	
5	Evidence of Ceiling of Treatment and Do Not Attempt Resuscitation (DNAR) recorded	100%	

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6	Daily medical review once a decision has been made that patient is dying	79%	25% died within 24 hours
7	Evidence of nursing staff attending to patient comfort	97%	
8	Evidence that patients and family have had opportunity to discuss spiritual needs	17%	If not recorded in MDT record, unable to evidence
9	Evidence that family have been offered practical information about RUH – including car parking, refreshments, staying overnight	37%	If not recorded in MDT record, unable to evidence
10	Evidence of anticipatory prescribing for patient symptom control	91%	77% anxiolytic 91% analgesia 71% anti-secretory 62% anti-emetic
11	Evidence that patients requiring a Continuous Subcutaneous Infusion (CSCI) have appropriate medication prescribed	100%	
12	Evidence that family given written information on bereavement and what to do after a death	57%	48% evidence of who was present at time of death

The audit identified that there continued to be good practice in care of the dying patient, but that there needed to be improvement in recording when a patient has been assessed as being in the last days of life, recording the outcome of conversations with the patient and family, regular review and recording a clear management plan daily or for the weekend, ensuring the spiritual needs of the patient family are reviewed and supported, recording information shared with the family on support available and recording the information provided to the family following a patient death.

In January 2015 the new RUH Priorities for Care documentation was implemented across all the wards. The documentation includes:

- Medical assessment that the patient is in the dying phase
- Comfort Care for the Dying nursing record
- Daily medical review sticker for the medical notes to clearly record individual plan of care for the patient
- Information leaflet for the patient's family on support available

It is hoped that this will support decision making and identification of patients in the last days/hours of life, patient centred care, assessment of physical, psychological, social and spiritual needs, on going review of the patient and

support for the patient's family. A post implementation audit and review will be undertaken August/ September 2015.

9. Ambassadors - a collaborative for end of life care

This palliative care team has continued to support ward 'Ambassadors' to champion communication, compassion and end of life care on the wards. The Ambassadors are supported by the palliative care team with their roles on the wards and have the opportunity to attend study days to promote and share best practice in end of life care. The Ambassadors include registered nurses, health care assistants, an occupational therapist and a physiotherapist.

Ambassador information	
Number of RUH Ambassadors for end of life care	39
Number of wards/units with Ambassadors	23
Ambassador study days 2014/15 – April and October	2

10. Support and education for staff

The palliative care team provide a programme of education in end of life care, which includes sessions on the Trust induction. The team also provides ad hoc learning to staff in end of life care, symptom management, care of the dying during clinical activity on the wards. This educational activity is not recorded. The palliative care team also provide placements and training for medical students Monday afternoons and Friday mornings, during oncology placement.

The following sessions have been provided in the last year:

Session title	Staff group	Number of staff trained
Induction – Patients At Risk End of Life Care session	Registered Nurses (RN) and HCAs	300
Induction – Introduction to care of the dying	HCAs	58
Ambassador study day	RNs and HCAs	38
Syringe driver management ward training adhoc	RNs	62

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Priorities for Care training to support implementation of the new documentation	RNs, Foundation Year (FY) doctors, Senior House Officers (SHO), Core Training (CT) year1, Specialist Registrars (SpR)	72
Palliative rehabilitation, end of life care and role of specialist palliative care	Occupational Therapists and physiotherapists	60
Management of breathlessness	Physiotherapists and RNs	10
Grand Round June 2014	Consultants, SpRs, CT1s, SHOs, FY2s, FY1s	No data available
Junior doctors sessions on palliative care	FY1s, FY2s, SHOs, CT1s, SpRs	23 sessions provided
Student nurse sessions on end of life care x2 sessions/year	1 st year students	30

The Trust training needs analysis data shows that 1273 staff working within the Trust in 2014/15 received end of life care training. 509 of these staff had their last end of life care training episode recorded as being completed on induction. There is currently no mandatory requirement for end of life care training to be updated on a regular basis.

11. Information for the public and staff

An Internet website provides some information for the public around the care of the dying at the RUH. Also a leaflet is available for families to answer some of their concerns and questions about end of life care at the RUH.

An internal intranet site for palliative and end of life care provides information and guidance for staff at the RUH, on all aspects of palliative and end of life care. All these resources have been reviewed and updated in the last year.

12. Partnership working with Dorothy House Hospice

Dorothy House continues to support the RUH with consultant in palliative medicine sessions. Over the last year these have been 5 sessions/week. The hospice medical team representative supports the specialist palliative care Multi-disciplinary Team (MDT) meetings with the RUH palliative care team, supports assessments and reviews of patients with complex needs, provides on-going training and learning for medical students and junior doctors.

In this last year Dorothy House supported the RUH palliative care team with a palliative care physiotherapist (0.2wte) and occupational therapist (0.2wte) on

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