Report to:	Public Board of Directors	Agenda item:	15
Date of Meeting:	1 September 2021		

Title of Report:	Annual Palliative Care and End of Life Report 2020/21
Status:	For approval
Board Sponsor:	Antonia Lynch, Chief Nurse
Author:	Helen Meehan, Lead Nurse Palliative and End of Life
Appendices	Appendix 1: Palliative and End of Life Care Annual Report, Palliative and End of Life Care Summary slides

1. Executive Summary of the Report

Caring for people nearing the end of life is one of the most important things we do in hospital. In 2020/21, the RUH supported 1251 patients that died. This includes all deaths. This report gives an overview of the palliative and end of life care steering group, the work plan for 2020/21 and how this has supported local and national priorities for palliative and end of life care over the last year:

- Palliative and End of Life Care Steering Group
- Palliative and End of Life Care Strategy
- Care Quality Commission and NHS England and Improvement Quality Visit
- Specialist Palliative Care (SPC) Team
  - Aims of the service
  - Operational Policy and team members
  - Business continuity during COVID pandemic
  - Clinical activity
  - SPC team 7/7 working
  - Consultant in palliative medicine support
  - Business case to support 7/7 working
  - Non Medical Prescribing
  - Lead nurse palliative and end of life care
  - Innovative team of the year
- Palliative and End of Life Care Work Plan
- NICE guidance NG31
- National audit of care at the end of life NACEL) for hospitals
- End of life care monitoring
- Care after death
  - Bereavement and Medical Examiner Office
  - Butterfly Bereavement Support service
  - Bereavement feedback
- Future developments and Assurance

Appendices include more detailed information on:

- Palliative and EOLC Steering Group Terms of Reference
- Quality improvement initiatives:
  - Conversation Project and CHAT Bundle

- Priorities for Care in the last days of life
  - Tissue Alliance
- Compassionate Companion Service
- Memory Boxes
- Palliative care training programme 2020/21

The Palliative and EOLC steering group will oversee a work plan for 2021/22 taking forward the areas to be progressed from this last year, learning from audits and feedback to drive forward further ongoing quality improvement in palliative and EOLC.

2.	Recommendations (Note, Approve, Discuss)
The Board of Directors is asked to approve the report.	

3.	Legal / Regulatory Implications
Nil	

4.	Risk (Threats or opportunities, link to a risk on the Risk Register, Board Assurance Framework etc.)
Maintaining SPC team 7/7 working	

5.	Resources Implications (Financial / staffing)
To sustain specialist palliative care team 7/7 working from 31/12/21, to meet NICE and CQC guidelines, investment will be required to support 2 wte substantive clinical nurse specialist posts	

6.	Equality and Diversity
Person centred care is integral to the palliative and end of life care strategy.	

7.	References to previous reports
RUH palliative and end of life care strategy.	

8.	Freedom of Information
This is a public document.	

Annual Palliative and End of Life Report

2020-21

Chairman, Alison Ryan
Chief Executive, Cara Charles-Barks

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1. Executive Summary

1.1 This report gives an overview of palliative and end of life care quality improvement work at the RUH that supported the local and national priorities, over the last 12 months.

1.2 The palliative and end of life care working group has continued to meet quarterly and oversee the annual work plan.

1.3 The SPC team had 1143 referrals. There has been a 42% increase in referrals over the last 5 years. Substantive funding for 7/7 working is still to be approved.

1.4 The palliative and end of life care work plan for 2020/21 aligns to the Trust values and goals within the strategy. Progress has been made on all 8 work streams. Quality improvement initiatives continue and includes the Conversation Project CHAT Bundle, Priorities for Care Bundle for care of the dying patient, Tissue Alliance project and implementation of Memory Boxes. Essential training compliance is at 87.4% (target 90%).

1.5 The RUH policy for care of the dying patient and care of the deceased patient aligns to NICE Guidance NG31. Palliative and end of life care guidance was developed to support person centred care during COVID-19 pandemic.

1.6 There has been an improvement in the recognition of expected deaths with clinical coding, enabled by the implementation of an electronic advance care planning template on Millennium from July 2020.

1.7 The bereavement and medical examiner office has been established as part of the national changes to assurance with medical certification of cause of death.

1.8 A bereavement butterfly service to provide compassionate telephone support has been set up during the COVID-19 pandemic to support bereaved families.

1.9 Future developments will include:

- Developing ‘gold’ end of life care quality standards for the ward ExCEL ward accreditation programme
- To work in partnership with Dorothy House Hospice Care to roll out the Compassionate Companion Service across all the wards
- To actively support the BaNES, Swindon and Wiltshire (BSW) Integrated Care System’s End of Life Alliance to promote and enable an integrated approach to palliative and EOLC.
- Progressing the business case for specialist palliative care

2. Introduction

Caring for people nearing the end of life is one of the most important things we do in hospital. In 2020/21, the Trust supported 1251 patients who died in hospital. This figure includes all deaths. This report gives an overview of the palliative and end of life care steering group, the work plan for 2020/21 and how this has supported local and national priorities.

3. Palliative and End of Life Care (EOLC) Steering Group

The RUH palliative and EOLC steering group meets quarterly. The objectives of the steering group include agreeing an annual work plan for EOLC and in 2020/21 the work streams aligned to the RUH Palliative and EOLC Strategy (2018-23) and national framework Ambitions for Palliative and EOLC (2015) - see appendix 1 – Terms of Reference.

4. Palliative and EOLC Strategy

The RUH palliative and EOLC Strategy was approved at Trust Board in December 2018 and continues to define the values and goals for supporting best practice over the last year.

To ensure that we provide the highest quality palliative and end of life care to our patients and their families, delivered by outstanding staff who live by our trust values.

5. Care Quality Commission (CQC), and NHS England and Improvement Quality Visit

EOLC was rated as 'outstanding' by the CQC in 2016. A CQC Core service meeting was completed 06/03/19 with continued positive feedback.

NHS England and Improvement EOLC Leads completed a quality visit 03/09/19. Sherree Fagge, Head of Nursing for End of Life Care and Professor Bee Wee, National Clinical Director for End of Life care, were impressed with the provision of compassionate end of life care.

There has been no review of end of life care in 2020/21.

6. Specialist Palliative Care Team (SPC)

5.1 Aims of SPC team

The aim of the SPC team is to promote the best achievable quality of life for adult patients and their families facing cancer and other life-threatening illness that are not responsive to curative treatment. This may be offered at any point in the palliative care trajectory from maximising potential for rehabilitation to supporting in the dying process. The SPC team reviews and supports patients with complex palliative care needs and provides advisory support to clinical teams for patients with palliative and end of life care needs.

5.2. Operational policy and SPC team members

The SPC team has an operational policy which was reviewed for 2020/21. The service supports a SPC multi-disciplinary team (MDT) meeting weekly.
SPC team operates 08.30-16.30, 7 days per week. Out of Hours clinical advice is provided through the Dorothy House Hospice 24/7 advice line.

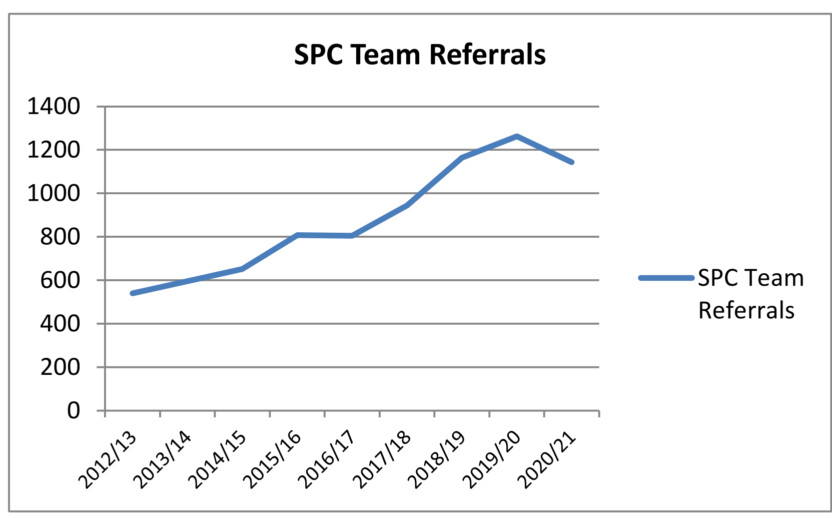
5.3 Business Continuity during COVID pandemic

During the COVID-19 pandemic, the SPC maintained business continuity and support across the Trust. This included supporting patients across three sites including RUH, Bath Clinic and Circle Bath. This added additional pressures to the team. During May, the team operated with x2 clinical nurse specialists on duty each weekend to ensure patients at the RUH and Circle Bath were reviewed appropriately.

5.4. Clinical activity

In 2020/21, the SPC team had 1143 patient referrals (1263 referrals in 2019/20). During the last year there were significant changes to hospital flow in response to the COVID-19 pandemic in wave 1, which impacted on the number of referrals to the team in April to June.

The referrals still represent a **42% increase in the last 5 years and 89% increase in the last 8 years.**



Graph 1 – Specialist Palliative Care Team referrals 2020/21

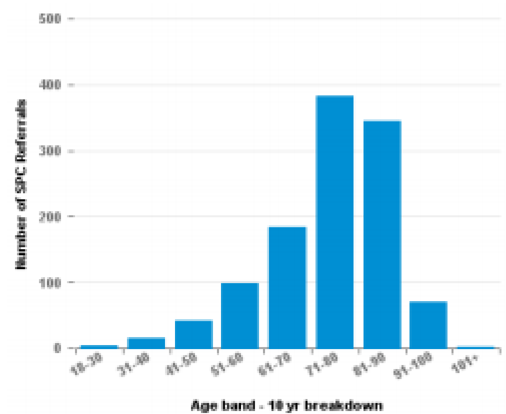
Of the 1143 patient referrals to SPC team, 38% died during their admission and 62% were supported with discharge to preferred place of care.

Day of Discharge/Death	Died		Discharged	
Monday	54	37.0%	92	63.0%
Tuesday	82	41.6%	115	58.4%
Wednesday	58	29.9%	136	70.1%
Thursday	63	32.0%	134	68.0%
Friday	56	27.3%	149	72.7%
Saturday	57	52.8%	51	47.2%
Sunday	62	63.9%	35	36.1%

Day of Discharge/Death	Died		Discharged	
Weekday	313	33.3%	626	66.7%
Weekend	119	58.0%	86	42.0%

Table 1 – percentage of deaths and discharges by week day in 2020/21

There has been an increase in complexity of patient need and an increase in support for patients with a non-malignant condition and frailty. In the last year 32% of patients referred had a non-malignant diagnosis.



Graph 2 – age range of patient referrals to SPC in 2020/21

5.5 SPC 7/7 working

The team has provided a 7 day service since November 2018. Increasing Clinical Nurse Specialist (CNS) capacity in the team to support 7/7 working was initially funded with a 2 year Macmillan Cancer Support grant. The 7 day service supports:

- Timely SPC patient reviews for symptom management
- Timely access to advice and support for staff working weekends and bank holidays
- Improved flow and timely discharge to preferred place of care for patients with complex needs

Continuation of the SPC team 7 day working requires investment for 2 wte CNS posts, enabling the team to operate with 5wte substantive CNSs. National Audit for Care at the End of Life (NACEL) benchmarking data from 2019/20 indicates that the SPC team should have 5.75 wte CNS posts.

5.6 Consultant in palliative medicine support

The team has 5 consultant PAs provided through the Dorothy House Hospice Care medical team. The hospice medical team also supports an on call rota which provides 24/7 telephone advice for out of hours to clinicians at the RUH. During the COVID-19 pandemic, consultant support was predominantly provided by one consultant with 1 PA each day Monday to Friday.

National Audit for Care at the End of Life (NACEL) benchmarking data from 2019/20 indicates that the SPC team should have 13 PAs of consultant in palliative medicine for 500 beds.

5.7 SPC business case 2020/21

The business case includes funding for 2wte CNS substantive posts at band 7 and an additional 5PAs consultant palliative medicine. Approval decision is still to be made at 31/03/21. Provision of 7/7 working is on the Trust risk register.

5.8. Non-medical Prescribing (NMP)

The SPC team has x1 CNS NMP and is supporting x1 CNS to complete the NMP course from January to July 2021. The SPC team can support a minimum of 1 CNS per year to complete the NMP course.

5.9. Lead nurse palliative and end of life care

The lead nurse palliative and end of life care manages the SPC team and is strategic lead on end of life care for the Trust.

The lead nurse leads on the palliative and end of life care work plan for the RUH and reports on progress quarterly to the RUH palliative and end of life care working group.

5.10. RUH Innovative Team of the Year

The SPC was awarded Innovative Team of the Year for 2020 for the quality improvement work supported by the team.

6. Palliative and EOLC Work Plan

In 2020/21 the work plan aligned to the ‘foundations’ as set out in the national framework Ambitions for Palliative and End of Life Care (2015). The work plan is reviewed at every palliative and end of life care working group meeting – see summary of work plan outcomes page 7 to 10.

Trust Value - Working Together

EOLC strategy goal - Our staff are supported to provide outstanding EOLC

Enabler - Personalised care planning

Key achievements	Developed and implemented the COVID-19 palliative and EOLC guidance to support communication and advance care planning across all wards, ICUs and ED. Developed and implemented COVID-19 palliative and EOLC guidance in symptom management for patients with COVID-19. Spiritual Care Centre (SCC) resources developed to support person centred care during COVID-19. SCC intranet resource set up for Ramadan. Continued support for use of the CHAT Bundle and Priorities for Care Bundle, with SPC team supporting wards with EOLC quality standards, as part of the ExCEL silver accreditation programme (see appendix 2). Priorities for Care Individualised Care Plan for care in the last days of life reviewed and updated (see appendix 2). Conversation Project films and an audio resource completed and added to the trust intranet and website resource to support learning in advance care planning.
Areas to be progressed	Support the silver ExCEL accreditation quality standards for EOLC across all wards and develop gold quality standards. Support the paperless inpatient record project to ensure palliative and EOLC records continue to support effective person centred care.

Enabler - Shared records

Key achievements	Community Treatment Escalation Plans used for discharge planning. Engagement with BSW Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) working group. Planning for implementation 2021/22. Implemented Conversation Project Advance Care Planning (ACP) PowerForm on Millennium to record outcome of ACP discussions. The ACP PowerForm populates the Depart Discharge Summary.
Areas to be progressed	Continue to engage with BSW EOLC Alliance and local stakeholders to work towards an integrated approach to support information sharing in relation EOLC and adoption of national ReSPECT form. Continue to promote and embed the ACP PowerForm to support recording of ACP discussions and recommendations. Develop ACP dataset to monitor patient outcomes in preferred place of care.

Trust Value - Everyone Matters

EOLC strategy goal - We will listen and we will provide patient centred, compassionate end of life care

Enabler – Involving, supporting and caring for those important to the dying person	
Key achievements	Memory Boxes implemented to support creating memories and keepsakes for patients and families (see appendix 4). Visiting arrangements reviewed regularly. Care at End of Life (COVID 19) leaflet developed. Visiting supported on compassionate grounds in all areas. Keeping In Touch Service established and supported through Patient Advice and Liaison Service (PALS) team for COVID-19. Trust iPhones issued to every ward, ICUs and ED to support virtual visiting using WhatsApp video calls. Guidance developed and shared with. Patient and Carer Experience Team created a short film to support compassionate and respectful packing of deceased patient's property. Butterfly Bereavement Support Service established with volunteers from the Spiritual Care Centre.
Areas to be progressed	Continue to review visiting arrangements for patients with EOLC needs. Ensure sustainability of the Memory Boxes to support family centred care. Ensure sustainability of the Butterfly Bereavement Support Service.

EOLC strategy goal - We will work with our partners to enable coordinated, responsive end of life care

Enabler – Co-design to support innovation and quality improvement	
Key achievements	Discharge to Access pathways agreed and implemented. Compassionate Companion Service (CCS) suspended in March due to COVID visiting restrictions. Guidance developed to support safe reintroduction of the CCS in October 2020 and March 2021 (see appendix 3). Tissue Alliance Project group developed new 'Care after death checklist' and information flowchart for medical and nursing staff. Resources piloted in ICU. RUH Bereavement Feedback questionnaire suspended in March due to COVID-19. Bereavement feedback questionnaire reviewed and now available on RUH website and in the RUH bereavement booklet. ACP films for community completed and added to RUH ACP website resource.
Areas to be progressed	Roll out the Compassionate Companion Service to support dignified and compassionate care in the last days of life to all wards. Tissue Alliance Project to extend to ED and wards over the next year.

Trust Value - Making a Difference

EOLC strategy goal - Quality improvement will be integral to all that we do

Enabler – 24/7 accessible services	
Key achievements	7/7 working model for SPC team continued throughout last year. Substantive funding still to be approved. SPC team provided support across 3 sites during wave 1 of the COVID-19 pandemic.
Areas to be progressed	Business proposal for substantive Clinical Nurse Specialist posts to support continuation of 7 day working to be approved. Benchmarking against the National Audit for Care at the End of Life (NACEL) indicates requirement for additional consultant in palliative medicine sessions. Business case for additional 5 PAs to be progressed.

Enabler – Evidence and information, improved data quality and information capture	
Key achievements	EOLC dataset reported to palliative and EOLC steering group (see appendix 6). National Audit of Care at the End of Life (NACEL) action plan developed and completed with learning from NACEL audit 2019/20. Priorities for Care audit completed (see appendix 3). Syringe driver audit completed and informed review of the syringe driver policy. The Lead for Patient and Carer Experience and the End of Life Lead Nurse presented information on Patient and Carer Experience in EOLC for the national webinar for Experience of Care Week in May, sharing the See It My Way film 'living with the loss of a loved one. Learning from incidents, complaints and feedback shared at the quarterly palliative and end of life steering group meetings. Academic Library produced monthly EOLC Bulletin.
Areas to be progressed	Disseminate findings from audits and ensure learning informs ongoing quality improvement. Support completion of NACEL in 2021/22. Develop an ACP dataset to monitor outcomes from ACP discussions, including recording of patient preferences and wishes for EOLC. Patient and carer experience team to develop a quarterly themed report on complaints, compliments, PALS and bereavement feedback.

EOLC strategy goal - We will strive to learn and develop, to sustain best practice in end of life care

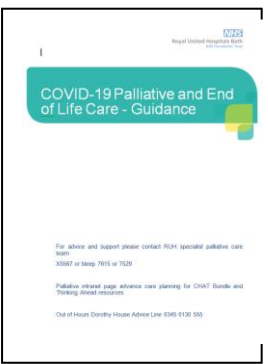
Enabler – Education and training	
Key achievements	End of life care 'essential training' compliance at 87.4% at end of March. Medical division 91.5%, surgical division 95.3%, therapies 91.3%, Women & Children's 90.3%, Bank 70.5% RUH eLearning EOLC module reviewed. Tea trolley training sessions developed for Care in the Last Days of Life, Mouth Care, CHAT Bundle. SPC supported ward staff with tea trolley training sessions. >150 staff trained in DICU as part of COVID preparation, staff trained in MAU, RAU, Midford, SSSU and Waterhouse. Virtual training sessions supported for ED and MAU staff, GPSTs and GPs in April and May on communication, compassionate conversations and symptom management during COVID. Nursing and medical grand round sessions provided for palliative and EOLC. Butterfly Ambassador Badge and guidance for best practice aligned to Priorities for Care Bundle, launched in Dying Matters Awareness Week. Ambassador group set up on Workplace to promote peer support and shared learning. Registered Nurse ambassadors offered placement day with SPC team.
Areas to be progressed	To continue to support 'Tea Trolley' training on the wards to support access to learning in aspects of palliative and EOLC on the wards. Continue to support compliance with 90% essential training compliance.

Enabler – Leadership to promote best practice	
Key achievements	RUH lead nurse palliative and EOLC chairs the south west hospital palliative leads forum to share and promote best practice. During COVID pandemic information has been shared to support guidance for hospital trusts. South West Palliative and EOLC network meetings attended and information shared on palliative COVID communication resource, CHAT Bundle and ACP films resource, palliative COVID visiting guidance and virtual visiting guidance, SPC business continuity plans. Dying Matters Awareness Week May 2020 supported: • Memory Boxes implemented • Butterfly Ambassador Badge launched • Chaplaincy Team also supported Time of Reflection service • Press release supported by communications team and information shared in local news publications. Lead nurse supported development of national guide 'getting to outstanding; with Sherree Fagge and Prof Bee Wee and small working group of hospital leads.
Areas to be progressed	Support the BSW EOLC Alliance, Vision and working groups to support an integrated model for palliative and EOLC.

7. NICE Guideline NG31 Care of the Dying Adult in the Last Days of Life

Care of the Dying and Deceased Patient Policy 711 supports guidance set out in NICE NG3 in 2019.

COVID-19 palliative and End of Life Care guidance was developed to support compassionate and person centred care during the COVID-19 pandemic. The guidance includes advance care planning and communication, symptom management, care of the dying patient and care after death.


NHS
Royal United Hospitals Bath

COVID-19 Palliative and End of Life Care - Guidance

For advice and support please contact RUH specialist palliative care team

X5567 or bleep 7015 or 7529

Palliative intranet page advance care planning for CHAT Bundle and Thinking Ahead resources

Out of Hours Dorothy House Advice Line 0345 0130 555

8. National Audit of Care at the End of Life (NACEL)

The NHS Benchmarking NACEL audit was suspended in 2020/21 due to the COVID Pandemic.

A NACEL action plan was developed 2020/21 to support ongoing improvement in response to the audit findings. The action plan included:

- The SPC team will continue to support the ward teams with embedding the Priorities for Care Bundle and Priorities for Care documentation.
- Standards for Priorities for Care are part of ward silver accreditation.
- The SPC team will continue to support Tea Trolley training for Priorities for Care in the last days of life with ward teams.
- The SPC team will launch the 'Butterfly Ambassador Badge' in 2020/21 to identify ward Ambassadors for EOLC to promote and support best practice on the wards.
- The SPC team will work with Bereavement and Medical Examiner Office in 2020/21 to support administration of the NACEL bereaved carer feedback quality audit.
- The SPC team will work with the divisional leads to seek opportunities for investment to support substantive 7 day working and increased consultant in palliative medicine sessions.

9. End of Life Care monitoring

The business intelligence unit (BIU) provides an EOLC dataset for the palliative and end of life care steering group. The dataset uses the Z515 (reviewed by SPC) and Z51.8 (supported with care at the end of life) clinical codes. The dataset includes:

- Patient admissions, discharges and deaths
- Patients admission, discharge and death trends across wards
- Patients admission, discharge and death trends by day of the week
- Patient admission, discharge and death trends for malignant and non-malignant conditions
- Length of stay
- Readmission within 30 days of discharge and the patient died

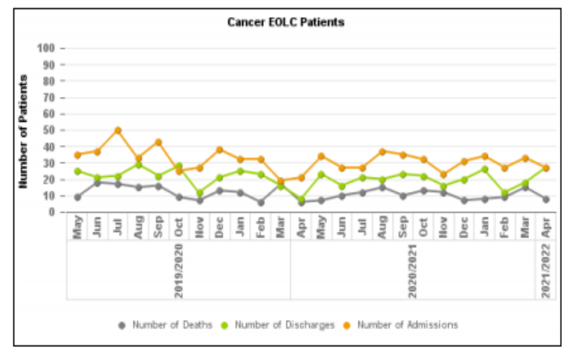
The dataset is reviewed at each working group meeting.

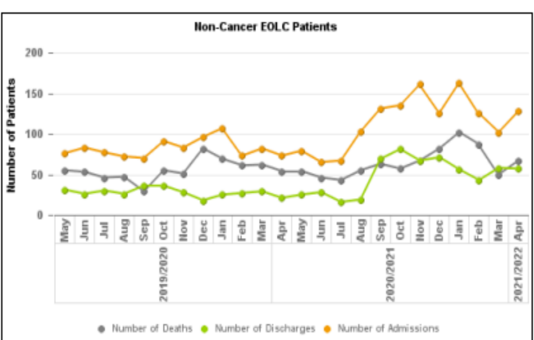
Data up until: 30/04/2021 2 month gap due to coding lag. Admissions will only appear once discharged & coded, resulting in longer lag & a drop in the latest month.

	2019/2020											Total
	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	
Deaths*	64	71	63	62	45	64	58	95	81	67	79	749
Discharges*	56	47	52	55	58	64	40	39	50	50	45	556
Admissions*	111	120	127	105	113	116	110	134	139	105	101	1,281
All In-Hospital Deaths	101	135	100	108	95	110	114	154	144	121	139	1,321
EOLC Deaths/All Deaths (%)	63.4	52.6	63.0	57.4	47.4	58.2	50.9	61.7	56.3	55.4	56.8	56.7

	2020/2021												Total
	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec	Jan	Feb	Mar	
Deaths*	60	61	56	55	70	73	70	79	89	110	96	65	884
Discharges*	29	48	44	37	39	92	103	83	91	82	55	76	779
Admissions*	94	113	92	94	140	166	167	184	157	197	152	135	1,691
All In-Hospital Deaths	94	90	82	76	92	93	98	124	132	158	119	93	1,251
EOLC Deaths/All Deaths (%)	63.8	67.8	68.3	72.4	76.1	78.5	71.4	63.7	67.4	69.6	80.7	69.9	70.7

Table 2 - number of patient admissions, discharges and deaths for clinical code Z515 (reviewed by palliative care) and Z51.8 (supported with care at the end of life)





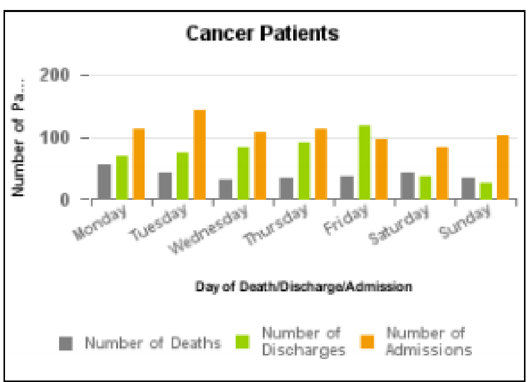
Graph 3 - the number of patient admissions, discharges and deaths for clinical code Z515 and Z51.8 by diagnosis (cancer or non-cancer)

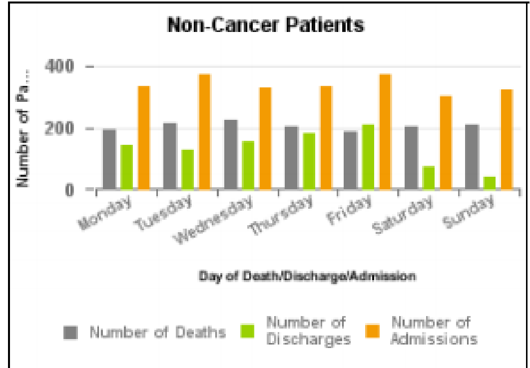
In July 2020 a new advance care planning (ACP) PowerForm was implemented and piloted with the care of the elderly wards to improve recording of patient wishes and preferences. A consequence of implementing the ACP PowerForm has been improved clinical coding of patients with end of life care needs.

From August 2020 the dataset shows an increase in the following due to improved clinical coding:

- Increase in admissions
- Increase in discharges
- Increase in patients dying with an expected death – 70.7% of patients, compared to 56.7% in 2019/20

In the last year there were 1251 patient deaths (70 less than 2019/20), but of these 270 patients died from COVID-19. The majority of these patients died between November 2020 and January 2021. Waterhouse ward cared for 75 patients and Parry ward cared for 54 patients that died from COVID-19.





Graph 4 – number of patient admissions, discharges and deaths for clinical code Z515 and Z51.8 by day of the week

The graphs identify a drop in discharges for patients with end of life care needs at the weekend. There is no significant increase in deaths over the weekend period. There is an increase in admissions on a Monday and Tuesday for patients with a cancer diagnosis.

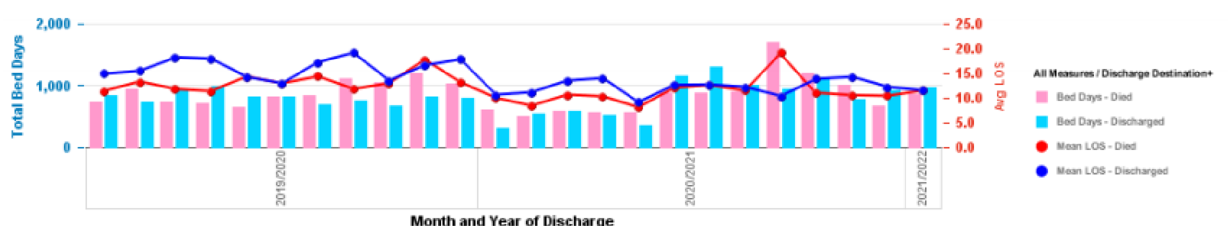


Table 3 Patient length of stay for clinical codes Z515 and Z51.8

The data indicates a reduction in length of stay over the last 2 years.

10. Care After Death

10.1 Bereavement and Medical Examiner Office

The bereavement and medical examiner office was established in April 2020, with the appointment of Medical Examiners, Lead Medical Examiner Officer and medical examiner officers. The functions of the Medical Examiner include:

- Supporting qualified attending practitioners (QAP) with the completion of Medical Certificates for the Cause of Death (MCCD) and cremation forms (part 4) thereby improving the quality of death certification
- Contacting the deceased's next of kin to explain what is written on the MCCD and answer questions in relation to the sequence of events that happened in the last days/hours of the deceased's life
- Seeking out any potential problems with the quality or safety of a patient's care through scrutiny of the patient's medical records, interaction with the QAP or the patient's next of kin and report any concerns through to the Trust's Mortality Review process.

10.2 Butterfly Bereavement Support (BBS) Service

The BBS service was set up during the COVID-19 pandemic with volunteers from the Spiritual Care Team. The BBS service provides compassionate telephone contact with the deceased patient's next of kin, within 1 week of death. The service was initially set up to support those that may be isolating or have limited family support during the pandemic.

A small working group supported the implementation of BBS service and now oversees continuation and sustainability.

10.3 Bereavement Feedback

The RUH Bereavement Feedback questionnaire was suspended over the last year. The Bereavement Feedback process has been reviewed with the Patient and Carer Experience Team in light of the One Survey One Voice evaluation. The new RUH Bereavement Feedback questionnaire will be included within the RUH Bereavement Booklet and an online version can be accessed on the Trust website.

11. Future Developments and Assurance

The Palliative and EOLC steering group will oversee a work plan for 2021/22 taking forward the identified areas to be progressed from this last year, learning from audits and feedback, and to drive forward further ongoing quality improvement in palliative and EOLC.

Representatives from the Palliative and EOLC steering group will continue to support partnership working, shared learning and quality outcomes for care across settings for patients with EOLC needs.

The SPC team will continue to embed the Conversation Project CHAT Bundle and Priorities for Care Bundle to support timely, coordinated and compassionate end of life care. This will include evaluation of wards

completing silver ExCEL accreditation standards. The work plan for 2021/22 will include development of ‘gold’ quality standards for EOLC.

The SPC team will continue to seek substantive funding for continuation of 7 day working to support timely symptom management, discharge planning to preferred place of care and reduced length of stay for patients with palliative and end of life care needs.

The SPC team will progress the business case to enable funding for an additional consultant in palliative medicine sessions to support appropriate consultant level support in line with national recommendations.

The SPC team will work in partnership with Dorothy House Hospice Care to roll out the Compassionate Companion Service across all the wards over the next year and seek opportunities for ongoing investment.

The SPC will seek opportunities to work in partnership with Dorothy House Hospice Care and partner organisations to develop services and promote best practice and support continuity of care for patients with EOLC needs and their families.

The palliative and EOLC steering group will actively support the BaNES, Swindon and Wiltshire (BSW) Integrated Care System’s newly formed End of Life Alliance to promote and enable an integrated approach to palliative and EOLC.

Appendix 1

Palliative and End of Life Care Steering Group

Terms of Reference

1. Constitution

1.1 The RUH Management Board has authorised the establishment of this steering group to oversee the delegated responsibilities outlined in these terms of reference. The group is made up of knowledgeable, experienced professionals with the ability to implement and sustain sound clinical and strategy developments in end of life care.

2. Terms of Reference

a. Purpose

- To promote a compassionate approach to palliative and end of life care, that ensures respect for, and dignity of the patient and their family/ carers, through the delivery of high quality, timely, effective individualised care.
- To direct and monitor the implementation of national and local policy with regard to palliative and end of life care within the RUH Trust.
- To ensure the RUH Trust complies with CQC regulation in relation to end of life care in relation to the 5 domains: safe, effective, caring, responsive and well-led.
- To oversee implementation of the RUH palliative and end of life care strategy.
- To ensure that end of life care is incorporated into the daily work of the RUH and that all employees acknowledge its importance as a part of their work.
- To identify opportunities to develop and work in innovative and collaborative ways to support ongoing quality improvement in palliative and end of life care.
- To identify opportunities to work collaboratively with our community partners to support coordination of care across organisational boundaries.

b. Objectives

- To agree the work plan for palliative and end of life care in line with the RUH palliative and end of life care strategy.
- To oversee and monitor progress of the RUH palliative and end of life care work plan.
- To review and monitor compliance against National and Local targets, and regulatory standards.

- To oversee and approve policies and guidelines relating to palliative and end of life care.
- To oversee plans to ensure that all staff involved in palliative and end of life care have access to relevant training and monitor compliance with essential training for end of life care.
- To ensure all complaint and adverse events themes relating to palliative and end of life care are reviewed and that appropriate changes are implemented.
- To ensure themes from the Patient and family feedback, including Bereavement Feedback are reviewed and appropriate changes are implemented.
- To make a contribution and influence across boundaries commitment to respond to national developments and guidance for palliative and end of life care.

3. Membership

3.1 The Palliative and end of life care working group membership will include:

- Executive Director Lead (Chair)
- Non Executive Director lead for end of life care
- Consultant in Palliative Medicine RUH and Dorothy House (Vice Chair)
- Lead nurse palliative and end of life care
- Palliative clinical nurse specialist
- Lead for Patient and Carer Experience
- Senior chaplain / Chaplain
- Patient /family representative
- Matron
- Medical consultant
- Ward manager
- Senior children's nurse
- Bereavement midwife
- Senior representative from therapies
- Ward Ambassador for EOLC
- Dementia coordinator
- Specialist nurse Long Term Conditions
- Discharge liaison nurse/continuing health care
- Representative from bereavement and medical examiner office
- Representative from Forever Friends memory and legacy officer
- Business Analyst
- Representative from commissioning/BSW
- Representative from Dorothy House Hospice Care
- Representative from VirginCare
- Representative from WH&C Community
- Representative from Somerset/Mendip Community
- Representative tissue services

a. Executive lead

The Executive Director is responsible for providing Board Level Leadership for End of Life Care. They will ensure that there are Trust wide policies, processes and structures to support the delivery of assurance regarding the quality of care. The Director also chairs the Palliative and End of Life Care Working Group.

b. Non Executive director

The Non Executive Director is supporting the development and on-going effectiveness of end of life care and that there is regular reporting to the Board of Directors.

c. Quorum

Business will only be conducted if the meeting is quorate. The palliative and end of life care working group will be quorate with 50% RUH members, including either the Chair or Vice Chair and a palliative care representative.

d. Attendance by Members

Members are expected to attend 75% of the meetings and to send a deputy if unable to attend the meeting.

e. Attendance by Officers

Other members of staff may be invited to attend the meeting, if appropriate.

4. Accountability and Reporting Arrangements

4.1 The palliative and end of life care working group will be accountable to the Management Board. Group members will be invited to declare any issues arising in the meeting that might conflict with the business of the Trust.

4.2 The palliative and end of life care working group will report to the Operational Governance Committee via the inter-committee reporting template on a six monthly (specify) basis.

5. Frequency

5.1 Meetings will be held quarterly. These may be virtual meetings.

6. Authority

6.1 The palliative and end of life care working group is authorised by the Board to investigate any activity within its terms of Reference

6.2 The Board will retain responsibility for all aspects of internal control, supported by the work of the palliative and end of life care working group, satisfying itself that appropriate processes are in place to provide the required assurance.

7. Monitoring Effectiveness

7.1 The palliative and end of life care working group will establish a work programme which:

- Reflects its accountabilities and responsibilities.
- Reflects risks arising from the organisation-wide risk register.
- Review the work plan in line with the end of life care strategy and national directives.

7.2 The palliative and end of life care working group will produce an annual report in line with best practice, which sets out how the working group has met its Terms of Reference during the preceding year.

8. Other Matters

8.1 The servicing, administrative and appropriate support to the palliative and end of life care working group will be undertaken by the lead nurse palliative and end of life, who will record minutes of the meeting. The planning of the meetings is the responsibility of the lead nurse palliative care and end of life.

9. Review

9.1 The palliative and end of life care working group will review its Terms of Reference and work programme on an annual basis as a minimum.

Appendix 2

Quality Improvement Initiatives

1. Conversation Project

The SPC team continues to support wards with using the principles of the Conversation Project and the CHAT Bundle in 2020/21:

- **Earlier recognition** of end of life or recovery uncertain for patients in acute hospital setting
- **Improving communication** and advance care planning (ACP) for these patients and their families
- **Improving documentation** of conversations related to end of life care to inform management plans
- **Improve sharing of information** related to advance care planning on transfer and discharge of these patients.

1.1 CHAT Bundle

The CHAT Bundle is included in the end of life care quality standards for the ward ExCEL accreditation programme. The SPC team supports the ward teams with using the CHAT Bundle.

CHAT Bundle

Consider

Consider whether the patient has an uncertain prognosis or is nearing end of life?

Consider:

- Rockwood Frailty Assessment
- SPICT - Supportive and Palliative Care Indicator Tool
- The 'surprise question'
- The patient's narrative
- Information from the family/carer
- Discuss at white board / MDT meetings
- Conversation Project magnet on the white board to identify patients

Have

Have conversations with the patient & their family to support Advance Care Planning (ACP):

- Think about the environment and your approach
- Check their understanding
- Acknowledge uncertainty of recovery
- Have honest conversations
- Listen compassionately to concerns, wishes and preferences
- Include discussion of TEP
- Offer 'Planning ahead' leaflet

Advise

Advise the MDT following ACP conversations:

- Share information on the patient's wishes & preferences
- Complete TEP
- Include information from ACP discussions in the plan of care
- Document ACP conversations in the MDT records - reverse of TEP and Millennium 'Conversation Project ACP template'

Transfer

Transfer information to support continuity of care:

- Offer use of 'Planning Ahead' leaflet to the patient and family
- Consider community TEP or share information on TEP decisions
- Include 'discussions had and decisions made' in the discharge summary
- Communicate with GP, DN or care home by phone

For information on the Conversation Project:

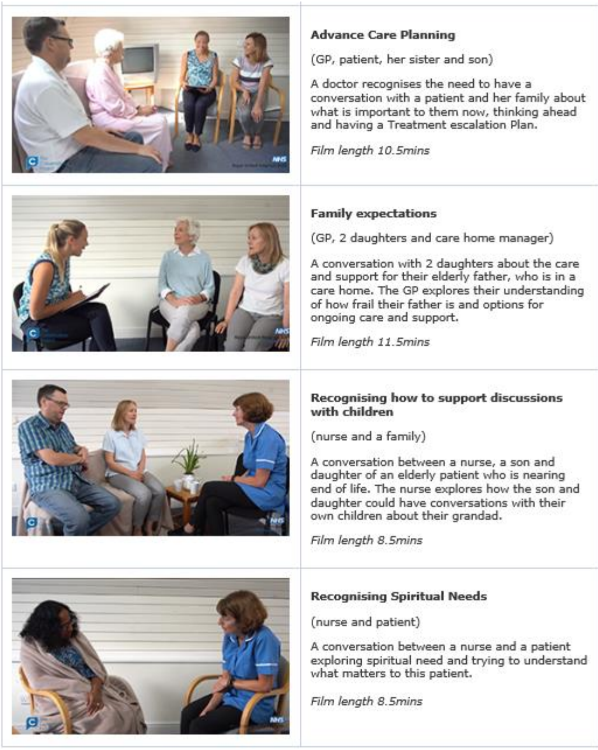
- Open the intranet and click 'P' for Palliative or 'E' for End of Life Care
- Contact the Palliative Care Team on ext 5567

Rachel Davis and Helen Meehan

Conversation Project Bundle v1, February 2018

1.2 Conversation Project resources

The SPC reviewed and updated the Conversation Project intranet and website resource. 3 new ACP films and an audio resource were added in 2020/21: https://www.ruh.nhs.uk/For_Clinicians/departments_ruh/Palliative_Care/advance_care_planning/index.asp

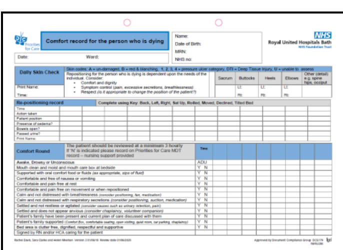


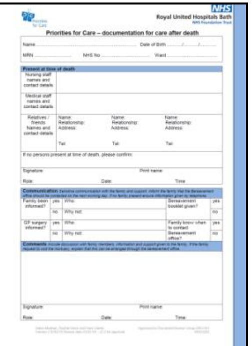
2. Priorities for Care in the Last Days of Life

2.1 Priorities for Care Individualised Care Plan

RUH Priorities for Care individualised care plan documentation version 5 includes:

- Priorities for Care Initial Assessment and Guidance
- Priorities for Care Comfort Care for the Dying nursing record
- Priorities for Care Continuation Sheet
- Priorities for Care After Death





The documentation supports decision making and identification of patients in the last days/hours of life, compassionate patient centred care, assessment of physical, psychological, social and spiritual needs, on-going review of the patient and support for the patient's family.

2.2 The Priorities for Care Bundle

The Priorities for Care Bundle and Butterfly Logo to support patient centred compassionate care in the last days of life continue to be used to support person centred care:

Priorities for Care in the Last Days of Life Bundle

Recognise

The possibility that the patient may die in the next few days or hours is recognised and communicated clearly:

- Consultant or Spr decision
- Commence Priorities for Care person centred care plan
- Review TEP
- Use of the butterfly magnet on the white board

Communicate

Sensitive communication takes place between staff and the dying patient, and those identified as important to them:

- Consider environment and manner
- Check their understanding
- Acknowledge uncertainty
- Have honest conversations
- Listen with compassion to concerns, wishes and preferences
- Consider use of 'care at the end of life in hospital' leaflet

Involve

The dying patient and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants:

- Consider physical, social, psychological and spiritual needs
- Consider side room or position in ward bay to support dignity
- Encourage the family to bring in items of importance from home

Support

The needs of families and others are identified as important to the dying patient are actively explored, respected and met as far as possible:

- Support with open visiting
- Support with car parking
- Comfort Box
- Use of sleeper chair/ z bed if staying overnight
- Consider Chaplaincy support
- Consider 'companion' volunteer support
- Consider palliative care team support

Plan and Do

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:

- Ongoing senior review of holistic needs of the patient daily or weekend plan using Priorities for Care
- Ongoing nursing review of comfort needs of the patient using Priorities for Care Comfort Chart

Further information on the intranet under 'P' for Palliative or 'E' for End of Life Care. *Contact the Palliative Care Team on ext 5567*

Helen Meehan and Rachel Davis — Priorities for Care Bundle v1, February 2018

2.3 Priorities for Care Audit

A Trust audit of Priorities for Care was undertaken in October and November 2020 to monitor patient outcomes in line with NICE NG31 – Care of the Dying Patient in the Last Days of Life (2015). The objectives of this audit were:

- To audit current evidence that clinicians are recognising when a patient's condition changes and that their care needs are reviewed to ensure comfort at the end of life.
- To audit whether patients, and carers as appropriate, are involved in discussions about dying.
- To audit whether families/carers are offered practical information on facilities at the RUH (refreshments, open visiting, car parking) and information on what to do following the death of a patient.

2.4 Key findings from the Priorities for Care audit

In this small audit of 20 patients completed in October/November 2020 - 65% had non-malignant diagnosis and 7% malignant. The age range was 41-103. The audit included 9 male and 11 female patients. For all 20

patients there was recognition of deterioration and Priorities for Care documentation was used to guide the care for 15 patients.

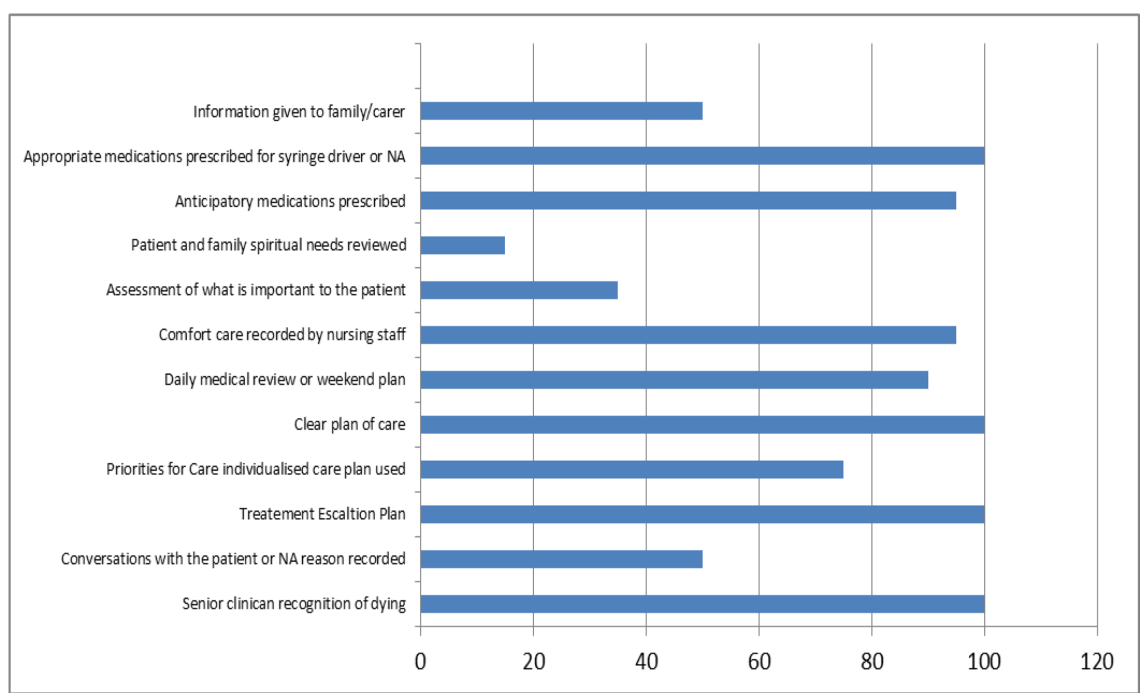


Table 4 – Key findings from Priorities for Care audit

Recommendations following Priorities for Care audit

- Ongoing education for ward teams in caring for patients in the last days of life.
- Ensure the paperless inpatient record project supports person centred care for patients in the last days of life, proactive decision making, ongoing assessment and reviews.
- Ensure communication with patients and families is timely, compassionate, effective and the outcomes recorded.
- Ensure compassionate visiting is supported, including virtual visiting
- Ensure the Compassionate Companion Service is promoted with ward when reinstated.
- SPC team to explore with chaplaincy team how best to support staff with recognising spiritual needs for patients and families. As part of the RUH Conversation Project a learning resource has been developed to support recognition of spiritual needs. This is now available on the intranet for staff to access.
- The Trust is piloting a new 'care after death checklist (Priorities for Care After Death) on ICU as part of the Tissue Alliance Project. This needs to be completed fully before the patient can leave ICU to be transferred to the mortuary. As part of the Paperless Inpatient Project the new care after death checklist for the Priorities for Care documentation will become part of the patient electronic record.

3. Tissue Alliance

The Tissue Alliance Project Group supports the NHS Blood and Transplant Tissue Alliance to improve referrals for tissue donation.

The Care After Death Checklist and referral pathway pilot for tissue donation continued on ICU. The checklist supports:

- Compassionate and dignified care of the deceased person.
- Appropriate recording of verification of death.
- Medical information to support medical certification of cause of death.
- Communication with the family/ next of kin.
- Referral to NHS Blood and Transplant.

In 2020/21 ICU referred 57 patients and increase of 12% on the previous year. 11 referrals led to donations of tissue (9 eye tissue, 2 heart value tissue and 1 research tissue). This represented a 19% conversion rate (KPI target 10%).

The project group did not progress to implementation in other areas due to COVID-19 pandemic, but plans to pilot the care after death checklist and Tissue Alliance referral process in ED from April 2021.

Appendix 3

Compassionate Companion Service

The Compassionate Companion Service' was launched in April 2019. The service is a partnership between the RUH, Forever Friends Appeal and Dorothy House Hospice Care. The service is supported with a 3 year grant from the Sperring Trust (November 2018 – October 2021).

The service provides companionship to patients nearing the end of life, who have limited family support or to give families a break. The CCS steering group oversees the project plan and implementation of the service. The CCS is chaired by the lead nurse palliative and EOLC. The volunteer service is coordinated through the existing Dorothy House Hospice Care companion service.

The service was implemented with a phased introduction in 2019/20 and was supporting 9 wards at the end of March 2021:

- Phase 1 – respiratory, acute stroke unit and Parry wards.
- Phase 2 – William Budd, Pultney and Combe wards.
- Phase 3 – Helena, Robin Smith and Waterhouse wards.

Compassionate Companion Service and COVID-19

The Compassionate Companion Service was due to roll out to a new ward each month from March 2020, but was suspended in March 2020 to October 2020. It was then suspended again in December 2020.

The CCS lead and support worker have maintained contact with the RUH and the volunteers were redeployed to provide telephone support to patients with palliative and end of life care needs at home.

The referral criteria and service offer has been reviewed in light of infection prevention guidance and visiting restrictions. CCS will restart in April 2021.

Due to the suspension of the service in 2020/21, Dorothy House Hospice Care has confirmed that it will extend the provision of the service through to May 2022 to support evaluation of the service. The service will require funding beyond May 2022.

Appendix 4

Memory Boxes
The Memory Boxes have been developed to support ward teams with creating memories for patients and their families. The Memory Box includes a number of resources that can be used, according to the individual needs of patients and their families.

The Memory Boxes have been developed with support from the RUH's charity, The Forever Friends Appeal and from kind donations from our community.

The resources include:

- Memory hearts
- Cards
- Voile purses
- Inkless hand print paper
- Keepsake memory books

Feedback from families about the memory box resources
From a patient… 'I've written down words and shared what I've wanted to say to my son and daughter for so many years….thank you.'

From a daughter… Thank you. This means so much to us as a family.'

From a patient….'I'll kiss each heart, place next to my heart and send with love to each of my grandchildren.'

Appendix 5 - **Palliative and end of life care training annual programme 2020/21**

Session (session code for ESR reporting in bold)	Target audience	Organised by	SPC team leads		Comments
T34 syringe driver training	RNs	Bettina Deacon	Clare, Annie and Sharon	Short film/ ad hoc face to face	30 mins
Induction Care Certificate – **Care of the dying patient** (until September)	Bands 2 and 3	Anita Paradise	Clare and Annie	Monthly	suspended
Preceptorship – **Principles and practice in palliative and EOLC** need to check	RNs and associate nurses	Linda Chapman	Kathy and Helen	Biannual	suspended
Student Nurse study day - **Principles and practice in palliative and EOLC**	Student nurses – NP6-7	SPC team and Josie	Annie and Clare	Every 6 months	suspended
Return to practice – **Principles and practice in palliative and EOLC**	RNs	SPC team	Kathy and Helen	Ad hoc	suspended
Ambassadors - **Principles and practice in palliative and EOLC**	RN	SPCT team	Helen, Clare, Sharon and David	Placement with the SPC team	1 day
Bands 2-4 study day – **Principles and practice in palliative and EOLC**	HCAs	Anita Paradise	Annie and Clare	Yearly (June)	suspended
Junior doctors - **Principles and practice in palliative and EOLC**	Medical teams	SPC team	Ed, Rebecca and Helen	Ad hoc	1 hour
Grand Round **– Principles and practice in palliative and EOLC**	Medical teams	Dr MacKenzie Ross	Morwenna and Helen	Yearly	1 hour
Nursing and Midwifery Grand Round - **Principles and practice in palliative and EOLC**	Nursing and midwifery	Jane Davies	Helen	X3 per year	1 hour
E Learning module – **Principles and practice in palliative and EOLC**	Medical teams, RNs, therapists and HCAs	SPC team	Helen	Available on ESR	45mins

Session (session code for ESR reporting in bold)	Target audience	Organised by	SPC team leads		Comments
Compassionate Companion Volunteers – **care at the end of life**	volunteers		Petrena and Catherine	6 monthly	3 hours
Conversation Project workshops - **Communication and ACP**	Medical teams, RNs, therapists and HCAs	SPC team	Rachel and Helen	6 monthly	3 hours
UWE EOLC Module – Advance Care Planning and CHAT Bundle session (from January 2020)	Doctors, RNs and AHPs	Dorothy House Hospice Care	Helen	6 monthly	1 hour
UWE EOLC Module – Innovation in palliative and EOLC in the acute setting (from January 2020)	Doctors, RNs and AHPs	Dorothy House Hospice Care	Helen	6 monthly	1 hour
Tea trolley training sessions from January 2020					
Conversation Project – **Communication and ACP**	Medical teams, RNs, therapists, HCAs, admin	SPC team	Rachel and Gill	Ad hoc	30mins
Priorities for Care - **Care of the dying patient**	Medical teams, RNs, therapists, HCAs, admin	SPC team	Helen and Annie	Ad hoc	30mins
Mouth Care - **Principles and practice in palliative and EOLC**	Medical teams, RNs, therapists and HCAs	SPC team	Petrena and Sharon	Ad hoc	30mins
Management of constipation - **Principles and practice in palliative and EOLC**	Medical teams, RNs, therapists and HCAs	SPC team	Kathy and Clare	Ad hoc	30mins
Palliative and EOLC during COVID pandemic - **Principles and practice in palliative and EOLC**	Medical teams, RNs, therapists and HCAs	SPC team	SPC team	Ad hoc	30mins