

End of Life Care Annual Report 2021



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1.0 Purpose:

1.1 This paper serves to share work and progress in regard to palliative and end of life care (PEoLC) across the Isle of Wight NHS Trust during 2021.

2.0 Introduction:

2.1 Palliative and end of life care is care that helps those with advanced, progressive incurable illness to live as well as possible until they die. It prompts support and enables end of life care needs of both the patient and those deemed as important to them to be identified and met through the last phase of life and into bereavement (End of Life Strategy 2008).

2.2 It is an emotive and important area of care that will affect us all and, ‘how we care for the dying is an indicator of how we care for all sick and vulnerable people’. It is deemed by the Department of Health as a measure of society as a whole, and it is considered as a litmus test for all health and social care services (End of Life Care Strategy 2008)

2.3 It needs to be noted that the impact of the COVID pandemic did challenge the way we delivered end of life care in hospital and in the community; and the staff providing this care. From this experience we have learnt how we can rapidly scale up end of life care services to meet demand and also up skill a non-specialist workforce to also provide high quality end of life care to patients and families.

2.4 On average the Isle of Wight has 1500 deaths per year, 48/49% of these deaths occur in the acute hospital and the other 50/51% of deaths happen in the community.

2.5 Over the last two years extensive improvements have been undertaken across all the divisions and care groups within the Trust underpinned by a clear end of life care strategy. These improvements have been made possible by developing a formal and constructive partnership with Mountbatten IOW. End of life care services within the Trust as a core service is rated by our regulator the Care Quality Commission as “Good” and we have in place an ongoing improvement plan to move this service to “Outstanding” in the near future.

2.6 The Ambitions for Palliative and End of Life Care (2015-2020) nationally have been updated and re-published this year and the new ambitions extend from 2021-2026. In view of this in 2022 our local strategy for end of life care will be reviewed and updated to reflect these new national ambitions for this core service.

3.0 End of Life Care Services within Isle of Wight NHS Trust:

- 3.1 Within the Trust end of life care is led by a designated Clinical Director for End of Life Care services. This post has been in place since October 2018 and held by the current post holder since then.
- 3.2 In 2019 the Trust made a further commitment to this agenda and supported a full time Consultant Nurse post for palliative care in the Trust.
- 3.3 Since 2018 the Trust has been in a formal Memorandum of Understanding with Mountbatten IOW in providing specialist palliative and end of life care in the Trust, to ensure the highest possible standard of care for our patients.
- 3.4 In all four areas of the integrated Trust all services provide end of life care to patients if needed with the support of specialist services in the Trust or Mountbatten.
- 3.5 In 2019 the Mountbatten Specialist palliative care team and the NHS end of care team based in the acute hospital were redesigned and integrated. This resulted in the Integrated Palliative and End of Life Care Team (IPET). The service went from a five-day service 9-16:30hrs to a seven-day service which functions 12 hours a day. The team is led by the Consultant Nurse for Palliative Care and made up of IPET Clinical Nurse Specialists, a Discharge Co-ordinator, Palliative Care Consultants, Specialty Doctors and a Consultant Psychologist.
- 3.6 The IPET team also work closely with the Chaplaincy service in the Trust and Chaplaincy form part of the weekly multidisciplinary team meetings.
- 3.7 IPET cover the acute hospital and in-patient mental health wards, in the community the community nursing team will care for end of life care patients and may share care with Mountbatten IOW. Out of hours in the community the Ambulance service support the role of the Community Practitioner to provide urgent end of life care advice and intervention alongside the Mountbatten IOW co-ordination hub which is available 24 hours a day.
- 3.8 In paediatrics we now have a designated Paediatrician that will lead of palliative and end of life care for children on the IOW. In addition to this we already have a well-developed children's community nursing team leader and team to provide palliative and end of life care to children on the IOW.
- 3.9 Maternity services in the Trust have an established bereavement Midwife to support families affected by sudden death and recently have also recruited a perinatal psychologist to support in this area of work.
- 3.10 The Trust's end of life care services are also supported by the bereavement and mortuary team based at St Mary's together with their medical examiners.
- 3.11 In 2020 a bold case was put forward that proposed that we care for our dying patients in hospital differently. This resulted in opening a pilot three bedded nurse led acute end of life care unit, which was named Wellow Unit. Within three weeks of opening we had to open a 30 bedded unit for end of life care due to the pandemic. We peaked in using 10 beds on this unit and then we returned to the 3 – 6 bedded unit. Unfortunately, in the second wave in 2021 we needed to move to meet demand

and the nurse led unit was moved to Mottistone suite and for a month we had demand for all 10 beds and a waiting list for transfer in. We then returned to the original Wellow Unit in February 2021 and have remained there ever since.

- 3.12 Wellow Unit has transformed the experience of the person that is dying in our hospital and has now been confirmed as an established nurse led acute end of life care unit (3-6 beds) and also has been confirmed the only one of its model and kind in the NHS in England.
- 3.13 Palliative and end of life care is underpinned by NICE guidance and relevant clinical evidence and outlined in local policies and standard operating procedures to ensure consistency and holding the system and individuals to account for the care that we deliver as a Trust in this fundamental element of care.
- 3.14 There is a clear governance structure in place to ensure oversight of end of life care and this includes a designated Trust Board member holding responsibility for end-of-life care (Director of Nursing). The Trust also has in place a monthly end of life care operational group that is chaired by the Clinical Director for End of Life Care for the Trust. This group reviews activity and performance in the previous month in all four areas of the integrated Trust. It monitors improvement plans associated with end of life care and discusses cases for change to ensure continued improvement.
- 3.15 The Trust's End of Life Care Operational Group then reports and escalates into the Patient Experience Sub-Committee and if requested, presents updates to the Quality and Performance Committee.

4.0 Activity in the last 12 months:

4.1 Integrated Palliative and end of life Care Team (IPET):

Measure	Jan 21	Feb	Mar	April	May	June	July	Aug	Sep t	Oct	Nov	Dec
Number of bleeps	168/54FTF	93/44FTF	99/46FTF	81/31FTF	129/32FTF	133/41FTF	167/36FTF	164/50FTF	219/35FTF	179/39FTF	176/53FTF	132/47FTF
No of referrals via bleep	97	77	73	59	65	71	86	72	69	83	82	71
No of referrals via E-Carelogic	7	4	6	7	8	12	8	13	9	5	12	3
Number of 1 st assessments	124	81	79	59	73	83	86	85	78	88	89	74
Time on advice/direct patient contact	317H	254H	291 H	193 H	343 H	210 H	265 H	290 H	271 H	309 H	233 H	259 H
% of cases cancer	17%	36%	33%	37%	50%	37%	47%	37%	33%	34%	31%	35%
% of cases non-cancer	83%	64%	67%	63%	50%	63%	53%	62%	67%	66%	69%	65%
Referrals seen within 48 hours	100%	100%	100%	100%	100%	100%	100%	100%	100 %	100 %	100 %	100%

Measure	Jan 2021	Feb	Mar	Apr	May	June	July	Aug	Sept	Oct	Nov	Dec
Cases referred to Share My Care	11	6	5	6	8	12	10	13	11	9	2	6
EOLC discharges	8	16	13	11	15	11	11	13	14	15	15	24
Number of Community bleeps	1	3	0	0	1	1	2	2	0	0	1	0
Fast tracks	2	4	3	2	4	3	4	5	5	3	8	6
Education delivered	1 H	1 H	1 H	5 H	5 H	9 H	7 H	1 H	8.5 H	11 H	2.5 H	1 H
ACPs	2	11	10	9	8	6	11	12	12	4	8	10
% of caseload that had ACP conversations	78%	83%	100%	80%	80%	66%	80%	88%	88%	96%	88%	80%

Staff debriefs	0	0	0	0	1	1	1	0	0	0	0	0
Follow up phone calls post death	1	1	0	0	2	0	0	0	0	1	0	0
Syringe driver in use	40	25	34	25	22	28	27	31	27	31	20	21

4.2 Wellow Unit:

4.21 Wellow Unit is for patients in the last hours up to the last 7 days of life and for palliative and end of life care patients that are being discharged to die at home as an alternative area to be cared for while waiting for discharge.

4.22 The average length of stay is 3.5 days and on average the unit has a one death a day. Most deaths occur on Wednesday and Sunday.

4.23 Wellow Unit had a total of 409 admissions in 2021.

Measure	Jan 21	Feb	Mar	Apr	May	June	July	Aug	Sep	Oct	Nov	Dec
Occupancy rate (3 and 6 beds)	N/A	127 %/ 64 %	94 %/ 47 %	88 %/4 4%	97% /48 %	97% /48%	123 %/6 1%	125 %/6 2%	150%/ 75%	155 % / 77%	139% / 66%	105%/53 % - 5pts
Number of admissions	64	36	36	30	22	28	29	31	40	31	29	33
% of cancer cases	14. 3%	13. 8%	16. 6%	23. 3%	22.7 %	17.8%	27.6 %	19.3 %	12.5%	9.7 %	27.6%	21.2%
% of non-cancer cases	85. 7%	86. 1%	83. 3%	76. 6%	77.2 %	82.2%	72.4 %	80.6 %	87.5%	90.3 %	72.4%	78.8%
Number of Datixes	2	13	4	5	13	5	11	11	8	7	9	6
Complaints	0	0	0	0	0	0	0	0	0	0	0	0
Concerns	0	1	0	1	2	0	0	0	0	0	0	0
Compliments	13	13	8	14	15	19	20	17	15	29	51	39

Sickness rate	15.7%	16.9%	24.5%	25.5%	24.8%	22.7%	22.7%	23.7%	0.42%	5.20%	2.56%	9.26%
Monthly audits compliance	100%	88.9%		98.3%	97.6%	99.3%	100%	100%		100%	98.3%	97.6%

4.3 Community:

Measure	Jan 21	Feb	Mar	Apr	May	June	July	Aug	Sep	Oct	Nov	Dec
End of life care patients on case load	19	13	17	18	13	16	23	11	18	17	22	18
Number of EOLC visits in a month	157	70	102	125	96	147	94	70	87	81	149	142
Number of bereavement visits undertaken	5	6	3	8	9	8	13	3	2	3	13	12

4.4 Ambulance:

Measure	Jan 21	Feb	Mar	Apr	May	June	July	Aug	Sep	Oct	Nov	Dec
End of life care patients attend overnight	16	12	10	10	14	13	17	13	17	6	6	10
Number of share my care referrals	0	1	3	3	6	6	3	8	4	3	2	1
Number of urgent DNACPR decisions made overnight	0	0	0	0	0	0	0	0	0	0	0	0

4.5 Paediatrics:

4.51 In 2021 there was one expected child death, end of life care was provided at home by Children's Community Nursing team.

4.52 In 2021 there were also two sudden child deaths, one of which was supported post death on Wellow Unit.

5.0 Performance in the last 12 months:

5.1 In the Trust we monitor the performance and quality of end of life care via auditing every death that occurs under NHS care against the national NICE guidance for end of life care and against set quality metrics that are agreed with the Clinical Commissioning Group (CCG). (**See Appendix A**)

5.2 In addition to this we also monitor local compliance with the DNACPR policy (Do No Attempt Cardio Pulmonary Resuscitation) and the quality of the documented DNACPR decision made. Current performance in this area has improved over the last 12 months and has been sustained. (**See Table Below**)

Monthly Trust Compliance with DNACPR policy and quality of DNACPR decision made	April 21	May 21	June 21	July 21	Aug 21	Sept 21	Oct 21	Nov 21	Dec 21
	93%	93%	96%	94%	94%	94%	92%	95%	94%

5.3 The core end of life care quality metrics over the last year has been maintained above local and national average and has been consistent in the last 24 months despite the pressures and challenges that COVID 19 have brought to services. (**See Table Below**)

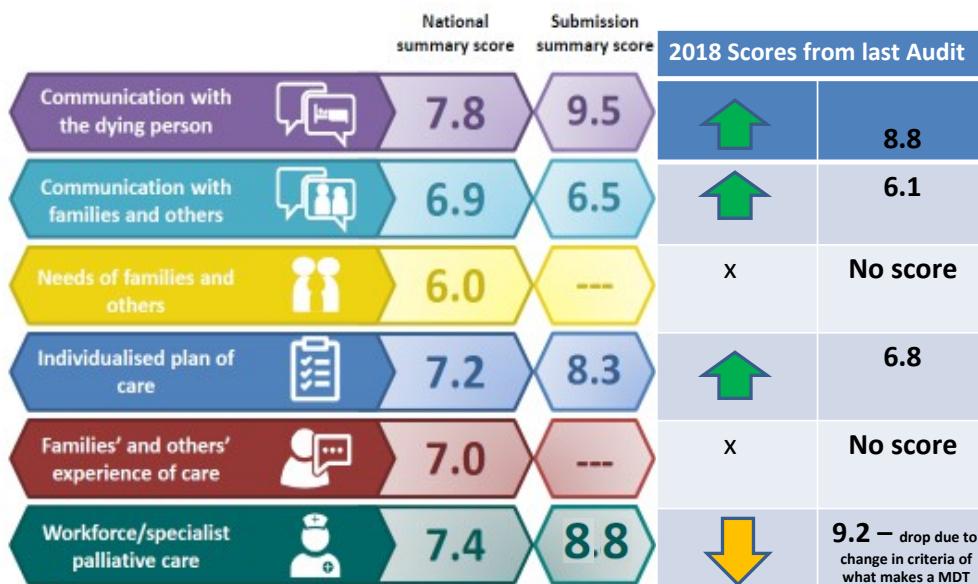
Month 2021	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Improved recognition that person is going to die	98.6	100%	100%	100	100	100	96.9	96.7	100	100	100	100
Percentage of Priorities of care in place	87.3	100	97.7	95.8	96	96.4	96.9	100	97.2	92.5	92.9	96.8
Preferred place of care identified	88.7	95.1	95.2	100	100	96.4	93.8	96.7	97.2	97.5	96.4	96.8
Preferred place of care met	87	95.1	95	95.7	96	92.6	100	96.6	91.7	92.5	96.3	100
Evidence of communication with the patient. (%)	11.7	25	58.3	22.7	80	17.9	16.7	30	27.8	40	28.6	35.5
Evidence of communication with those deemed as important. (%)	95.8	100%	97.7	91.7	100	96%	97	93.3	100	97.5	92.9	96.8

5.3 The above performance is monitored monthly at the Trusts End of Life Care Operational Group and a quarterly report goes to the Patient Experience Sub-Committee.

5.4 The Trust has also participated in the National Audit of Care at the End of Life (NACEL) which was commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Government in October 2017. NACEL is a national comparative audit of the quality. The first round of the audit took place in 2018. The second round of the audit taking place in 2019/20 and the third round in 2021.

5.5 In rounds 1 and 2 of the NACEL audit the Trust saw a step change improvement in the quality of end of life care and this has triangulated with local audit and data that demonstrated the same. (**See results from round 1 and 2 below**)

National Audit for Care of the Dying- National summary scores compared with Isle of Wight submissionsummary scores 2019 Round 2



NB: Please note due to low response rate from relative feedback questionnaires metric 3 and 5 have not been benchmarked and this is the same nationally

5.7 Round 3 of the NACEL results will be published in the Trust in April 2022.

5.8 Round 4 of the NACEL audit begins in April 2022.

6.0 Actions and developments in the last 12 months:

6.1 We have formed partnership with the national Good Grief Trust and ensure all bereaved people while under NHS care receive their booklet/card. This means that they have a resource to gain access to bereavement services, which is particularly importance for bereaved families not from the Isle of Wight.

6.2 The Trust's end of life care champions group meetings have been relaunched in 2021 and this is now represented by staff members across the whole organisation. The members

aim to ensure standards for end of life care are followed in their area and support any local changes when they need to happen.

6.3 In October 2021 Ruth May, England's Chief Nursing Officer, visited the Trust and went to see Wellow Unit to speak to the team about the nurse led unit and also the innovation of widening the access of the unit for children to use it.

6.4 End of life care has been added as a core element in the QASS inspections.

6.5 In 2021 the IPET team have been able to deliver formal education again, this has included the four hour enhanced communications skills training, one two day advanced communication skills training, core knowledge and skills training for the Trusts student nurses and associate nurses and introduction sessions on end of life care for our new overseas nurses.

6.6 A member of the IPET team presented an update on the proceeding bill on assisted dying in England to the Ethics Committee. This stimulated discussions and points to consider going forward if this is nationally progressed.

6.7 A formal review was undertaken in the Trust in how DNACPR decisions are made based on the national concerns raised by the Care Quality Commission in relation to blanket DNACPR decisions being made during COVID. The review demonstrated high compliance with local policy and best practice in this area and provided the Trust with strong assurance in this area and no points of serious concern were found.

6.8 Wellow Unit has widened its scope and undertaken a significant piece of work with the Lead for Children's Community Nursing to enable children that die in hospital and cannot be moved to be hosted on Wellow Unit after death to enable families to spend quality time with their child after death(to date this has happened once in 2021). The SOP that supports this also puts in an option as well for the community nursing team to use Wellow Unit to provide end of life care for a child on the unit rather than the standard children ward environment.

6.9 In November 2021 Wellow Unit went live with offering bereavement follow up calls for family members that have been bereaved whilst on Wellow Unit. This will formally be monitored and evaluated in 2022.

6.10 In response to changing patterns of dying during the COVID pandemic, Dr Paul Howard developed a number of symptom control guidelines that could be used in the hospital and community to ensure staff were supported in making the right clinical decision when managing systems and alongside developing Patient Group Directions (PGDs) for the community to avoid delay in access to end of life care drugs when they are needed.

6.11 We have now enabled E-carelogic to support the electronic completion of advanced care plans for patients before discharge and also the ability for ward based staff to refer to the Mountbatten share my care register if indicated.

6.12 The Emergency Department and the Acute Assessment Unit have been given access to System1 to enable them to see if there are any advanced decisions in place like DNACPR or an advance care plan setting out the patients future care wishes. This has been put in place to avoid unnecessary admission to hospital or identification of patients that are high risk of dying during their admission and promote early referral to palliative and end of life care services.

6.13 Charitable Funds: Since Wellow Unit has opened we have had over 10k donated plus odd charitable donations. With this we have added things specifically to the unit to enhance the environment to make it less clinical. This has included sofas, new table and chairs in the open public space, 2 televisions, CD players, soft lights, memory boxes and glass hearts made locally on the IOW that we give to families.

6.14 One of our dedicated members of staff on Wellow Unit has run **six marathons** over the last year for the Unit and has raised several thousands of pounds for the benefit of the unit – Thank you!

6.15 The Trust is now regularly being contacted to share our local developments and in recent months have been approached by Trusts about how we set up Wellow Unit and requesting a local site visit.

7.0 Looking Forward and Future Developments:

7.1 In April 2022 the NACEL audit results will be published in the Trust, alongside a comprehensive improvement plan that will be approved at the Patient Experience Sub-Committee and monitored at the End of Life Care Operational Group monthly.

7.2 We have just launched our ‘community conversations’, whereby our staff are going out to meet the community to establish individual’s preferences. They ask one simple question; “What matters most to you about end of life care”. By doing it this way we fully understand exactly what is important to people, rather than asking them to fill in a survey about things that we *think* will be important to them. We will use this information to develop our End of Life Care Strategy for the next three-five years.

7.3 The Trusts End of Life Care Strategy in 2022 will be refreshed based on the community conversation work that was started in March 2022, with support from Solent NHS Trust.

7.4 Looking ahead the Health and Social Care Act is being changed to make it a legal requirement for the NHS to provide palliative and end of life care to all. This will have potential positive impact on resources provided and service provision going forward.

7.5 Charitable Funds: we are currently awaiting approval of a business case to buy a ‘cuddle bed’ for Wellow Unit. This will enable patients to lie alongside their loved ones in their dying moments.

7.6 We are currently developing a business case to secure funding to ensure as a Trust we can fulfil our statutory responsibility to provide a key worker to all families that experience the death of a child. Currently this provision is inconsistent in the Trust and sometimes undertaken by services that would have a conflict of interest in conducting this function. Case to be finalised by the end of April 2022.

Appendix A

Key Performance Indicators 2021

The Key Performance Indicators were realigned in 2019 with the data collected via the daily audit process. This data is available on a monthly basis and is presented at the End of Life Care Operational Group meeting.

	Key Performance Indicator	Data Collection
1	Is there an improvement in documented evidence within the last episode of care that it was recognised that the patient would probably die in the coming hours or days?	Monthly EoL Audit. Supported by PIDS
2	Once the person was recognised as dying, is there an improvement (against April's baseline) in documented evidence of a holistic assessment of the patient's needs. (I.E. Is the priorities of care end of life care plan in place?).	Monthly EoL Audit. Supported by PIDS
3	Is there an improvement against baseline in documentation that the preferred place of care was discussed (where appropriate) and that this was achieved?	Monthly EoL Audit. Supported by PIDS
4	Is there an improvement against baseline in documented evidence that communication has been held with the patient and the opportunity given to have concerns listened to.	Monthly EoL Audit. Supported by PIDS
5	Is there an improvement against baseline in documented evidence that communication has been held, and the needs of those identified as important to the dying person asked about?	Monthly EoL Audit. Supported by PIDS