Dying Well in Custody Charter

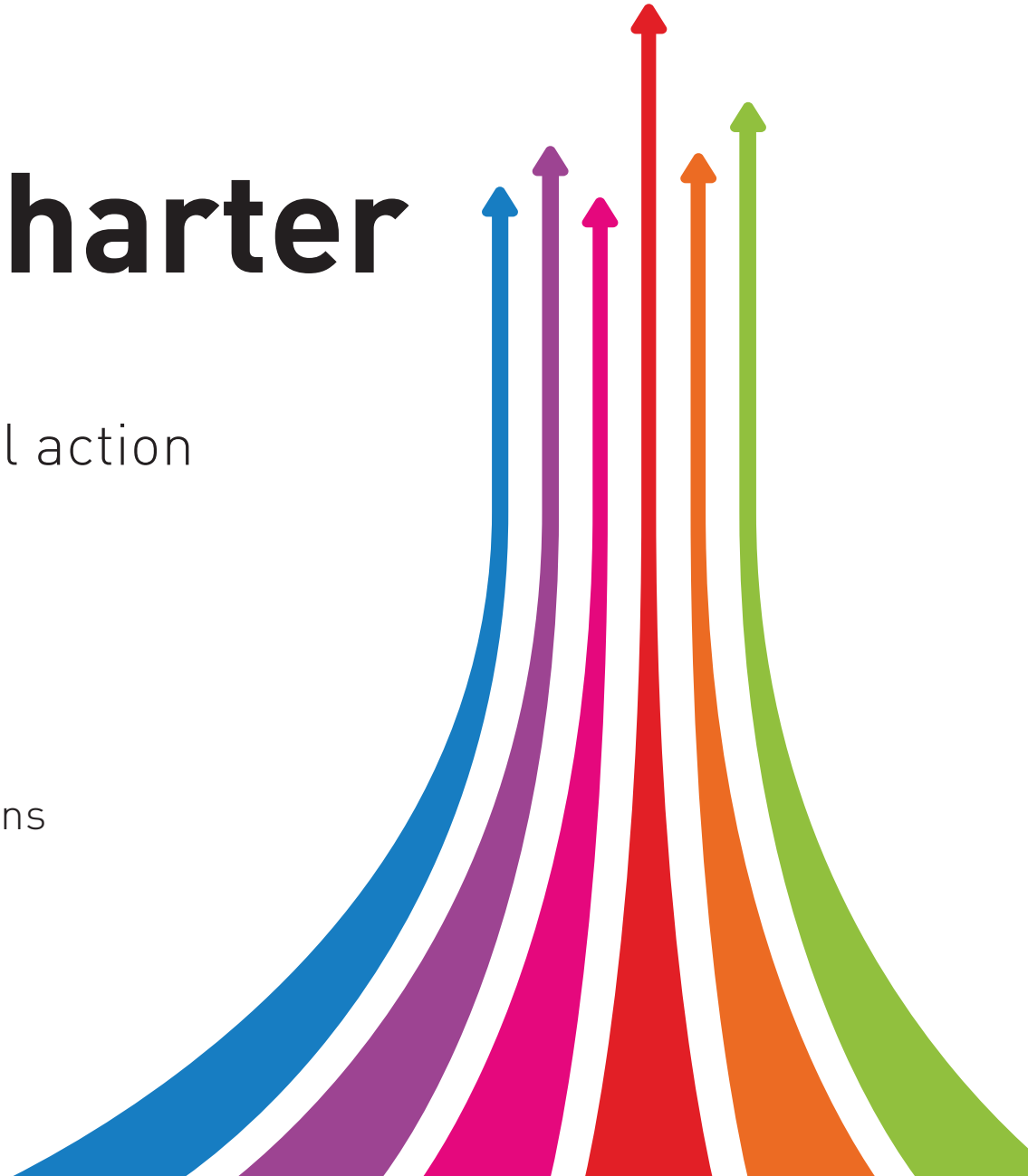
Self-Assessment Tool

A national framework for local action

April 2018

endoflifecareambitions.org.uk/tag/prisons

Ambitions for Palliative & End of Life Care Partnership



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Foreword

Dying well wherever you are and whatever your background or circumstances are fundamental aspects of human dignity. As part of a compassionate humane society, we need to do everything we can to make sure that people who are facing their last months, weeks and days of life receive the best possible palliative and end of life care. Those who care for them, including their families, others important to them and staff around them, equally deserve this consideration and support.

As co-chairs of the Ambitions Partnership, we are delighted that the Ambitions for Palliative and End of Life Care Framework has been applied to the context of the prison setting and interpreted as a Charter. To our knowledge, this is the first time anywhere in the world that the principle of equity has been applied in such a practical way. This is truly a remarkable first.

The articulation of a set of standards, which are a set of guidelines setting out best practice, underpin each of the six ambitions and the development of a self-assessment tool to use alongside it has the potential to make a huge difference. Our shared vision is: '*I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carers'.* No matter where any prison is on the trajectory towards that vision, they will be able to use this Charter and self-assessment tool to help them continuously improve.

We recognise that the custodial environment is different to other settings in which clinical care takes place, and that providing the best possible end of life care in prison is complex and challenging. It is precisely because of that that we welcome this publication so enthusiastically.

We would strongly encourage commissioners, leaders, staff and supporters of prison services to read this and, more importantly, use it to help them in their endeavours to improve the way in which each person can live and die well in custody.

Prof Bee Wee
National Clinical Director of End of Life Care
NHS England

Dr Jane Collins
Chief Executive Officer
Marie Curie, UK

Co-Chairs of the Ambitions for Palliative and End of Life Care Partnership

Introduction

It remains a contentious position that anyone should experience a planned death in prison. However, for some individuals compassionate release to alternative premises in which they can end their life is either not possible or unwanted and therefore there is a requirement that those individuals who do have a planned death in a custodial setting experience the highest standards of care.
In the community close friends and family are key and central to the individuals care yet in the prison environment are often forgotten or their role misunderstood when planning end of life care. Also, the support for close ones is key to the holistic care of the individual.

Many of the people in prison who are coming to the end of their life have been in prison for a number of years and are surrounded by staff and fellow prisoners with whom they are comfortable. The staff may well have been a consistent presence in their lives during their period of custody and their peers are their friends and support.
It is for these reasons that I truly welcome this Dying Well in Custody Charter. The Charter mirrors the Ambitions for Palliative and End of Life Care and provides a framework for establishments to act, help and support all staff who are involved in the care of an individual preparing to die, many of whom will not have experienced supporting an individual in their planned death. This framework provides a set of standards sitting underneath 6 statements of Ambition which place the individual at the centre of the care being planned and delivered.

The Ambitions and Standards in the Dying Well in Custody Charter ensure that care is co-ordinated across the establishment and supports all staff being able to achieve a level of competence and confidence in delivering professional care to these individuals with dignity and calm.
End of life care is enormously important for the individual being cared for as it is for their friends, families and carers. It is the last thing that can be done for a living person and it is critical that it is done well. This Dying Well in Custody Charter enables those involved in caring for individuals to manage this event with compassion, inclusivity and ensures that there is dignity in the death irrespective of their place of death.

Kate Davies OBE

Director of Health & Justice, Armed Forces and Sexual Assault Referral Centres (SARCs) NHS England

Implementation Guide - Preparing for Self-Assesssment

The following ACT & ADOPT checklist provides some suggestions to support the implementation of the Dying Well in Custody Charter (DWiCC) and self-assessment process.

A

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Acknowledgement

- Secure organisational support for the implementation of the DWiCC across the prison estate
- Acknowledge that the DWICC aligns with the National Framework Ambitions for Palliative and End of Life Care and that each establishment needs to consider how and when to implement the charter.

Communication

- HMPPS, HealthCare Commissioners and Providers to advocate implementation of the DWiCC in support of the National Framework Ambitions for Palliative and End of Life Care

Tactics

- Develop and agree an overarching dissemination plan e.g. Senior Leaders Bulletin, Intranet, Learning Bulletins

Implementation Guide - Preparing for Self-Assesssment *Continued*

A

Adoption

- Agree formal adoption of the DWiCC and self-assessment with the establishments Senior Management Team
- Discuss and promote the benefits of adopting the DWiCC with key stakeholders including: service improvement aligning with PPO, CQC, HMIP and commissioner's expectations
- Identify an establishment and healthcare lead; agree who should be included in the self-assessment team ensuring healthcare and operational representation, partner organisations could be involved e.g. Hospice, specialist palliative care staff
- Consider making adoption and self-assessment an establishment priority and agree timescales for implementation.
- Allocate time for self-assessment e.g. one working day or hours per week
- Review the self-assessment tool including evidence required – it is indicated who should take the lead in producing the evidence required – Health, Prison, Joint
- Consider collating evidence in one place to demonstrate self-assessment and on-going review to visiting inspection teams
- Carry out self-assessment process, rate achievement against each ambition using the RAG scale; Red – *to achieve*, Amber - *working towards*, Green - *achieved*
- Develop an action plan with agreed dates for review
- Consider liaising with other establishments to share best practice
- Consider as a minimum annual self-assessment

D

Dissemination

- Develop a communication strategy appropriate to the establishment which ensures inclusion of all staff, prisoners and external partner agencies.

Implementation Guide - Preparing for Self-Assesssment *Continued*

O

P

T

Organisational Issues

- Identify any enablers or barriers to implementation.
- Identify resources to support enablers and address the barriers

Policy / Procedure Revision

- Identify which policies and procedures require review e.g. end of life care policy, open cell door, medication management

Training

- Identify existing training / knowledge gaps in palliative end of life care for all staff groups (operational and healthcare staff) and prioritise relevant groups e.g. nursing teams, FLOs, Safer Custody staff, operational staff working with individuals on the palliative and end of life care register.

Ambition 1: Each person is seen as an individual

I Statement: *I and the people important to me have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible.*

Standard	Evidence	Lead
A: Each prison will treat an individual with dignity and respect.	1. Evidence that the prison has Palliative End of Life Care Guidance for all involved in the care of the individual. Guidance should be compliant with NICE standards. ○ https://www.nice.org.uk/guidance ○ https://www.nice.org.uk/guidance/ng31 ○ Safer Custody Bulletins 2. Evidence the individual is offered the opportunity to discuss advance care planning and any documented preferences are reviewed with the individual. 3. Evidence that those who care for and manage individuals on the palliative end of life care register are aware of any advance decisions. 4. Evidence the establishment seeks stakeholder feedback relating to the development and provision of palliative end of life care.	Joint Health Health Joint
Review Date	RAG	Notes & Actions
B: Each prison has a palliative end of life register to identify individuals and enable care, support and holistic needs to be met.	1. Evidence a palliative end of life care register is in place with a clear process for including and monitoring individuals via a multi-disciplinary team (MDT) approach. 2. Evidence that the individual is involved in their personalised care planning. Evidence the approach to personalised care planning aligns with ○ 5 Priorities for Care of the Dying Person ○ The Governments 6 point commitment to end of life care https://www.gov.uk/government/uploads/system/uploads/attachment	Health Health

	3. Evidence that all staff are aware and key staff (health, safer custody, managers) understand the approach to: Recording and communicating decisions around Cardio-Pulmonary Resuscitation. ○ [Resuscitation – Decisions relating to cardio pulmonary resuscitation ○ Evidence applications for Early Release on Compassionate Grounds, or release on temporary licence are made in a timely way, when appropriate.		Health Joint
Review Date	RAG	Notes & Actions	
C: Information and support will be provided to the individual, their family and significant others and their concerns listened to.	1. Evidence staff have access to and share information with the individual's family and those important to them, to prepare them for what happens when the individual is close to death. ○ [What to Expect When Someone Important to You is Dying] 2. Evidence the prison has a holistic approach to bereavement and support . ○ https://www.nice.org.uk/guidance ○ PPO lessons learned (PDF Download)		Joint Joint
Review Date	RAG	Notes & Actions	

D: A Family Liaison Officer (FLO) should routinely be appointed, to support co-ordination of care at end of life including family access, unless otherwise indicated.	1. Evidence a FLO has been appointed once the individual's details are included on the palliative care register, or evidence the individual has declined FLO involvement. 2. Evidence there is a process in place to support family visits at end of life, including out of hours regardless of the individuals' location	Joint Joint
Review Date	RAG	Notes & Actions
E: All care should be holistic, person centred, safe and decent with a process in place to support appropriate self-management.	**1.** Evidence of a holistic approach to care planning. **2.** Evidence of an agreed holistic care plan in joint discussion with the individual. **3.** Evidence of a process to enable and support self-management e.g. to remain on wing / current establishment where possible. **4.** Evidence the individual is offered the opportunity to discuss advance care planning; any documented preferences are reviewed as required with the individual. **5.** Evidence of guidance/policy supporting assessment of mental capacity where appropriate. **6.** Evidence of documented guidance for staff and individuals on: ○ Advance Decision to Refuse Treatment [NHS Choices Guide] ○ Lasting Power of Attorney [NHS Choices Guide]	Health Health Joint Health Health Joint
Review Date	RAG	Notes & Actions

F: Open and informed honest conversations about individual expectations and preferences are facilitated, and acted upon.	**1.** Evidence of discussions with the individual about personal preferences and future wishes for end of life care are acted upon. **2.** Evidence of defensible decision making where wishes cannot be fulfilled. **3.** Staff have access to palliative end of life care training that includes communicating with individuals about end of life issues including advance care planning.		Joint Joint Joint
Review Date	RAG	Notes & Actions	
G: Each individual is offered spiritual and religious support appropriate to their needs and preferences.	1. Evidence of involvement of chaplains or relevant religious leaders as required. 2. Evidence the individuals spiritual and religious needs are met during their illness and care after death whenever possible.		
Review Date	RAG	Notes and Actions	
H: The individual's care and management is delivered in partnership to allow access to a flexible, progressive prison regime according to need.	**1.** Evidence of multi-disciplinary team working. **2.** Evidence of consideration to family / carer access to prison as the individual becomes more unwell and at end of life **3.** Evidence of systems to ensure rapid access to needs based social care. **4.** Evidence of central information point where staff can access clear information about local social / palliative end of life care services.		Joint Prison Joint Joint
Review Date	RAG	Notes & Actions	

Ambition 2: Each person gets fair access to care

I statement: *I live in a society where I get good end of life care regardless of who I am, where I live or the circumstances of my life.*

Standard	Evidence		Lead
A: Each individual's needs are identified, assessed and met regardless of a prison's location or category.	1. Evidence of a timely process to identify individuals requiring inclusion on the palliative care register. 2. Evidence of consideration of any need for transfer to ensure individual's holistic needs are met including application for Early Release on Compassionate grounds if appropriate. 3. Evidence of personalised care planning assessment and on-going review with a multi-disciplinary approach for patients included on the palliative end of life care register.		Health Joint Health
Review Date	RAG	Notes & Actions	
B. An individuals protected characteristics inform assessments and on-going care and steps are taken to meet needs accordingly.	**1.** Evidence that the individuals protected characteristics e.g. gender, religion, ethnicity inform holistic assessment and on-going review with a multidisciplinary approach.		Joint
Review Date	RAG	Notes & Actions	
C: Each prison ensures access to 24/7 clinical advice for individuals.	1. Evidence staff are aware of how to access medical advice 24/7. 2. Evidence staff are aware of how to access Specialist Palliative Care advice 24/7.		Joint Health
Review Date	RAG	Notes & Actions	

Ambition 3: Maximising comfort and wellbeing

I statement: *My care is regularly reviewed, and every effort is made for me to have the support, care and treatment that might be needed to help me to be as comfortable and as free from distress as possible*

Standard	Evidence	Lead
A: Each prison has a clear process for timely assessment and care planning of any identified and changing needs and preferences of the individual.	1. Evidence policies / guidance state clinical assessments should be reviewed in a regular and timely way. Including review of care following any changes in condition, preferences, health status or following any outpatient reviews. ○ Links with NICE End of Life Care for Adults ○ Quality Standard 3: Assessment, care planning and review **2.** Evidence of communication with operational staff to enable appropriate changes required to support the delivery of care.	Health Joint
Review Date	RAG	Notes & Actions
B: All assessments of need are made by an appropriately qualified person.	1. Evidence that clinical assessments are carried out by an appropriately trained healthcare professional. 2. Evidence of referrals to specialist teams, allied healthcare professionals. 3. Evidence training needs assessments include access to palliative and end of life care. 4. Evidence any shortfalls are included in recruitment and training plans.	Health Health Joint Joint
Review Date	RAG	Notes & Actions

C: Pain and symptoms are assessed and reviewed in a timely way using an MDT approach to enable delivery of safe and effective pain and symptom management.	1. Palliative End of Life Care policy / guidance includes a section on symptom and pain management which is in line with local and national guidelines: o https://www.palliativedrugs.com/ (subscription required) 2. Evidence of regular pain and symptom management which include planned reviews. 3. Evidence of individual clinical review following any changes in condition, health status or following any outpatient reviews. 4. Palliative medicines stock is held at the site for prompt access and is based on a local palliative care formulary which is in line with national guidance. 5. Evidence of access to syringe pumps for people no longer able to take oral therapy used safely in line with evidence based guidance. 6. Evidence of anticipatory prescribing for people in the last days of life o https://www.nice.org.uk/guidance/qs144 o https://www.nice.org.uk/guidance/ng31/chapter/Recommendations#anticipatory-prescribing	Health Health Health Health Health Health
Review Date	RAG	Notes & Actions
D: Advance Care Plans including DNACPR decisions are reviewed at key trigger points in the individuals care and as required and recorded.	**1.** Evidence of policy / guidance that outlines an approach to initiating conversations about advance care planning and DNACPR discussions with the individual. **2.** Evidence policy / guidance includes involvement of the individual and his/her family and/or carers in conversations at the individual's request.	Joint Prison
Review Date	RAG	Notes & Action

E: Joint assessments between healthcare and security inform dynamic risk assessment for restraints for individuals on the palliative end of life care register.	**1.** Evidence that policy / guidance includes a joint, safe and decent approach for the use of restraints. **2.** Evidence that decisions regarding use of restraints are dynamic and risk assessments reflect the individuals changing health and presentation in line with the Graham Judgement.		Joint Joint
Review Date	RAG	Notes & Actions	
F: Each prison has a process to initiate 'open cell door' protocol when required.	**1.** Evidence of policy / guidance which outlines a clear process for identifying, requesting and implementing open cell door to meet the changing needs of the individual and those who are in the last days of life. **2.** Evidence that all staff are aware of the policy/guidance and understand how to request and implement the process.		Joint Joint
Review Date	RAG	Notes & Actions	

Ambition 4: Care is coordinated

I Statement: *I get the right help at the right time from the right people. I have a team around me who know my needs and my plans and work together to help me achieve them. I can always reach someone who will listen and respond at any time of the day or night.*

Standard	Evidence		Lead
A: Each individual is offered the opportunity to be involved in the planning of their care which is regularly reviewed and shared appropriately with health and care professionals and those important to the individual where requested.	**1.** Evidence that the individual is involved in planning of their care. **2.** Evidence the individual has consented to sharing of information. **3.** Evidence any information shared is appropriate to the consent given.		Health Health Joint
Review Date	RAG	Notes & Actions	
B: There is a prison and healthcare lead for palliative end of life care with clearly identified roles and responsibilities. This is outlined within policy / guidance.	**1.** Evidence the role of the healthcare and prison palliative end of life care lead is outlined in local policy/guidance. **2.** Evidence the healthcare and prison leads drive the on-going development for palliative end of life care in the establishment. **3.** Evidence all healthcare and key prison staff are aware of the palliative end of life care leads and their roles.		Joint Joint Joint
Review Date	RAG	Notes & Actions	

C: Policy/guidance includes a clear outline of MDT approach.	**1.** Evidence policy / guidance state an MDT approach is required for care and management of individuals on the palliative end of life care register. **2.** Evidence the individual has access to MDT meetings if requested.		Joint Joint
Review Date	RAG	Notes & Actions	
D: Clear MDT roles and responsibilities are identified and communicated to individuals and staff	**1.** Evidence that individuals and staff are aware of roles and responsibilities of those involved in palliative end of life care within the establishment.		Joint
Review Date	RAG	Notes & Actions	
E: Each individual has named clinical key worker/s.	1. Evidence there is a system in place for allocation of a clinical key worker/s. 2. Evidence the individual's key worker/s are known to the individual. 3. Evidence all health and key prison staff are aware of the role of the key worker. 4. Evidence of involvement of the individual's key worker /s at significant times in their care and at the individual's request. 5. Evidence of involvement of the individuals Personal Officer at significant times in their care and management and at the individual's request.		Health Health Health Health Prison
Review Date	RAG	Notes & Actions	

F: There is co-ordinated and clearly documented transfer/release plans for individuals using national SystmOne clinical template to ensure continuity of care.	1. Evidence that a system is in place to co-ordinate a safe transfer/ release to meet the needs of the individual. 2. Evidence the SystmOne template is being used.		Joint Health
Review Date	RAG	Notes & Actions	

Ambition 5: All staff are prepared to care

I statement: *All staff are prepared to care. Wherever I am, health and care staff bring empathy, skills and expertise and give me competent, confident and compassionate care*

Standard	Evidence		Lead
A: All staff can identify and raise any concerns about an individual's health and wellbeing.	1. Evidence of a process in place to enable health and prison staff to raise concerns about an individual's health and wellbeing. 2. Evidence staff are aware of their roles and responsibilities related to raising a concern about the individuals health and wellbeing.		**Joint** **Joint**
Review Date	RAG	Notes & Actions	
B: Concerns/queries raised by other members of the community i.e. prisoners about individuals on the palliative end of life care register are listened to and acted upon.	**1.** Evidence of a timely process to enable concerns and queries raised by other members of the community to be listened to and acted upon.		**Joint**
Review Date	RAG	Notes & Actions	

C: Each prison includes access to education and training in generalist palliative end of life care appropriate to staff role and their responsibility.	**1.** Evidence of access and attendance at education and training for all staff involved in palliative and end of life care. **2.** Evidence education and training includes holistic assessment e.g. physical, psychological, emotional, social and spiritual aspects of palliative end of life care.		**Joint** **Joint**
Review Date	RAG	Notes & Actions	
D: All staff have access to supervision and time for reflective learning and are confident to raise concerns.	**1.** Evidence of a policy guidance for the provision and delivery of professional supervision for all staff involved in the care of individuals with palliative and end of life care needs.		**Joint**
Review Date	RAG	Notes & Actions	
E: Each prison has a system in place which provides accessible up to date information and key contacts	**1.** Evidence of a process/approach where information and key contacts are reviewed and updated.		**Joint**
Review Date	RAG	Notes & Actions	

F: All staff involved in the care of an individual on the palliative and end of life care register will adhere to 'duties of confidentiality'.	**1.** Evidence of policy/guidance that supports all staff involved in the care of an individual on the palliative and end of life care register to adhere to 'duties of confidentiality'.		**Joint**
Review Date	RAG	Notes & Actions	
G: All staff are able to recognise distress including physical, emotional, psychological, social or spiritual as appropriate to their role and understand the referral process to the appropriate agency for support.	1. Evidence of an approach where all staff are able to recognise, understand and support an individual to alleviate all forms of distress as appropriate to their role.		**Joint**
Review Date	RAG	Notes & Actions	

Ambition 6: Each community is prepared to help

I statement: *I live in a community where everybody recognises we all have a role to play in supporting each other in times of crisis and loss. People are ready willing and confident to have a conversation about living and dying well and to support each other in emotional and practical ways.*

Standard	Evidence	Lead
A: Each prison fosters and develops good relationships with internal and external partners (stakeholders).	**1.** Evidence of whole a prison approach which includes all internal and external partners / stakeholders. **2.** Evidence of agreements in place with local palliative care providers – including Hospices, local Specialist Palliative Care teams and other specialist services e.g. Tissue viability, continence.	**Joint** **Health**

Review Date	RAG	Notes & Actions

B: Each Prison has timely access to a suitable care environment and equipment to enable delivery of quality palliative end of life care in the preferred and permitted place.	1. Evidence of assessment and action for timely in cell adjustments e.g. toilet rails, pressure relieving mattresses. 2. Evidence of local agreements with home loan/equipment services. 3. Evidence the prison has access to a palliative care suite, or enhanced environment. 4. Evidence of the use of local transfer pathways to support the individuals preferred and permitted place of care including when release is granted on compassionate grounds. 5. Evidence patients die in their preferred place of care when possible.	**Joint** **Joint** **Joint** **Joint** **Joint**

Review Date	RAG	Notes & Actions

C: Sources of support required for people affected by or involved in the care of an individual will be communicated to everyone involved in a timely and effective way.	1. Evidence that support services have been identified and communicated to those involved in the individual's care in a timely and effective way.		**Joint**
Review Date	RAG	Notes & Actions	

Examples of Evidence

Here are some examples of evidence, the list is not exhaustive, and establishments may identify others relevant to their own practice

- Policies - Guidance - Standard Operating procedures
- Palliative and end of life care register – complex case register
- Social Care Register – care plans – Continuing Healthcare Assessment
- Advance Decision – DNACPR Documentation
- Wing Books and Logs
- FLO logs
- Staff Training registers
- ERCG – ROTL Documentation
- Care Plans
- MDT Terms of Reference- Minutes
- Patient leaflets
- SystmOne – CNOMIS
- Key Worker system – patient information leaflets
- Palliative Care Information Folder
- Shared Drive
- Supervision records (number and type of sessions offered/attended
- Duty rotas, appraisal/PDP, staff discussion
- Discussions with Healthcare – Nurses –Doctors - Administration Staff - Social Care Staff – Chaplaincy – IMB - Palliative Care Leads – Health and Prison Staff – Safer Custody – Officers – FLO – palliative care champions - patients and prisoners - Specialist Palliative Care teams - Mental Health team - Family Significant others
- Questionnaires – Audit Results
- Focus groups
- Education Sessions

Glossary of Terms

Advance Care Planning (ACP): is a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. An ACP discussion might include:

- the individual's concerns and wishes,
- their important values or personal goals for care,
- their understanding about their illness and prognosis,
- their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these.

(Advance Care Planning: a Guide for Health and Social Care Staff NHS End of Life Care Programme, published February 2007, revised August 2008)

Advance decision: In the Mental Capacity Act this applies specifically to an advance decisions to refuse treatment (ADRT) - see below

Advance Directive/Advance Decision/Advance Decision to Refuse Treatment (ADRT): This is a decision to refuse specified treatment made in advance by a person who has capacity to do so. This decision only applies at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in section 24 (1) of the Mental Capacity Act. Specific rules apply to advance decisions to refuse life-sustaining treatment.

- An advance decision to refuse treatment can be made by someone over the age of 18 who has mental capacity;
- is a decision relating to refusal of specific treatment and may also include specific circumstances;
- will only come into effect if the individual loses capacity;
- only comes into effect if the treatment and any circumstances are those specifically identified in the advance decision;
- can be verbal, but if an advance decision includes refusal of life sustaining treatment, it must be in writing, signed and witnessed and include the statement 'even if life is at risk';
- is legally binding if valid and applicable to the circumstances.

Advance Statement: a statement that conveys a person's preferences, wishes, beliefs and statement values regarding their future care. The aim is to provide a guide to anyone who might have to make decisions in the person's best interest if that person has lost the capacity to make a decision

Best interests (in the context of patients lacking capacity to make a particular decision): Any decisions made, or anything done for a person who lacks capacity to make specific decisions must be in the person's best interests. The Mental Capacity Act 2005 (England and Wales) sets out how a best interests decision should be made. Any staff involved in the care of a person who lacks capacity should make sure a record is kept of the process of working out the best interests of that person for each relevant decision.

Mental Capacity: The ability of an individual to understand the issues of a decision, retain that information, weigh up the facts and communicate their decision. Capacity must be assumed in all individuals unless there is a suspicion of an impairment or disturbance of mind or brain. In this situation, capacity for that decision must be tested (see MCA 1&2 form in the resources section of the *Deciding Right* website). A person with capacity can make any decision they wish, even if others view that decision as illogical or unwise. Capacity is specific to the decision being made - therefore an individual can have capacity for one decision, but not another. If an individual lacks capacity for a specific decision, carers must make the decision following the best interest's requirements of the Mental Capacity Act (see MCA1&2 form in the resources section of the *Deciding Right* website).

Do not attempt cardiopulmonary resuscitation (DNACPR): A decision to withhold CPR in the event of a future arrest. Communication is a key part of making such a decision. Consent to refuse CPR is required if the individual has capacity for that decision *and* an arrest is anticipated *and* CPR could be successful. A DNACPR form is completed by a clinician with responsibility for the child, young person or adult. A DNACPR decision can be made for an individual who does not have capacity but must follow the best interest's requirements of the Mental Capacity Act.

End of Life Care: Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with: a) advanced, progressive, incurable conditions; b) general frailty and co-existing conditions that mean they are expected to die within 12 months; c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition; d) life-threatening acute conditions caused by sudden catastrophic events. In General Medical Council guidance the term 'approaching the end of life' also applies to those extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death.

Family Liaison Officer: Is a member of prison staff who will act on behalf of the governor following a death in custody, a prisoner becoming critically ill and/or receiving a terminal diagnosis and on other occasions where supporting a family is required. Provide immediate appropriate information to the family concerning the death of their relative or other person. Offer to attend the funeral and act as the named point of contact for the family they have been assigned, managing the day-to-day partnership between the prison and the family before and after the inquest. Support families leading up to and during the inquest and offer support, practical help and advice. They will also liaise with other key agencies.

Guidance: this refers to local instructions issued to assist staff in the delivery of palliative end life care. These can be both clinical and operational.

Holistic Care: takes all of the individuals needs into consideration. This will include physical emotional psychological spiritual needs.

Key Worker: A qualified Nurse who, with the patient's consent and agreement takes a key role in co-ordinating the patient's care, promoting continuity, ensuring the patient knows who to access for information and advice.

MDT: Multi-Disciplinary Team – the core MDT would usually comprise key workers, palliative care leads, safer custody, chaplaincy, FLO, GP, the individual and their residential manager. Although grade is not important there needs to be involvement from people with authority to make decisions.

Open Cell Door: A process to assess when up to 24-hour healthcare staff access is required to the individual's cell to meet individual healthcare needs. For example, to provide end of life care or when a syringe pump is in use.

Palliative Care: Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's illness and in their own bereavement; uses a team approach to address the needs of patients and their families; enhances quality of life and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications. Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions.

Palliative End of Life Care Register: A register of patients with supportive palliative and end of life care needs. The register identifies both cancer and non-cancer patients who may be in the last year of life.

Preferred place of Care: The individuals preferred place of care and death.

Permitted place of care: The place the individual is allowed to be care for following risk assessment and multidisciplinary discussion

Person Centered Care: A term for healthcare and social services which reflect the individual's unique preferences, values and needs, identified and agreed upon in partnership with the individual.

Specialist Palliative Care: The active total care of individuals with progressive, advanced disease and (of) their families, care is provided by a multidisciplinary team who have undergone recognised specialist palliative care training.

Stakeholder: may be patients, caregivers, clinicians, prison staff, researchers, advocacy groups, professional societies, businesses, policymakers.

Useful Links and References

Below you will find a list of helpful links for both healthcare and prison staff. Please ensure that you access the most up-to-date guidance and information available. **You will find the Dying Well in Custody Charter and Self-Assessment tool here - Ambitions website and Special Interest Prisons including Dying Well in Custody Charter http://endoflifecareambitions.org.uk/tag/prisons/**

- All PPO Reports available www.ppo.gov.uk
- Advance decision to refuse treatment [NHS CHOICES GUIDE]
- Core Competencies end of life https://www.nwcscnsenate.nhs.uk/files/7314/3505/4519/core_competencies_for_end_of_life_care.pdf?PDFPATHWAY=PDF
- Deciding Right « NECN Advance Decision Deciding Right « NECN
- E Learning - https://www.nwcscnsenate.nhs.uk/strategic-clinical-network/our-networks/palliative-and-end-life-care/network-groups/education-strategy-sub-group/e-elca/ http://www.e-lfh.org.uk/programmes/end-of-life-care/
- Graham Judgement.
- Links to patient information NHS CHOICES GUIDE
- Lasting Power of Attorney [NHS CHOICES GUIDE]
- Macmillan Cancer Support https://www.macmillan.org.uk/
- National Council for Palliative Care http://www.ncpc.org.uk/
- NICE guidance https://www.nice.org.uk/guidance
- https://www.nice.org.uk/guidance/ng31 – New Guidelines on Care of dying adults in the last days of life (NICE)
- PPO bulletins / website PPO lessons learned (PDF Download)
- Preferred priorities of care www.dyingmatters.org/sites/default/files/user/images/PPC final
- 5 Priorities for Care of the Dying Person
- https://www.palliativedrugs.com/ (subscription required)
- quick guide to identifying patients for supportive and palliative care
- RESPECT https://respectprocess.org.uk/faqs.php

- [Resuscitation – Decisions relating to cardio pulmonary resuscitation]
- Safer Custody Group learning bulletins Safer Custody Bulletins
- Supportive & Palliative Care Indicators Tool *https://www.spict.org.uk/*
- Palliative Care for People with Learning Disabilities network http://www.pcpld.org/
- PPO Older Prisoners Report http://www.ppo.gov.uk/app/uploads/2017/06/6-3460_PPO_Older-Prisoners_WEB.pdf
- The Gold Standards Framework http://www.goldstandardsframework.org.uk/
- http://www.dc.nihr.ac.uk/themed-reviews/Better%20endings%20FINAL%20DH%20single%20page.pdf – Better Endings – right care, right place, right time
- https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/496231/Faith_at_end_of_life_-_a_resource.pdf – Faith at the end of life

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Members of the Community of Practice Steering Group included:

- Gill Scott — Macmillan Palliative End of Life Care Lead North East Prisons, County Durham and Darlington FT
- Fiona Grossick — National Clinical Quality Lead Nurse Health and Justice
- Sarah Whyte — Macmillan Project Lead for Palliative and End of Life Care HMP Stafford Staffordshire and Stoke on Trent Partnership Trust
- Sue Rafferty — Intervention Manager Palliative Care Lead HMP Frankland
- Nicola Spencer — Programme Support Manager End of Life Care NHS England
- Mick Butler — Custodial Manager End of Life Care Lead Officer HMP Wymott
- Annelise Matthews — Consultant in Palliative Medicine Sue Ryder Hospice
- Nigel Jones — Equity and Diversity Lead HMP Littlehay
- Annette Edwards — Consultant in Palliative Medicine Leeds Teaching Hospitals NHS Trust / Sue Ryder
- Vikki Levick — Equality, Rights and Decency Group National Offender Management Service
- Jacqui Hallam — Macmillan Learning and Development Manager North England
- Lorraine McBride — Macmillan Project Lead for Palliative and End of Life Care in Prisons Compton Hospice
- Lily Beckwith — Senior Nurse Palliative Care Lead HMP Low Newton
- Helen Parker — Head of Medical Operations Spectrum Community Healthcare CIC North East Prisons
- Rebecca Daddow — Macmillan PABC Leadership and Support Programme Lead

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