

Report Title	Supporting a Good Death in an Integrated Care Organisation		
Sponsoring Executive	Paula Gardner Chief Nurse, David Carruthers Medical Director		
Report Author	Tammy Davies Group Director PCCT, Paula Gardner Chief Nurse, David Carruthers Medical Director		
Meeting	Trust Board (Public)	Date	4th June 2020

1. Suggested discussion points *[two or three issues you consider the Trust Board should focus on]*

The definition of a good death is unique to each individual and can only be achieved by communicating with patients and their carers to ascertain their wishes and provide sufficient information to enable informed choices. In line with national data, the Trust finds that people cared for by the specialist palliative care team have more positive experiences at the end of their lives with fewer unnecessary interventions, dying in a place of their choosing. Access to the palliative care team is variable and significantly less likely for people with non-cancer diagnoses who are from BAME groups. It is therefore, imperative that access to specialist palliative care is improved. However, this should not be pursued in isolation; delivering high quality end of life care is required from all staff.

The paper narrates the current Trust position, highlighting strengths and exploring areas for improvement. A focus on lessons learnt from the covid-19 pandemic and the importance of patient centred treatment escalation plans is presented.

2. Alignment to 2020 Vision *[indicate with an 'X' which Plan this paper supports]*

Safety Plan	X	Public Health Plan	x	People Plan & Education Plan	
Quality Plan	x	Research and Development	x	Estates Plan	
Financial Plan		Digital Plan		Other <i>[specify in the paper]</i>	

3. Previous consideration *[where has this paper been previously discussed?]*

Patient stories in recent Board meetings

4. Recommendation(s)

The Trust Board is asked to:

- a. **Discuss good practice and areas for improvement**
- b. **Note** work underway to further improve patient outcomes
- c. **Agree** the recommendations for further improvements to the delivery of end of life

5. Impact *[indicate with an 'X' which governance initiatives this matter relates to and where shown elaborate]*

Trust Risk Register					
Board Assurance Framework					
Equality Impact Assessment	Is this required?	Y		N	x
Quality Impact Assessment	Is this required?	Y		N	x

SANDWELL AND WEST BIRMINGHAM HOSPITALS NHS TRUST

Report to the Public Trust Board: 4th June 2020

Supporting a Good Death in an Integrated Care Organisation

1. Introduction

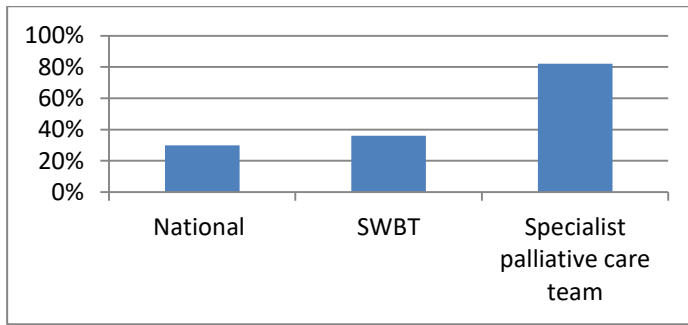
- 1.1 Defining a good death is problematic as it relies on the assumption that all people have similar views and requirements. In reality this is a personal view with cultural, family and experiential influences. The definition from the National Palliative and End of Life Care Partnership offers a general encompassing overview but should still be adopted with caution and an emphasis on individual wishes

"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".

- 1.2 Traditional outcome measures to evaluate end of life care centre on key factors such as achieving preferred place of death and reducing unnecessary hospital admissions. However, such markers assume their priority for the individual patient. In reality we can only understand the meaning of good by asking the individual. This relies on clinical staff and others across the health and social care system identifying those most at risk of dying, communicating compassionately, assessing individual needs and planning appropriately.
- 1.3 The following paper narrates the current Trust position for delivering good end of life care compared with national data with an emphasis on accessibility of services. Barriers to achieving good are discussed alongside lessons learnt from the Covid-19 pandemic and suggestions for future practice.

2. Trust position

- 2.1 Despite a favourable Trust position against national data, there remains a significant difference between the experiences of patients at the end of life for those with involvement from the palliative care service compared to those without across all recorded metrics including achieving preferred place of death.



% of people achieving preferred place of death

- 2.2 The inequity of experience is further compounded by the under-representation of certain groups within the community. The majority of the current specialist palliative care caseload is White British (68%) with low numbers of people from LGBTQ groups which is difficult to fully quantify due to a lack of recording in electronic records. People with learning or sensory disabilities are also under-represented (1%).
- 2.3 In 2018 SWBT participated in the **National Audit of care at the End of Life**. Audit methodology included randomly selecting and reviewing medical records of adult patients dying in hospital in May and June 2018. Selection criteria included those that were in hospital more than 24 hours, were recognised as dying or were not recognised as dying but had a life limiting diagnosis. The audit identified areas of good practice such the provision of high levels of practical support and symptom control. However, results were less favourable regarding communicating with patients and relatives / carers. Despite documenting the likelihood of imminent death, discussions with patients were only documented in 52% of cases. In addition only 47% of patients and / or their carers were involved in discussing plans of care and treatment.
- 2.4 The audit is due to be repeated this year with a detailed action plan underway to facilitate improvement. However, the trends in complaints suggest that communication with people and their carers at the end of life remains at times substandard and improvement in this area is required to produce an overall increase in patient and carer experience.

3. Barriers to achieving a good death

- 3.1 Both national and local data indicate a correlation between poor communication by clinical staff and a substandard end of life experience. Successful communication with dying people requires the following key elements:
- Ascertaining what the individual wants to know
 - Discussing the reality of the situation (honest account of prognosis)
 - Assessing individual requirements including treatment options (advance planning)

A positive experience also requires a compassionate communication style undertaken at the right time in the right place. However, despite these basic requirements there are many examples of conversations not taking place at all or taking place in a rushed manner in a busy ward or clinic.

- 3.2 Medical and pre-registration nurse education has evolved to include components of end of life care and specifically communication skills training but there remains a disparity in how this translates to practice. Explanations such as prognostic uncertainty, pre-eminence of the curative medical model and fear of causing distress are often sighted. In reality, the avoidance of communication leads to poor care in other areas such as an increase in non-beneficial (often painful) interventions, lack of choice for patients and a reduction in symptom control.

- 3.3 **Public perception** of end of life care planning influences the willingness of clinicians to engage in end of life discussions with fear of litigation. Equally this avoidance further exacerbates public perception. For example, cases where clinicians only discuss do not attempt cardiopulmonary resuscitation (DNACPR) orders in isolation rather than as 1 aspect of an appropriate treatment plan, compound perception that care of the dying is centred on withdrawing treatment. The misconception that CPR success rate is high (in reality only 18%) is driven by the lack of full and clear explanation by clinicians. An appetite for 'last chance' medications and interventions can be improved with clear and honest explanations of the risk benefit ratio.
- 3.4 Avoidance of communication and advance planning frequently leads to rapid deterioration of patients during **out of hour's periods**, both in hospital and at home. Decision making is then required by staff who do not fully know the patient and over treatment often results. A unsubstantiated belief that under-treatment rather than over-treatment causes more harm and fear of making inappropriate decisions further influence actions. Decisions to resuscitate, for example, are often made by on call teams and nursing staff due to a lack of documented escalation of treatment plans. This leads to poor patient and carer experience in addition to unsatisfactory experiences for the staff involved.
- 3.5 **Lack of perceived time** by clinicians to engage in therapeutic and meaningful conversations with dying patients is sighted as a barrier. Rushed conversations are both futile and inappropriate; however it is not a requirement to discuss every aspect of care at 1 time; frequent short interactions can be more beneficial. A review of Trust fast track data has found that patients were in hospital for an average of 10 days prior to referral for fast track support. Likewise, in General Practice patients make frequent visits to the surgery prior to initiation of palliative care. This suggests there is sufficient opportunity to communicate the situation and plan care with the patient.

4. Lessons from the covid-19 pandemic

- 4.1 Significant numbers of patients admitted with covid-19 had multiple comorbidities and poor outcomes. During the initial surge in admissions, high volumes of deaths in the acute medical units in people who underwent non-beneficial treatments were noted. However, the demand on services and redistribution of resource to support the pandemic necessitated focused support from the palliative care team. A 'pull' model to identify patients rather than wait for referrals enabled earlier specialist intervention and decision making. There was also frequent evidence of team based decision making within and across teams to support decision making.
- 4.2 To support good end of life care, Leasowes intermediate care centre has been transformed to provide a 20 bedded specialist end of life care ward with single room, hospice style facilities and support from the specialist palliative care team and Your Health Partnership (YHP) GPs. Both anecdotal evidence and reviews of relative / carer experience indicates that this provision had favourable outcomes and led to a good end

of life experience. Systematic Judgement Reviews are being undertaken for deaths that occurred to assess lessons learnt. However, evidence to date supports the notion that rapid decision making and provision of supportive care for dying people improved experience.

5.0 Recommendations for future practice

- 5.1 Data suggests that achieving a good death is less likely for certain groups, with certain diagnoses and particularly those not cared for by specialist palliative care teams. However, reliance on increasing referrals to the specialist palliative care team in isolation is unlikely to be sufficient. Caring for dying people is a key skill required by all clinical staff and improving overall patient experience will only be achieved through a workforce confident and competent in delivering end of life care.
- 5.2 Significant investment by the Trust to improve end of life care through the **Quality Plan** and the recruitment of 2 additional palliative care consultants will focus on improving access to the service by working with community groups, GPs and specialties with low referrals. In addition there will be a focus on enabling teams through coaching to develop skills in identifying dying patients, communicating appropriately and planning treatment. Palliative care clinicians will work alongside other acute speciality teams and GPs to enable teams to improve outcomes. Altering the mind-set of clinicians from one where carrying out unnecessary interventions is seen as causing less harm than not doing so is vital. In addition raising the confidence of all members of the team to challenge decisions constructively is anticipated to further improve experience.
- 5.3 Effective communication and appropriate patient centred treatment plans will only produce successful outcomes if plans are documented and shared across the health-care system. The utilisation of **treatment escalation plans** for all patients admitted to hospital can significantly reduce harm caused by inappropriate interventions at the end of life. In addition they significantly improve continuity and communication out of hours. Treatment escalation plans are intended to provide information about, as well as appropriate limitations to interventions which are likely to be futile and contrary to the patient's wishes. It is imperative that completed documents are guided by discussions with the patient and updated as the clinical situation evolves. **The Recommended Summary Plan for Emergency Treatment and care (ReSPECT)** provides detailed tools for the recording of plans and would provide a standardised format for the Trust to adopt. Suitable options are being explored with a digital focus to further ensure sharing capabilities.
- 5.4 In order to alert clinical staff to recognise people with altered treatment escalation plans, processes such as the use of purple wrist bands as a form of identification have been considered. However, their use does not improve the initial identification of individual needs or facilitate the required levels of communication. In addition there are associated risks in the assumptions that may be made about the exact nature of any alterations in treatment escalation. A system where every patient receiving medical care in hospital and the community has a documented plan which is reviewed at all encounters in conjunction with the patient and carers is the gold standard.

6.0 Recommendations

6.1 The Trust Board is asked to:

- a. **Discuss** good practice and areas for improvement
- b. **Note** work underway to further improve patient outcomes
- c. **Agree** the recommendations for further improvements to the delivery of end of life care

Tammy Davies
Group Director, Primary Care, Community and Therapies

04 June 2020