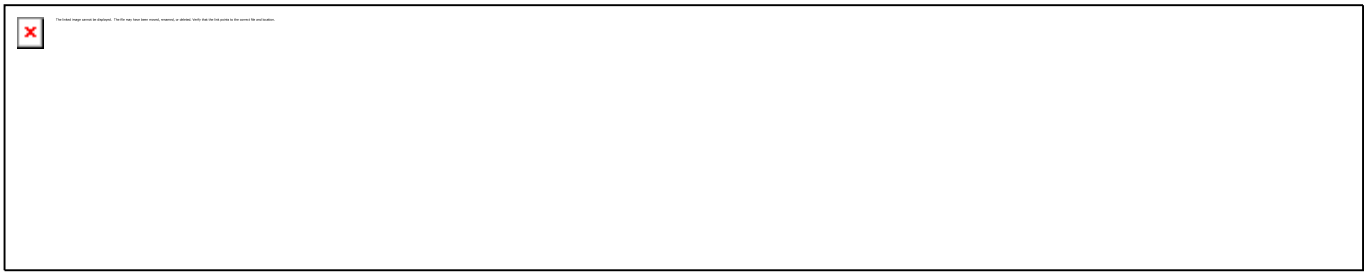

END OF LIFE CARE IN MIDDLESBROUGH

EXECUTIVE SUMMARY

1. As the Health Scrutiny Panel progressed through its work programme in 2009/10, it held numerous debates around range of topics including emerging national policy, the performance of the local NHS, how high performance could be maintained and propagated and areas for improvement. On numerous occasions, the Panel heard the view expressed by senior officers from the local health and social care economy that End Of Life Care in Middlesbrough, was an area in need of development and improvement. This, allied with the higher national profile afforded to End of Life by the publication of the first national strategy, convinced the Panel that it was a good time to consider End of Life Care in Middlesbrough.

2. End of Life Care is an emotive and sensitive topic to consider, perhaps necessarily so. Death and how society cares for the dying remains, to some extent, a taboo topic that people do not wish to speak about. Indeed, the Panel has come across the view more than once that to speak about it is somewhat morbid and macabre.

3. Still, we live in a time when around 60% of deaths could be considered to be predictable or expected, following illness or frailty. We also live in a time when the proportion of older people in the population is increasing and sadly, death becomes more likely the older one becomes.

4. The changing nature of society and the sorts of death that are prevalent is something that the Panel has heard a great deal about. As Professor Edwin Pugh advised the Panel, the three great causes of death in 1900 were infectious disease, childbirth and accident. These sorts of deaths are relatively quick and do not include a great period of disability, nor require a great deal of support, before death occurs. End of Life Care, therefore, in such an environment is understandably not a major concern.

5. The changing nature of health and healthcare problems, however, now dictates that other causes of death have now become the most prevalent. Such diseases as cancer, dementia and COPD[1] are now significant causes of death, yet are increasingly ‘treatable’, with some

[1] Chronic Obstructive Pulmonary Disease

people even being cured of cancer. Nonetheless, the advances of medicine dictate that even those who eventually lose the fight against such illnesses, will have had treatment for their conditions and as such, will live longer with the illness before dying. The fact that people are living with illnesses for longer before dying, raises the very obvious questions of how does, and how should, society support such people at the end of their lives.

6. Demographics indicate that such considerations about End of Life Care should become a bigger and bigger part of health service planning. Gomes & Higginson[2] highlight that the Government's Actuary Department predict that from 2012, there will be a gradual increase in deaths. There are expected to be nearly 590,000 deaths per year in 2030, which is 16.5% more than in 2012. By then, those aged 65 and over will account for 86.7% of all deaths and the very elderly (85 and over) for 43.5%.

7 Aside from *how* we care for people at the end of their life, there is also a debate to be had about *where* we care for them. The Panel has heard a great deal of views expressed about where people die and the choice that people can, or can't exercise, when they are at the end of life. The Panel has heard that around 40% of deaths are those that could not be predicted and it is inevitable that a high proportion of those will take place in hospital.

8. It is the place of death for the 60% of deaths that could be considered to be expected or predictable that the Panel wanted to explore. Gomes & Higginson have highlighted that non-NHS institution deaths have decreased, whilst deaths in NHS hospitals have increased considerably[3].

9. The key question to explore is whether society, and those at the end of their life, want to receive their end of life care in an acute hospital setting, or whether there are other options for people, such as at home or in a hospice setting. The Panel has heard that it is key to given people choice over this and to respect that choice. Of course, those choices can only be respected and honoured, if the capacity of services allows for the exercising of that choice.

10. Research indicates that a significant number of people would choose to not die in a hospital, although whether services have the capacity to meet those demands is another issue. It would certainly appear to the Panel that there is presently a huge disparity between preferences and reality. Gomes and Higginson highlight this point perfectly when they say

---

[2] Where people die (1974-2030): past trends, future projections and implications for care. Barbara Gomes and Irene J. Higginson, Palliative Medicine 2008;22;33

[3] ibid

"In England and Wales the trend up until 2003 has been for decreasing numbers and proportions of deaths at home, especially among older people. A reversal of this trend will be an enormous task."

11. As such, the Panel explores in the report how, if those choices are to be respected and acted upon, what is it about services that need to change?

12. Either way, demographics highlight that an expansion of palliative care services is inevitable, such is the likely increase in deaths. The question that remains is where does that expansion take place, in community based services? Hospices? Acute centres? Or should it be a combination of all three? Gomes and Higginson again demonstrate this point clearly when they say

Either inpatient facilities must increase substantially, or many more people will need community care towards the end of life from 2012 onwards.

13. The evidence that the Panel has collected is fairly clear: End of Life Care in Middlesbrough needs development and quickly. A question that remains is what do we develop? Do we invest more and more in expensive acute facilities when evidence indicates that most people don't want to die there, or do we reinvest resources in community and hospice services? That is a question for the local health and social care economy to answer and answer it must, fairly swiftly.

Conclusions

14**.** EOLC is not commissioned or provided in a vacuum and people in the local health and social care system appreciate perfectly well the challenges that national budgetary retrenchment will bring. Given this reality, it seems all the more surprising that the local health system does not seem to be sufficiently addressing the numbers of unnecessary admissions into JCUH at the end of life, which are an expensive and (often) undesirable way of managing someone's care at the end of life. Having made that point, the evidence is fairly clear that there has not been sufficient historical investment in community based services to be able to accommodate the desired shift on End of Life Care provision and this remains a pressing concern. That is, if people were to begin to exercise more choice over their preferred place of care (and death) and it was away from hospital, community services would struggle to cope with the demand.

15. The Panel has heard the unanimous view that lowering the numbers of unnecessary admissions into JCUH for people at the end of life, would typically be a better experience for patients and create significant savings, which could to be invested elsewhere, over time. With that in mind, the Panel finds it very surprising, and rather alarming, that the Teesside Hospice Care Foundation is expected to run a 24 hours

advice telephone line 'out of goodwill'. NHS Middlesbrough has, however, previously decided against commissioning the service, whilst advising the Panel that the development of a telephone line is required. The Panel has heard that the prime reason for the admission of people at the end of life is that there are very little other forms of support for people and their carers, and admittance to JCUH often represents the last resort. It strikes the Panel that an adequately resourced telephone advice line could be a very useful tool in keeping as many people as possible in their preferred place to receive their EOLC. The fact that NHS Middlesbrough has not invested in the (apparently much needed) advice line, despite two formal bids supported by South Tees Hospitals Foundation Trust, leaves the Panel uncomfortable.

16. Presently, the Middlesbrough health and social care system does not offer a viable alternative, on a sufficient scale, to dying in hospital, for those who may require some clinical assistance in the last days of life. The Panel has heard that hospices would have to increase capacity by six fold to accommodate those who say they would prefer to use a hospice, according to the 'Good Death' research. Further, community services are not provided on a sufficient scale to keep people out of hospital when their health deteriorates. This is especially true when one considers the apparent paucity of appropriate service provision in the 'Out of Hours' period, as most services dedicated to EOLC seem to be concentrated on a 8am-6pm, Monday to Friday basis. The Panel has learned that a 'typical scenario' exists where:

A Patient's health worsens 'out of hours', relatives/carers understandably worry and call for assistance and those attending (usually an Out of Hours GP or ambulance) do not understand the patient's situation. They adopt a safety first approach and typically admit into the patient into hospital and the person often dies shortly after admittance and often after unnecessary tests have been performed by JCUH, who also do not know the patient's situation.

Until there is adequate 24-hour service provision, the aim to have more people receiving EOLC outside of hospital will never become a reality, as 24 hour service provision is the biggest single issue. The Panel would point to the experience in North Tees and the Butterwick Hospice regarding the reduction of hospital admissions, that an adequately commissioned and provided out of hours service can have. The absence of such a service in Middlesbrough is very significant.

17. The Panel has heard a great deal about the fairly recent orthodoxy, which states that if someone is dying, it indisputably follows that they need to be in a hospital environment with doctors on hand. The logical conclusion of this approach is that everyone, irrespective of medical complaint, dies in hospital. We already know that this is not necessary, or in line with what people in that position tend to want. As such, this orthodoxy requires strong challenge. As society, and specifically

society's ability to treat illness has advanced, the Panel has heard that a culture has developed that views death as a failure and a failure for health services. It is the Panels view, that death should not be seen as a failure of health services, but a normal part of the life cycle. Death, per se, should not be seen as a failure of the health and social care system, but a death where the patient does not have their wishes applied, or is not able to exercise choice over their death, should certainly be seen as a failure of the system. In short, death is not a failure of the system, but a bad death is.

18. The Panel has discussed the concept of compassionate communities and specifically, empowering communities to support their members through their end of life and those bereaved. The Panel has heard that as death has become 'medicalised', communities have almost learned to fear death and not to consider it a matter for them. Communities behaving compassionately towards those facing the end of life and their carers, is something tangible that can be done and recognises that death is a natural event. The Panel is pleased to note that Middlesbrough Council already has in place a carers leave policy, where members of staff would be able to assist loved ones at the end of life, whilst still receiving full pay (for a maximum of 5 days). This is a very good example of a compassionate community approach.

19. The Panel has been impressed with the role of JCUH to date in the consideration of EOLC in Middlesbrough and how it can be developed. The Panel would point to the project aimed at rapid discharge as an example of the Trust's commitment to improving the End of Life Care experience in Middlesbrough.

20. The panel would express a concern over the progress that can be made over the development to EOLC services when one considers the limited future of Primary Care Trusts. The Panel has considered a great deal of evidence pertaining to End of life Care, which indicates that the areas for improvement centre on the capacity of existing services and gaps that exist in service provision. The development of new services and improving the capacity of existing services is essentially a commissioning function. The Panel is concerned whether those commissioning needs can be met, given the limited lifespan on PCTs and the uncertainty surrounding the mechanisms to replace them.

21. The Panel has heard from the Cleveland Local Medical Committee that EOLC is an area that General Practice considers of crucial importance and values its contribution to and involvement in, very much. Given this and the clear need for developments in EOLC, the Panel considers that there is an opportunity for the local health and social care economy to develop and test service models under the arrangements described in the *Liberating the NHS – Equity & Excellence* White Paper. The consensus around EOLC's importance and the need for improvement

makes it an obvious priority, which could also assist in developing and testing the new commissioning arrangements.

22. The economic turbulence of recent years and the climate that still prevails has had a noticeable and detrimental impact on the financial viability of hospices. Public donations are predictably under pressure and NHS commissioners appear to favour contracting with such organisations on a yearly basis, which creates its own pressures and uncertainty. The Panel fully understands and accepts the financial picture facing commissioners of health and social care. Still, the Panel feels that there should be an explicit recognition of the important role that hospices play in the provision of EOLC and Commissioners plans should reflect that. It is in the local health and social care economy's own interest to have strong and financially viable hospices to commission and call upon. Delivering high quality EOLC in any locality would become significantly more difficult without an active and viable hospice sector and this needs to be recognised.

23. The Panel has considered demographic projections relating to End of Life Care and those projections have stayed with the Panel. The United Kingdom has an ageing population and from 2012 will experience a gradual, but significant, upturn in the numbers of deaths. The numbers of deaths is, however, only half the story. As people live longer and healthier lives, with better and better access to medical technology, they will have longer periods of ill health or disability before they die, creating a greater demand for end of life care. Our health and social care system stands at this juncture with the option of continuing to do the same thing and essentially build bigger and bigger acute hospitals, with greater and greater sections of those facilities dedicated to end of life care. Alternatively, it can look to develop a network of sustainable local services, aimed at keeping people in their preferred place of care, which will probably be a more positive experience and represent greater value for the taxpayer. It is, however, absolutely clear that service development needs to begins soon, to better meet the expectations and wishes of those at the end of life now and future generations. Current practice is not sustainable either financially or if we are to better meet people's wishes.

24. The Panel has heard of the progress made in increasing the uptake and application of the Gold Standards Framework, particularly within a nursing home environment. It is of crucial importance that staff in homes are empowered to provide care for residents and therefore keep people there for longer and avoid unnecessary admissions. It is, however, worth noting that staff in such facilities are not, typically, highly paid and it places a great deal of responsibility on them. The Panel also noted evidence that perhaps unsurprisingly, nursing homes tend to have a better record at keeping people at the end of life for longer, whereas residential homes are typically quicker to suggest or arrange an admission. It may be that further work is required with the residential sector, to empower staff to keep residents at home for

longer, when they are at the end of life. The Panel was interested in the idea put forward by the Consultant from JCUH, of Middlesbrough having a few 'superhomes' with particularly high levels of skill relating to EOLC. Those homes could be rewarded with a higher tariff, which could encompass better pay for staff with certain expertise. It would be interested to see if this idea could be progressed.

Recommendations

25. The Panel has gathered a great deal of evidence, from a range of different sources on the topic of End of Life Care in Middlesbrough. The Panel has come across some areas of disagreement, particularly around how services could be configured to deliver end of life care. The Panel has, however, found that one view is held unanimously and that is that End of Life Care in Middlesbrough is not working well and needs significant consideration and development, as a matter of urgency. The following is recommended:

26. That the emerging GP Commissioning Consortia, Department of Social Care and NHS Middlesbrough engage to conduct a root and branch review of End of Life Care in Middlesbrough. That review should identify a new 'whole system' strategic vision for End of Life Care, which should be articulated in new strategy for the development of End of Life Care Services (and their capacity) in Middlesbrough. This is all the more essential given that NHS Middlesbrough's Strategy Delivery Groups, including the one focused on End of Life Care, have been discontinued. The new strategy should include the following:

- How patient choice will become a more important factor in the location of someone's end of life care and death

- How the system can better share care plans so patients wishes and status as an end of life care patient can be more widely known, particularly by paramedics and out of hours GPs

- How commissioners will continue to support the rapid discharge programme from JCUH, when its current grant funding expires

- Explicit articulation as to how community services for end of life care and hospice services will be improved and developed in both range and capacity to meet anticipated demand. The Panel feels that community services for End of Life Care should be led by a community based physician, of consultant rank, and supported by specialist GPs.

- How an adequately resourced telephone advice line for those at the end of life and their carers will be provided and made sustainable through mainstream funding. Further, how that phoneline will connect to community teams providing end of life care

- How services will become significantly more 24/7 in focus

- How residential and nursing homes will become an integral aspect of the delivery of high quality end of life care in Middlesbrough, whilst receiving adequate medical support

- The timescales this will be achieved by

- Measures by which the End of Life Care Strategy's implementation can be judged

- An explicit reference to the level of financial resource dedicated to the improvement of End of Life Care

- A commissioning plan as to how the above will be achieved.

The Health Scrutiny Panel would like to be involved with the development of that strategy.

27. NHS Middlesbrough and the Department of Social Care satisfy themselves that commissioned nursing and residential homes have sufficient capacity, support and skill to facilitate effective End of Life Care on their premises. The Panel would like to hear the outcome of this.