



# LIVING WELL AND DYING WELL

Ensuring modern, sustainable Hospice provision as an integral part of an integrated Health and Social Care Service across Greater Manchester:

**Report by James Frith MP**

“”

*What gives a life meaning is not only how it is lived but how it draws to a close*

**Baroness, Rt Hon. Tessa Jowell**

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# EXECUTIVE SUMMARY

## FINDINGS

1. Hospices are underfunded and overlooked in existing health and social care model
2. Huge disparity between NHS funding of hospices
3. Underrepresentation of non-cancer, Black, Asian and Minority Ethnic (BAME), Lesbian, Gay, Bisexual, Transgender, plus (LGBT+) and other marginalised patients
4. A third of people dying in hospital have no clinical need or preference to be there
5. Under-occupancy as high as 65%

## RECOMMENDATIONS

1. Create clear, sustainable, long-term funding plans for all hospices
2. Expand and secure hospice provision and the perception of hospices for better inclusivity in a diverse, modern health and social care service with a Greater Manchester MP and Mayoral-led campaign to discuss what *dying well* looks like for every one of us
3. Establish more consistent *Continuing Health Care and Spot Commissioning* funding plans to ensure patient choice is protected to allow for appropriate hospice care - at hospice, at home or community-led
4. Guarantee equity of access to hospice care for all patients, including non-cancer, BAME, LGBT+ and other marginalised groups.
5. Ensure referrals through GP, Hospital Consultant and all meaningful medical engagements include appropriate consideration of the expanded hospice provision via training and improved sharing of data.



1

Funding



2

Expansion



3

Commissioning



4

Equity



5

Referrals

## INTRODUCTION, JAMES FRITH MP

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***'After an aggressive six months since the diagnosis ambushed her and us all, my wife's brilliant mum lost her life to a predatory and ruthless cancer. Fortunately, there was time, just, to have the last loving conversations with her most-loved, including correctly predicting that her next grandchild would be a boy. But on a sweltering Sunday in June 2011 I stood consoling my heavily pregnant wife and our family in a busy hospital ward corridor during visiting hours, with Liz having died just moments before.***

***On reflection of this, treatment should immediately have been focused on life quality not quantity for Liz, as the months that followed her diagnosis included severe treatment-induced illness, depression and amputation; such is the relentless and non-discriminatory nature of chemotherapy and radiotherapy. And such is the rigidity of our approach to treating terminal illness, it really felt, and still does, that the treatment took months of life away from her. Instead of an honest conversation about living well with terminal illness before dying well we followed a standard pattern that is all too frequently experienced by many families.***

***My mother-in-law was in a busy hospital with the comings and goings of visiting hours and new patients with minor complaints in comparison. This is nobody's preferred place to die. Such is the state of things in the social care crisis we face. This un-answered crisis presents us with a timely opportunity to better integrate hospices into our formal NHS.'***

I am inspired to write this report and to have led this review of hospice provision in Greater Manchester because of my personal experience of the issues many patients and families face.

The argument is simple; that we must expand and involve a modern hospice care service in a long overdue overhaul of our healthcare system. I see little parliamentary focus on the challenges and questions I am posing, until now, and believe the problems extend from our lack, both culturally and medically, to discuss and make provision for living well before dying well. I see hospices as the conduit of the change that must be instigated to health and social care and the role they can play if they are integrated in to it.

My earlier report *Saving Bury Hospice Together* helped secure additional funding from the local NHS and sharpened focus on the challenges facing our local hospice. These issues included chronic underfunding and challenges with its governance and leadership. Following my election to Parliament I made supporting and strengthening the hospice one of my parliamentary priorities.

The devolution to Greater Manchester of our NHS budget means that we have a degree of self-determination to make the changes we need. I did not hesitate, after presenting my case for a review of Palliative and End of Life Care and hospice provision in GM to Mayor Andy Burnham and Jon Rouse at the GM Health and Wellbeing board, to take up their request that I review and report on the case for more integrated hospice provision across Greater Manchester.

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THE ARGUMENT IS SIMPLE; THAT WE HAVE TO EXPAND AND INVOLVE A MODERN HOSPICE CARE SERVICE IN A LONG OVERDUE OVERHAUL OF OUR HEALTH CARE SYSTEM.

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## YOUR LOCAL HOSPICE

It's a feature of life in many British towns that the local hospice is held dear to the heart of the community it serves. Hospices are vital community assets. Those of us familiar with or who have used the local hospice will be humbled at the commitment and dedication of the staff and the army of volunteers who care for and support patients and their families as life draws to a close. More of us still will be familiar with the efforts, donations and time given by communities, businesses and local press in support of hospices.

Hospices are an important part of our local care network, providing peaceful and comfortable conditions for patients and their loved ones. However, we need to ensure they are better integrated within our health and social care services in Greater Manchester. Where a local hospital will

focus on dealing with curing those who are ill, a hospice's primary focus is on the care of patients for whom cure is unlikely but the need for specialist end of life care is certain. Multi-disciplinary teams serve to provide care which gives freedom from pain and ensures dignity, peace and calm on the final lap and end of life.

This specialist care can include confident prescribing for pain control, symptom relief, skilled nursing care, counselling, complementary therapies, spiritual care, art or music therapy, physiotherapy, reminiscence, beauty treatments, bereavement support, hospice at home and day care. Our challenge here is to change the perception of hospices and what hospice care provides by demonstrating they offer far more than just care for the final days of life.

## How hospices can help the NHS improve choice and reduce costs for end of life care

### What is hospice care?



There are more than  
**220**  
hospices in the UK



**90%**  
of hospice care is  
delivered through day  
services or at home



**Hospice teams**  
work with  
**local hospitals**  
and  
**care homes**

[www.hospiceuk.org](http://www.hospiceuk.org)

Provided by Hospice UK

***'Even at the end of our lives we have hopes and aspirations. We want to be where we feel most comfortable, do what brings us joy, and have those we love by our side. We want to be, despite everything, ourselves'.*** Patient cared for in a hospice.

Hospice care aims to meet all the needs of the whole person; physical, emotional, social and spiritual. Hospices care for their patients at home, in day care or in the hospice itself, surrounded by those they love and are loved by. Special emphasis is given to controlling patients' pain and discomfort in a highly specialist and fully attentive palliative care setting.

Specialist Level Palliative Care is required by people with progressive life-limiting illness, with or without combined medical conditions where the focus of care is on quality of life for those with unresolved complex needs that cannot be met by the capability of their current care team. Throughout the trajectory of their illness - sometimes episodically, sometimes for prolonged periods - they may require expert assessment, advice, care and support from professionals who specialise in palliative care. These professionals work as part of multidisciplinary teams providing the service directly to the person with need - and those important to them - and /

or supporting other care teams to do so. Specialist level palliative care services are therefore an integral and core part of resourcing care for people who have been assessed as having more complex or complicated palliative care needs.

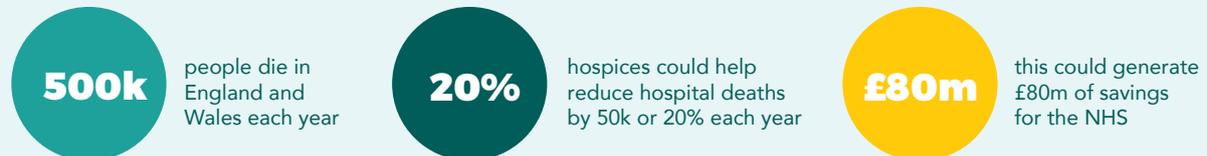
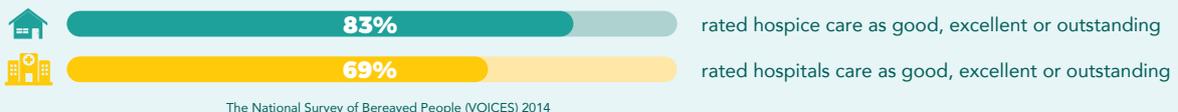
We need a wider, national conversation about what modern hospice and health and social care needs to become, tackling current perceptions of hospices to ensure we see them as providing more than care in the final days of our lives. Along with an affirmation that longer life expectancy is to be celebrated and we should not be afraid to discuss the concept of living well and dying well.

The term 'hospice' has a variety of meanings to each of us. Along with the expansion of services as detailed, a wider engagement with the public is needed. As well as the cited related care work undertaken by hospices in Greater Manchester, efforts including community use of buildings, complementary therapies and the leadership they can provide across the charitable sector will greater enhance public knowledge of their changing offer. For the hospices it's about fulfilling their potential, learning from each other and setting national or GM-wide standards. For the health professional it means far better education on and inclusion of the work hospices can do, providing the first point is met.

# HOSPICE FUNDING AND PROVISION

## How hospices can help the NHS improve choice and reduce costs for end of life care

### Good end of life care costs less



Hospice UK

[www.hospiceuk.org](http://www.hospiceuk.org)

Provided by Hospice UK

Hospice care has radically changed the way in which death and dying is approached.

In the UK, hospices rely heavily on charitable donations, gathering the majority of their funding from local communities through donations, legacies, fundraising, hospice charity shops, hospice lotteries and investments. Hospices do receive statutory funding, but this varies greatly across the UK. Overall, UK hospices receive on average **32%** of their income from the Government. In Greater Manchester, this is as low as **18%** in the case of Bury Hospice. Hospices in the UK need to raise around **£1 billion** a year, or about **£2.7 million** every day. UK hospices spent a total of **£1.4 billion** on their services last year, of which **£914 million** was spent directly on care, with the remainder on costs including fundraising, compliance and governance.<sup>1</sup> Donations fluctuate in line with the ebb and flow of local economies. Whilst hospices do an excellent job of raising money and this should continue as an important part of the funding mix, it should be alongside a longer-term funding plan commissioned in conjunction with health and social care services.

There is an as yet unanswered crisis growing in health and social care and the pressure on NHS

services in Greater Manchester is well documented. Additional resources are needed, but we also need to join up our health and social care system to avoid unnecessary waste and address the needs of the whole person. We know that many patients are staying in hospital longer than necessary, with delayed transfer of care (moving someone to a more suitable care environment) often higher than the national daily average.<sup>2</sup> Last year in Greater Manchester, the daily average number of delayed transfers of care per 100,000 population was 13 compared to the national average of 12.4<sup>3</sup>. Figures show that **£104 million** could be saved by reducing emergency hospital admissions and lengths of stay by **10%**<sup>4</sup>. Bed capacity remains an issue, though this is not the whole picture.

This review has highlighted that hospices are overlooked and can be further integrated as part of the patient's journey of care and to support and relieve some of the pressure on the wider health and social care system. In a recent written parliamentary question, the Department of Health confirmed that **no consultation** with hospices had taken place as part of its national response to the most recent NHS winter crisis.<sup>5</sup> Where were the conversations with our hospices and primary care

about providing extra capacity where appropriate and helping alleviate the pressure on local hospitals before operations were cancelled? Hospices could use their spare capacity in a flexible and productive way to provide access and support for patients with complex needs and therefore support the wider NHS. Hospitals are significantly affected by the issue of delayed transfer of care or the historic unpleasant term *bed blocking*.

In the winter of 2017/18, bed delays across Greater Manchester per occupied bed were at **3.8%** and occurred in **63%** of acute hospitals and **37%** of non-acute hospitals.<sup>6</sup> The main reasons for delayed discharges were:

- **Awaiting care package in own home**, which accounted for 21% of all delays in Greater Manchester.<sup>7</sup>
- **Awaiting residential and nursing home placements**, which, for example, accounted for as much as 30% of bed delays in Bury.<sup>8</sup>

We have significant under-occupancy in our hospices, ranging from **8% to 64%** (Wigan & Leigh and Bury respectively).<sup>9</sup> Some spare capacity is necessary, but we can devise a plan that establishes lead roles, specialist services and universal packages to address hospice under-occupancy and alleviate some pressure on our hospitals. This makes financial sense for both our hospices and hospitals. The cost per night for care in a hospice across Greater Manchester ranges from **£400 - £568**, with the more expensive rates applying to those with the lower occupancy rates.<sup>10</sup> In comparison the cost per night for care or 'hotel night' rate is on average **£400** for the same period on a hospital ward.<sup>11</sup> Better alignment would allow for a proportion of the hospital night rate to supplement the specialist care rate for hospice care thus reducing the cost of the both and simultaneously releasing capacity. The cost of care can be shared between a hospice's community and fundraising efforts and a strengthened agreement between hospice and acute care partners whilst delivering a fully attentive, specialist care package. This can be achieved through the efforts of all agents within a local NHS and social care conurbation and in practical terms is thought to be a Continuing Health Care (CHC) plan.

The experience of Greater Manchester hospices has highlighted a lot of variation across localities in how Clinical Commissioning Groups (CCGs) and commissioners interpret the CHC funding process.<sup>12</sup> This results in different financial treatments of patients who access this funding following discharge from acute care within hospitals. The CHC process should enhance patient choice, following the patient and enabling that person to receive the care they need in the place they want. For instance, if patients are transferred to a Care Home, then the funding follows the patient and the Care Home receives spot funding.<sup>13</sup> However, if the patient is transferred to a hospice, often no funding is received by the hospice and the full cost of care must be borne by the community through its charitable giving. The process can also be prohibitively bureaucratic, delaying discharge while hospices wait for a package of care to be put in place. This lack of consistency may actively restrict patient choice. It may also prevent the use of hospice beds to ease winter pressures where this is appropriate and practical.

Following this review, CHC funding following the patient in most such cases is advocated. It is in the interest of the patient to exercise choice, and for hospitals to enable earlier discharge. Fast track CHC funding for hospices should not encourage queue jumping over existing waiting lists, where those patients have less urgent or complex needs. CHC funding does not negatively affect CCGs' core contribution to hospices' costs, as CCGs potentially interpret this as the hospice being paid twice and respond accordingly.

It is important to caution against our hospices becoming seen as a place of intermediate care, enabling transfer out of hospital and arriving at hospice for those with no medical reason. I do challenge here though, that we might include aspects of what is known to be a step-down provision. It remains my view that for those patients in their final lap of life, experiencing hospice provision initially through a step-down plan will help expand the perception and involvement of hospices in the wider health eco-system. I well appreciate that the medical definition of such a plan needs reconciling to the policy idea, but it is kept here as a constructive challenge for us all to settle

on. Incorrect use of hospice care must be avoided. Appropriate use has to be protected along with the celebrated uniqueness and independence our hospices provide. Hospice discussions with local hospitals should centre on appropriate and timely referrals for nearing or at end of life patients and happen all year regardless of seasonality.

The acute hospital sector in our region demonstrates that a more detailed triage and robust hospital admissions policy prevents unnecessary in-patient related illnesses. The highest performing hospitals put significant emphasis on this increased triaging to ensure patients are put on the right advanced care plan, rather than just admitted to hospital.<sup>14</sup> This is a strong step forward in the management of patients for their own good health. Though the initial idea of being *turned around* takes some adjustment, it is based on clinical learning and is clinically led.

The high numbers of patients held up in hospital without a place or plan to be discharged emphasises the need to for more effective

discharge plans across Greater Manchester. It is also why expansion of hospice services should include provision for patients in transition (specifically for less complex patients). The answer for so many of us will come in the form of appropriate, timely advanced care plans. We need a greater mix of environments that patients can be sent to from hospital to better meet their needs. One such destination can be the hospice with its expanded offer of service in-hospice or at home and utilising the extraordinary dedication of loyal volunteers, their expertise and endless compassion.

In summary, there is evidence of disparity in sustainable funding arrangements across GM for hospice provision and this needs to be radically improved to enable universal standards, equality of access to funding and services for patients and their families and to complete the bid for integration across Greater Manchester. Further, bed delays and social care pressures are a real and growing issue as financial pressures continue and our hospices can play a part in alleviating some of this pressure.

## EQUITY OF ACCESS

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We know that more needs to be done nationally and across Greater Manchester to improve access to hospice services. Evidence from my Greater Manchester hospice survey and nationally from the Care Quality Commission demonstrates that non-cancer patients, Black, Asian and Minority and Ethnic (BAME) communities and LGBT+ people are under-represented in hospice care. Whilst there are cultural and historic reasons why some groups are more easily reachable by traditional means of engagement or find it easier to access medical support, evidence suggests it has proven harder to access hospice care for BAME, LGBT+, homeless and other marginalised groups.<sup>15</sup>

Currently, patients with a non-cancer diagnosis tend to be referred to hospice care in fewer numbers and later than those with a cancer diagnosis. Nationally, the average time from referral to death was found for those with **cancer** to be **53 days** and **non-cancer** to be **27 days**, although for dementia and stroke patients this is as little as **9 days**.<sup>16</sup> This review reminds us that across Greater Manchester people are living longer with increased complex health conditions. More patients require primary, secondary and specialist level palliative care, but for too many patients with advanced diseases their referral to hospice with an advanced care plan comes far too late after diagnosis. Data from the National Survey of Bereaved People (VOICES) highlights that people with non-cancer diagnoses were less likely to experience *outstanding* and *excellent* care in their last three months of life, compared with people who had cancer.<sup>17</sup>

Hospices should care for more of those suffering from a wider range of illnesses, including; motor-neurone disease, cardio-vascular diseases, dementia, multiple sclerosis, Parkinson's disease and many other life-shortening conditions. This might also include going further and contracting with specialist charities to provide respite and care for specific diseases, which in turn could provide further financial sustainability for hospices.

There are numerous difficulties with engaging BAME communities, including cultural and language barriers which need to be addressed individually and locally along with how hospices communicate with these groups. There is evidence that BAME groups

are less likely to access hospice and palliative care services in Greater Manchester and this needs urgent review and redress.<sup>18</sup> Existing evidence suggests that BAME groups may have more unmet end of life care needs as they experience several barriers in accessing good and personalised care.<sup>19</sup>

Analysis of data from the National Survey of Bereaved People (which asked about care in the last three months of life in England) revealed that people from BAME backgrounds were either more or at least as likely to receive help at home and less likely to rate overall care as outstanding or excellent, particularly among those who had spent time in a care home or hospice and are more likely to die in hospital than a care home.<sup>20</sup>

We know that members of the LGBT+ community are not accessing palliative and end of life care.

A study found **3 in 5** older gay people aren't confident that social care and supportive services will understand and meet their needs.<sup>21</sup> LGBT+ groups reported having varied support networks, in which next of kin may not be a relative and are often worried people won't understand.<sup>22</sup>

Our hospices in Greater Manchester strive to access *difficult to reach* groups and disadvantaged communities. They acknowledge the challenge and are proactive in expanding their services to include BAME and LGBT+ patients, prison and homeless populations, Urban Village and patients with special needs with an ethos of inclusivity. Additionally, GM hospices are doing some exemplary work to engage with non-cancer patients. Examples include Willow Wood hospice, which holds disease specific events at the hospice for MND sufferers and caters strongly for non-cancer patients. St Ann's Hospice formed a joint Motor Neurone Disease clinic with Salford Royal Hospital at Heald Green, so that MND patients from South Manchester would not have to travel all the way to Salford.<sup>23</sup> Greater Manchester hospices continue to spread their reach into 'difficult to reach' and disadvantaged communities and to extend their care to any patient in need of hospice care, irrespective of diagnosis; and to better understand why certain groups feel, if they do, that they cannot access the expertise of hospices' end of life palliative care.

## How hospices can help the NHS improve choice and reduce costs for end of life care

### Where do people want to die?

The VOICES survey found that...



but...



**50%**  
of us die in hospital

The National Survey of Bereaved People (VOICES) 2014

[www.hospiceuk.org](http://www.hospiceuk.org)

In Greater Manchester, many people dying in hospital have no clinical need or preference to be there.<sup>24</sup> Patients here would not choose hospital as their preferred place to die, with care experiences usually **rated lower** than the care available from hospices or the hospice at home service visiting the patients' own home.<sup>25</sup> It is worth noting however that not everyone in hospital who is going to die would need specialist palliative care. **82%** of people say that they would prefer to die at home, therefore community services more broadly (both health and social care) need investment to enable people to die in their preferred place.<sup>26</sup> Hospice services in the community have to be embedded in these expanded approaches, alongside or perhaps leading the other providers in each locality. For example, hospice at home, community specialist palliative care services, befriending, rehabilitation, domiciliary care and carer crisis prevention.

It must be made clear to NHS hospital providers and patients and families that hospice care and services are available for all those in need of end of life care. This further strengthens the argument that we need to change the perception of hospice care from last days of life, to life drawing to a close. If we want to deliver a high-quality hospice service, we must provide personalised end of life care for all and guarantee equity of access for all.

## DISCUSSING DYING WELL

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This review has highlighted that opportunities to discuss end of life care are regularly missed in hospitals, with evidence of lack of knowledge to recognise patients in need of palliative and end of life care, alongside inadequate training on how to deliver discussions on dying, both in a patients' final admission and in the final 3 months before admission.<sup>27</sup>

We know that **30%** of those non-electively admitted to hospital die within a year.<sup>28</sup> Being rushed to hospital is an unsettling and unnecessary experience for those coming to the end of life. With better preparation, training and data sharing we can improve referrals to palliative and end of life care and ensure better clinical provision sooner for patients as well as the better use of finite resources.

Hospice care in Greater Manchester supports thousands of patients each year who have end of life and life-limiting conditions.<sup>29</sup> This amounts to more than **four in ten** people of those estimated to need expert end of life care. We know that this number is set to rise with our ageing population. Without substantial reform to our health care system in Greater Manchester, hospices are at risk of being denied the support needed to transform and be sustained in preparation for growing demand.

If we are to change the approach and cultural perception to one of *living well with and dying well from*, the conversation about care should be a continued discussion over the length of a patient's illness trajectory. Honest conversations must take place in hospital settings which emphasise the importance of joined up care, which are as important for carers and families as patients. The

need for support from and for empathetic and competent healthcare staff is as important for carers, families and those who are bereaved, as it is for the dying.

A Consultant Doctor recommended to me Atul Gawande's excellent award-winning book *Being Mortal* in which he describes how we might have gotten here: **'I learned a lot of things in medical school, but mortality wasn't one of them... Our textbooks had almost nothing on ageing or frailty or dying. How the process unfolds, how people experience the end of their lives and how it affects those around them seemed beside the point.'**<sup>30</sup> There are structural and professional problems with the current approach. If you've heard about or experienced a loved one having a 'bad death' and listen as well to those who had a peaceful, loving, good death then you can begin to understand the need for talk. Notions of *passing away* can sanitise it. For some, the throws of death can be unnecessarily distressing and painful, as I have personally experienced. The use of deeply specialist expertise for the dying must feature as prominently as the attention and language we give the safe arrival of life.

We must foster a culture that embraces talking about dying well. One that promotes final advanced care plans. It's not always easy to know how to talk about dying. Awkwardness, embarrassment and, quite naturally, denial or fear can mean a reluctance to connect with those who are dying about the best preparations for what's ahead. I hope this report can ignite or amplify the national conversation we need about this all. A refusal to do so will only increase isolation, loneliness and distress at the end of life.

## PLAYING TO STRENGTHS AND PRACTICAL STEPS

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It is vital not to confuse the roles between hospital and hospice. By design or unintended consequence this must be resisted. One of the greatest strengths of our hospices is their charitable, independent status. Their better involvement in the health and social care system can afford the system greater flexibility and adaptability. There is a clear understanding across our health care system in Greater Manchester about what care should be provided by hospitals and hospices (acute care and specialist palliative care respectively, for example).

Better integration between acute hospital services and hospice care can be achieved by much earlier advance care planning, right at the point of diagnosis. Currently this is often missed, with discussions taken too late on in a patient's admission. Early intervention of palliative care teams and better education of health care professionals is imperative. The Greater Manchester hospice teams have expert clinicians and nurses

who could support and advise on this training programme, some which is already in place in some acute hospitals, but a Greater Manchester role out would ensure better equality for our patients.

Education and information efforts like the *Dying Matters* events are an excellent resource to educate health care workers and the public on what end of life care is.<sup>31</sup> Better integration with acute providers is key as documented, but the next key step is improved integration with community services, local support groups and established key points of contact as part of any enhanced contracting or future agreement. Key to all of this is better data sharing, benchmarking standards across the sector and key outcome data for patients. Sharing of data will ensure more and faster transition of patients between services and closer monitoring of standards, such as the Electronic Palliative Care Co-ordination System (EPACCs).

## RECOMMENDATIONS

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### 1. FUNDING

*Create clear, sustainable, long-term funding plans for all Greater Manchester hospices.*

Working across Greater Manchester Authorities, hospitals, CCGs and hospices we can significantly improve integration. Focusing on funding opportunities and the need to agree a funding strategy from health and social care budgets that is recurrent over 3 years, as opposed to the current 1-year funding, can drive this. The Greater Manchester hospice consultation highlights the fragility of some services and the unfulfilled potential in the system, with the arguments to move from 1-year to multi-year funding settlements well appreciated within traditional healthcare funding.

To delivery sustainability, we need to see greater investment in community services to ensure 7/7 cover to enable patients to remain in their home, at their choosing or where it can enable a speedy discharge from hospital with an appropriate package of care that meets their needs. Greater focus on the vital role of community-based care rather than the use of inpatient beds, for example; or focus on services such as Nurse Specialists or Hospice at Home, which can work towards preventing access into acute services in the first place or speeding up discharge. Far more hospice patients are cared for in their own homes than in hospice beds and so enhanced community services will make a greater impact on addressing demand and capacity issues in acute settings, whilst likely proving more cost-effective.

There is also recognition of greater investment in nurse prescribing and clinical examination skills for NHS teams to ensure rapid access to appropriate medication in the home. Development of services to support the staff in care homes and nursing homes to give them the skills and confidence to better care for their residents at the end of life thus reduces the numbers of inappropriate transfers into hospital.

The hospice team can ensure better working with local authorities and CCGs to develop integrated community services that provide social elements of care through services such as Hospice at Home, including help with basic daily needs and befriending services (use of volunteers) to fill the gaps in current statutory provision.

Finally, investment in rehabilitation services for patients with life-limiting conditions is vital either in the home or through day service provision, to provide people with the skills and confidence to better cope with their advancing disease.

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IT'S A FEATURE OF LIFE IN MANY TOWNS THAT THE LOCAL HOSPICE IS HELD DEAR TO THE HEART OF THE COMMUNITY IN WHICH IT SERVES. HOSPICES ARE VITAL COMMUNITY ASSETS.

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## 2. EXPANSION

*Expand and secure hospice provision and the perception of hospices for better inclusivity in a diverse, modern health and social care service. A GM MP and Mayoral-led campaign to discuss what dying well looks like for every one of us in GM should lead this effort.*

Mapping the full spectrum of GM Hospice services provided now and those established subsequently should be undertaken to help identify the range on offer. Public services and local health boards along with local authorities, CCG's and acute and primary care should recognise the full range of services on offer including specialist nurses in the community, palliative care prescribing, day therapy work, carer and support groups, bereavement work and signposting for wider support for the frail, elderly and terminally ill. And where it exists in a hospice in one area of GM but is required locally by the CCG, then expectations should be forthcoming on the local hospice to be relied on to deliver such an offer, where it is viable to do so. For the dynamic hospice leader, there is a role for leadership within the wider charitable sector. Hospices continue to have large retail footprints where other charities do not. They can also provide expert temporary homes for project work, research or local business events. They hold an enviable level of volunteer expertise and inspiration, with every bit of effort here pointing the way of serving the community for who it may one day enable to die well. Let me note here also the crucial role this volunteering plays in helping prevent loneliness and isolation for the volunteers too.

It is imperative that key standards for hospices are maintained that allow for their progress to be monitored, including data benchmark, peer reviews and support for each other via the GM Hospice group.

Clear accountability, public engagement on performance and rigorous governance structures are key and demonstrated well in GM hospices, though not without significant opportunity to enhance. There should be improved mechanisms for the public to challenge these and so public meetings or a public aspect to hospice AGMs should be considered. This assists strong decision making, improves the democratic exposure of these organisation and is all designed put our hospices on a sustainable footing with integration.

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ALL TOO  
FREQUENTLY  
FUNDING IS  
DETERMINED BY  
THE EBB AND  
FLOW OF THE  
LOCAL ECONOMY  
THEY SERVE AND  
THE DONATIONS  
THEY RECEIVE.

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### 3. COMMISSIONING

*Establish fast track Continuing Health Care plans or spot commissioning funded admissions to appropriate hospice care - at hospice, at home or community-led.*

All parties need to consult and negotiate from their own position of strength, playing to these, but adopting the expanded role and formal integration of hospice services in to the wider healthcare system. Formal recognition for the existing economic model that combines NHS funding with fundraising but one that seeks to make this a sustainable model by ensuring better reliance on hospices and ensuring greater efficacy as they expand and are better adopted across the wider health provision. The opportunity to receive Continuing Health Care funding to support fast tracking admissions to hospices comes with the proviso to retain their independence for patient admission, on basis of clinical need, instability and their capacity, whilst appreciating the contractual obligations will establish the prior terms here. Wherever there is clinical appropriate capacity in the system, hospices will work in partnership with CCGs and acute trusts to seek ways of better utilising capacity appropriately to reduce some of the pressures on hospital beds. However, in such cases a rate or method of payment should be agreed to enable hospices to recover their costs (this is not a charitable activity); for example, consistently applied CHC funding, recognising that this rate should provide a net saving to the health economy.

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MORE NEEDS TO BE  
DONE TO IMPROVE  
ACCESS TO HOSPICE  
SERVICE.

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#### 4. EQUITY

*At the first and fastest available opportunity, hospice care should be made available to the most appropriate patients, in addition to a new GM-wide guarantee to ensure equity of access to hospice care for under-represented groups.*

These should include those with non-cancer diagnoses, BAME, LGBT+, prisoners, homeless and patients with learning disabilities.

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WE MUST  
FOSTER A  
CULTURE THAT  
EMBRACES  
TALKING  
ABOUT DYING  
WELL.

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## 5. REFERRALS & DATA

*Ensure referrals through GP, hospital consultant and all other primary and secondary care referral source include proper consideration of the expanded hospice provision via training and improved sharing of data.*

Hospital staff must receive education and training on the perceived transition of inpatients to palliative care, on referrals to hospice care at the point of admission and be able to identify patients in need of end of life care. This includes opening the conversation with patients and families in hospitals about the support and care that is offered within the hospice setting. Hospices offer multi-faceted services; including complementary therapy and carer support services and other services including Hospice at Home, some provision for respite, and use of resources as a community asset. This also includes continued support for education events such as 'dying matters'. Data sharing between services to ease transitions between hospital services, community services and hospices is key. Robust data and analysis on death and dying is needed across the health and care system to drive improvement and shape future service. It is imperative that the right data is collected that will lead to meaningful change for people receiving palliative care and their carers. Hospices and people using their services should be involved in this work to ensure the right data is in scope. Better intelligence will also support the Greater Manchester hospice group, health care boards and local authorities in compiling their statutory Future Trends reports as well as informing Population Needs Assessments. To achieve these aims, hospices will need additional support from the Greater Manchester health boards and local authorities.

In conducting this review in my first Parliamentary year, I have found the people at the heart of this area of work to be open, passionate and determined to see and enact the changes this report recommends to address the challenges we face. I want to pay special thanks to GM Hospices who called this report; '*an urgent and heart-felt report on palliative and end of life care*' and welcomed the aims of the paper and hope, as I do, that it can support, press and amplify work already being undertaken across Greater Manchester.

In fact, we have everything and everyone we need in Greater Manchester to do even better than we are. I am very hopeful about the significant changes we can make to ensure hospice provision in Greater Manchester is the best nationwide and leads by example. And that together, we will prove to be the first to truly and formally incorporate the hospice movement into our Health and Social Care service. If we do, we can ensure that everyone gets the chance of living well and dying well.

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ONE OF THE  
GREATEST  
STRENGTHS  
OF OUR  
HOSPICES  
IS THEIR  
CHARITABLE,  
INDEPENDENT  
STATUS.

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# APPENDIX

## APPENDIX 1

	Range	Average
<b>Patient Primary Diagnosis</b>		
Cancer	55% - 89%	78%
Non-cancer	11% - 45%	22%
<b>Patient Ethnicity</b>		
White British	84% - 99%	91%
Other	1% - 16%	9%
<b>Inpatient Unit Care</b>		
No. of Beds	12 - 45	18
Average Occupancy Rate	36% - 92%	71%
Cost of 24 Hour Inpatient Care	£400 - £568	£460
<b>Finances</b>		
Total Spend on Charitable Services	£1.8m - £8.8m	£3.5m
% NHS Contribution (based on above costs)	18% - 47%	33%
Total Costs (incl. costs of raising funds)	£2.5m - £11.5m	£3.8m
% NHS Contribution	23% - 39%	27%
<b>Volunteer / Social Impact</b>		
Number of Volunteers	290 - 900	577
Number of Hours Given Annually	50,000 - 129,000	81,046
Number of Charity Shops / Coffee Shops	5 - 14	10

*GM Hospice Group Data (March 2018). Ranges and averages of accumulated data from all 7 GM hospices - collected on behalf of the office of James Frith MP for the purpose of this report.*

## ACKNOWLEDGEMENTS

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This report has been written and developed by numerous groups and individuals and I would like to give special thanks to:

- **Andy Burnham**, Mayor of Greater Manchester.
- **Jon Rouse**, Chief Officer, Greater Manchester Health and Social Care Partnership.
- **The Greater Manchester Hospice Group** and in particular **Dr Leigh Vallance**, Chief Executive, Bolton Hospice.
- **Kim Wrigley** and **Dr David Waterman** of the Greater Manchester and Eastern Cheshire Strategic Clinical Network.
- **Claire O'Rourke**, Associate Director, Greater Manchester Cancer.
- **Bury/Rochdale Care Organisation** (and particular thanks to **Steve Taylor**, Managing Director/Chief Officer).
- **All Party Parliamentary Group on Hospice and Palliative Care.**
- **Barbara Keeley MP.**

## ENDNOTES

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# NOTES



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