Hospice UK response to Health, Social Care and Sport Committee’s inquiry into winter preparedness

July 2023

About Hospice UK

Hospice UK is the national charity for hospice and end of life care. We work to ensure everyone affected by death, dying and bereavement gets the care and support they need, when they need it. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life. Our membership includes all charitable hospices in Scotland.

1. Winter Resilience Overview 2022-23

How effective were government actions to support winter resilience across health and care systems last year?

There were significant challenges last winter with long waiting times, slow discharges, staffing pressures and inadequate resources put into admission avoidance.

Nationally and locally hospices were not viewed as equal partners or seen as frontline services in responding to winter pressures. While last year’s winter plan prioritised supporting people at home and makes a reference to end of life pathways, the contribution of hospices within this was not recognised or valued. Hospices support people to stay at home and avoid unnecessary admissions to hospital, significantly reducing pressure on statutory services. However hospices were often seen as an afterthought or not considered at all during winter planning processes. For example, hospices were not involved in discussions about patient flow or did not know about local winter pressures funding until it was already allocated. Hospices were not routinely asked what support they could provide and while some proactively offered help and staff resource to the NHS, this offer was not necessarily taken up by. There needs to be a greater recognition of preventative support and the contribution of the third sector, with hospices recognised and valued as equal partners.

Scottish Government did not consider the hospice workforce in any of its strategic planning around the health and social care workforce. Crucially, it did not consider the impact of the NHS pay award on the hospice sector during the pay negotiations. As a sector, Scottish hospices will see their wage bill increase by £15.5m over 2022-23 and 2023-24 as a result of trying to match the NHS pay award for their staff. Hospices are already facing a perfect storm of rising staffing costs, increasing energy and running costs, and a tough fundraising environment due to the cost of living crises. Hospices can only support and ease the pressure on the NHS and social care if they can attract and retain skilled and experienced staff, by ensuring their salaries are competitive to those offered by the NHS. Hospices are now looking for urgent support from the Scottish Government in response to their rising staffing costs, which could have been avoided if the impact on the hospice sector was considered during the NHS pay award negotiations.

During the COVID-19 pandemic hospices in some areas had to fight to be recognised in PPE supply chains and have access to testing and to vaccinations for staff. National guidance often fails to recognise hospices and it’s not clear whether they should follow guidance for acute services, community services or for care homes.
As a wider point, the approach around winter resilience is very short-term. Funding offered is too short-term and requests for additional capacity fail to recognise that it takes time to put this into place.

What additional priorities should inform actions to support winter resilience across our health and care system this year?

The needs of people at the end of life should be given greater priority within the winter planning process and the contribution of third sector providers including hospices should be given greater prominence.

The cost and pressure on the health and care system of caring for people at the end of life is huge. A snapshot of 11,000 hospital inpatients across 25 Scottish hospitals showed that almost one third of patients were in their last year of life, with one in 10 dying during their current hospital admission. 95% of people in Scotland use NHS unscheduled care services in their last year of life, representing a total cost of nearly £190 million. People in Scotland typically spend more than a month of their last year of life in hospital, over several admissions, costing an average of more than £10,000 per person. With demand for palliative care rising, this will add additional strain on an already overstretched health and care system. About 60,000 people in Scotland die each year and between 74% and 95% of them will need palliative care. By 2040, up to 10,000 more people a year are likely to need palliative care and the care they need will be more complex.

Charitable hospices support over 22,000 people each year that would otherwise be relying on statutory services. Hospices work in partnership with the NHS and social care services to meet the rising need for palliative care in communities. Hospice care lessens demand on acute services by supporting people to stay at home, reducing emergency admissions, reducing length of stay in hospital and facilitating discharges, and enables preventative investment that is supporting recovery and benefitting public services. It eases some of the pressure felt in the community by supporting overstretched GPs and district nurses. Hospice care brings significant funding to the table and provides significant value for money. Children’s hospice care generates over £6 in public return for every £1 of statutory funding spent and adult hospice care generates nearly £4 for each £1 of public funding.

Hospices are well placed to support the challenges being faced during the winter but they are often limited in capacity by funding. Currently only just over a third of hospice income comes from statutory sources, with the rest coming from fundraising and donations. Where winter pressures money is available, hospices should be made aware of funding opportunities, included in planning meetings, and be valued as equal partners to help support national and local priorities. Other third sector organisations, community and hospital palliative care teams also need to be included in discussions.

There is scope for greater partnership working with third sector providers, including hospices, and opportunities to pool resources together. Everyone is facing the same challenges and the same issues and working in partnership gives much more opportunity for wider impact. For example, hospices might be able to offer available staff to the NHS to respond to winter pressures, or social work and allied health professional resource within hospices could be used more creatively and effectively across the system if there was a partnership approach. There could be better use, resourcing and partnership working with hospice at home and other hospice community services locally. There should be also be greater consideration of how front door medicine and the Scottish
Ambulance Service can prevent unnecessary admissions or respond to people more quickly with a terminal or life shortening condition.

Social care must be a priority within winter planning. With health and social care partnership budgets under pressure, any impact on care homes and social care will have a huge impact on patient flow. In order to place people, who are medically fit to discharge a larger social work resource is vital for timely assessment and discharge. Hospices also face problems with delayed discharges, poor patient flow and inappropriate use of specialist beds, because of delays in social care assessments and lack of available care packages. Hospice beds should be given the same priority for discharge planning in social work teams as other specialist acute beds, with the same access to resources. Some Health Boards have developed legal teams to help clinicians appropriately discharge people with Power of Attorney or under guardianship where there is disagreement. This resource should also be made available to hospices to support timely discharges.

There needs to be a longer-term, whole system approach to supporting winter resilience. While this inquiry is informing plans for 2023-24 winter, Scottish Government already needs to be looking ahead to 2024-25. The focus needs to be on the community and a preventative approach, not just a focus on beds. Block contracting could be considered where capacity is paid for up front and ahead of time, which will be cheaper than trying to pay for it urgently. Better use of population data and previous years’ service data could help better predict and map where people might need care and prepare accordingly. Within this, hospice and wider palliative care data should be considered together. The costs associated with data collection and analysis need to be considered within Service Level Agreements.

2. Capacity and system flow

What were the key factors limiting capacity and delivery in the NHS and social care last winter?

One of the biggest challenges was inadequate staffing and heightened sickness in winter months which was further exacerbated by winter weather and outbreaks. These issues were also felt by the hospice workforce. One hospice had to close four beds because they could not recruit nursing staff. The hospice workforce is relatively small, so any absence has a big impact on the service that can be provided and also limits the support and flexibility that a hospice can provide to the NHS and social care partners.

All parts of the system are battling for the same workforce and attempts to boost capacity last minute are often reliant on the ability to source additional staff. Although Scottish Government’s strategy is to increase staffing over winter months, in reality it is unclear how many staff would want to pick up 3-6 months fixed term contracts and how viable this is as a solution. Some hospices felt that the 4% sick leave target is unachievable across the board and that workforce planning needs to be more realistic.

The strain on social care and community services was a major factor last winter. Lack of rapid access to care in the community and equipment is a significant barrier to keeping people at home or supporting discharge planning. These systems need to be more responsive. In some areas local community teams are under immense pressure, particularly within district nursing where there have been a lot of people retiring or and resigning in the last year. Some hospices found it difficult to discharge patients back into the community because of the lack of care available. One
hospice raised a concern that their services, particularly Hospice at Home, were being used inappropriately to provide front-line social care support due to lack of social care support available, with some locations being impossible to secure a care package. When trying to discharge patients swiftly, care assessments can be done quickly and inaccurately, meaning hospices take on people with greater needs than initially expected, or that social care packages do not reflect needs.

More could have been done last winter to divert or avoid inappropriate admissions. For example by making better use of hospice at home services or other specialist resources. Ensuring better access to specialist advice when needed could also avoid admissions, for example, Scottish Ambulance Service staff should be able to access specialist palliative care advice as part of the flow navigation centres to help avoid appropriate admissions.

The commissioning process for winter specific contracts can be seen as not worth the trouble. There can be lots of reporting, slow decision-making and poor communication. There is also a risk that short term funding will not cover a patient requiring several months of complex care and that patients will have needs different to those a hospice would normally support.

Was the flow through the NHS and social care adequately maintained last year?

No, there were delays in people being assessed by social work, challenges with care packages and long waiting times for admission and discharge. Hospices also experienced delayed discharges because of delays in social work assessment and care packages not being available.

Hospices have also seen more people being diagnosed with a terminal condition later on in the disease trajectory and more younger people being diagnosed, because of them not accessing care early on.

How can capacity be maximised to meet demand, and maintain integrated health and social care services, throughout the coming autumn and winter?

Hospices should be valued as equal partners. There should be better integrated planning and more joined up partnership working that values the contribution and potential of hospices within the wider system. There should be more relationship building and better communication and engagement between IJBs, local partners and hospices.

Hospices’ workforce are their greatest asset but they are facing significant challenges which is impacting their ability to attract and retain skilled staff to meet current and future demand. Staffing costs represent over 70% of hospices’ expenditure and has been rising at a rate significantly over the rate of inflation for the last decade. To attract and retain skilled and experienced staff, charitable hospices need to ensure their salaries are competitive to those offered by the NHS. The impact of trying to match the NHS pay award on hospices’ wage bill over 2022-23 and 2023-24 is £15.5 million and hospices need urgent funding to meet this cost. Without sufficient funding to ensure a stable workforce, hospices are at risk of having to reduce services and close beds. This will impact patient care and prevent hospices from having the flexibility to support NHS services when needed, for example aiding swift discharges from hospital.

There should be more effective use of specialist palliative care beds but also a recognition and greater understanding of specialist palliative care in the community. As part of this there should be better use of hospice at home and other hospice resources. For example there is a lot of emphasis and funding attached to Hospital at Home to provide a safe patient centred alternative to acute hospital admission that provides a better outcome for patients in their own homes while also reducing pressure on hospital sites. Hospice at Home services provide the same improved
outcomes for patients and avoid unnecessary admissions to hospitals but they are not necessarily recognised within the local system and hospices can struggle to fund these services. Hospice services also provide excellent public value for money as they are only part funded by statutory funding. Professional to professional direct links should be facilitated and access to specialist advice to help avoid unnecessary admissions to hospital.

There should also be more funded education and support for care home staff to support them to care for people at the end of life and reduce unnecessary hospital admissions. Some hospices have reported that their offers of support to care homes had been challenging because care home staff couldn’t be freed up to attend the training due to staff shortages.

3. Workforce and staff wellbeing

What factors affected the wellbeing of those providing health and social care support, including both paid and unpaid carers, over the 2022-23 autumn and winter periods?

The health and care workforce is still experiencing burn out from the covid-19 pandemic. Some staff have not had a chance to stop and process what they went through during the pandemic and the long term impact is only now starting to be felt.

The burden on unpaid carers/family members supporting people at the end of life is huge and was made more challenging through the COVID-19 pandemic and as a result of the cost of living crisis. Unpaid carers are still not being identified or assessed routinely, which will impact the support they can receive.

What should be done this year to ensure staff wellbeing, and ensure those providing support (in all settings) are able to continue to do so?

Charitable hospices need urgent funding from Scottish Government to help them offer their staff the fair and equitable wage they deserve that is competitive to what they could receive in the NHS. By having a supported, sustainable workforce hospices will be able to continue to offer support and flexibility to NHS and social care services in response to winter pressures. Over the longer-term there needs to be a new national framework for hospice funding that will support local negotiations and long-term planning in response to increased need for palliative care, changing models of care and rising costs.

Hospice UK has recognised the need to support and build resilience within the hospice workforce. We have a range of resources and programmes to support wellbeing and resilience, including a resilience-based clinical supervision project.

While there are many resources, apps and wellbeing spaces for staff, a bigger priority for staff is enough colleagues with them to deliver safe care. The focus needs to be on effective long-term, integrated workforce planning and resourcing to prevent an annual crisis response. This needs to underpin the future implementation of the Health and Care (Staffing) (Scotland) Act. The hospice workforce needs to be considered and included within any current and future workforce plans.

The full range and breadth of health and social care professionals, across all sectors, should also be supported to be able to contribute to their full potential or to be used in different or more innovative ways to support a multi-disciplinary team approach.

There needs to be more support for unpaid/family carers. Health and social care professionals should be supported to more actively identify carers and carry out carer assessments. More AHP assessments across acute and in the community could also help prevent admissions and support
carers. Hospices have AHP staff, which could potentially be used in a more partnership/collaborative approach.

Staff could also be provided with more support, communications and conflict management training to help support patients and families who are experiencing high levels of stress and distress.

4. Outcomes

Were patient outcomes affected last winter, either positively or negatively?

Patient outcomes have been affected negatively last winter, compounded by the covid-19 pandemic. Hospices anecdotally have been seeing an increase in people who have been diagnosed with a terminal diagnosis much later and of more younger people receiving a terminal diagnosis, as a result of them not being seen early enough by health care professionals during the pandemic. It is possible that some of these people might have had a better outcome if they had been diagnosed earlier. This has also had a big impact on family members and carers. There has been more distress and some families are understandably very angry that they think there loved one might have missed out on care. Hospices are still hearing of concerns from families struggling to access GP appointments.

Some are also concerned that acute services are slower in referring younger adults to hospice and palliative care support and that there needs to be a cultural shift to support people being referred earlier to get the palliative care support they need. There are also some concerns that poor flow and pressure within hospitals makes it harder to have an initial conversation about palliative care or hospice support with a patient and their family.

Hospice staff have also raised concerns that one of the long-term impacts of covid is much higher levels of distress and poor mental health and wellbeing in communities, as well as high levels of complex grief and bereavement.

What recommendations would you make to ensure services best support vulnerable communities and achieve positive outcomes this year?

People with a terminal diagnosis and living with a life-shortening condition are more vulnerable to the challenges faced during winter, particularly in relation to cost of living and high energy prices. Marie Curie research found that 8,200 people in Scotland die in poverty at the end of life every year in Scotland, and the costs of living with a terminal illness in the UK can be up to £16,000 per year as a result of income loss and increased costs associated with terminal illness, such as energy bills and home adaptations.

Many terminally ill people experience a vicious cycle of fuel poverty. Their deteriorating health means they have to spend a lot more to heat their homes sufficiently, which some may struggle to afford due to depleted incomes and the other significant costs associated with their illness. This is particularly acute in rural areas of Scotland, where energy costs are higher and over 50 percent of households in remote rural Scotland experience fuel poverty. People with palliative care needs or at the end of life may be unable to afford to heat their homes adequately for a range of reasons, for example if they (or their carer) need to give up work or reduce their hours following a diagnosis. Many conditions can also make people more sensitive to the cold, as can some treatments such as chemotherapy. The consequences of living in a cold home can be severe – leading to new infections, making existing symptoms worse and exacerbating pain. Keeping people warm can help prevent an escalation of need and medical intervention/admission to hospital.
Many people living with a terminal or life-shortening condition are reliant on medical devices and assisted living equipment to allow them to stay at home. Living at home with complex medical needs can require a wide range of medical equipment to be in use, including: air mattresses; hoists; electric wheelchairs; ventilators; feed machines; suction machines; electric beds. There is no support provided for the operation of any of this equipment. Support is only available for the use of an oxygen concentrator (NHS Scotland provides a rebate, which needs to be claimed on a quarterly basis). Caring for someone with a terminal illness at home may also involve using the washing machine and dryers very intensively, for example if the person being cared for has incontinence issues.

While there are a range of supports available to individuals currently from both Scottish Government and UK Government there are limitations to the support available. Accessing these supports is not always easy, systems can be complex, and successfully applying for one support doesn’t mean others are then automatically available. Even if someone does access all support they are eligible for that has been proven to be insufficient for some of those most vulnerable. There are no support schemes or initiatives targeted specifically at people with a terminal or life shortening diagnosis. There needs to be more targeted support to support people with a terminal diagnosis and those caring for them and to protect them from high energy costs and the cost of running essential medical devices at home. They also need to be prioritised and protected in case of issues with interrupted energy supply.

As a wider point to ensure services better support vulnerable communities, we should listen more to what the public are telling us about where the gaps are and proactively ask members of vulnerable communities where they face challenges. We should make better use of data so we can better understand unmet need and where there are inequalities in people’s access to and experience of care.

5. Do you have anything else to tell us?

The learning from the pandemic needs to be implemented. One of the positives from the pandemic was the breakdown of traditional barriers and bureaucracy, and improved partnership working that allowed teams to respond swiftly and effectively. However the old barriers have returned and developments are taking longer to implement again. We need to be able to cut through unnecessary governance structures the way we did during covid. Specific issues in relation to hospice and palliative care, is the dual regulation of some hospices between Healthcare Improvement Scotland and the Care Inspectorate and issues around regulation of just in case grab bags in local primary care settings to support rapid access to palliative care medications.

The impact on hospices of shifting resources within local health boards/IJBs is not always considered or communicated to hospices. For example one hospice had a service level agreement with their local health board for several years ensuring they can access support and training in infection control from the health protection team in the health board. Staffing was shifted away from the team and there was no longer capacity to support the hospice. This left a significant gap in expertise and it was not feasible for the hospice to employ a dedicated infection control nurse with the required level of expertise given current challenges. Exploring a service level agreement with the NHS infection control team was also knocked back and hospices are left feeling that they have to continually fight for access to something that should be seen as core and essential support.

For further information please contact: Helen Malo, Policy and Advocacy Manager Scotland, Hospice UK
h.malo@hospiceuk.org