

BASW NI response to NI Assembly inquiry into palliative care services in Northern Ireland

4. Are you a healthcare professional? If yes, what is your role: If no, what is your interest in palliative care services:

- Yes
- No ✓

The British Association of Social Workers Northern Ireland (BASW NI) is part of the British Association of Social Workers (BASW), the largest professional body for social workers in the UK. The Association has 22,000 members employed in frontline, management, academic and research positions in all care settings, including palliative care social work.

7. In your view what is the current state of palliative care services in Northern Ireland?

- Excellent
- Good
- Neither ✓
- Poor
- Very Poor
- Don't know

8. Do you think there is an understanding by the public of what palliative care is? If no, what are the main barriers to the public understanding palliative care?

- Yes
- No ✓
- Not sure

Open text for No—1500 Characters

The findings of the Ulster University research paper 'Where Are We Now? - Examining public knowledge and attitudes towards palliative care and advance care planning in Northern Ireland' "indicate a dearth of awareness, lack of knowledge, and misperceptions among the Northern Ireland general population regarding palliative care". The paper highlights the need "to increase public views and knowledge of palliative care across the life span and different age groups", underscoring the failure

to deliver the 2010 'Living Matters Dying Matters' strategy outcome of "a raised awareness and understanding of palliative and end of life care".

BASW NI's engagement with palliative care social workers highlights that, in general, the public have a limited understanding of palliative care. Often the focus is on the care provided in the final weeks and days of life with a lack of understanding of the range of services available to palliative patients which help them have a better quality of life. These services include rehabilitation, symptom control, advance care planning, social support, pre-bereavement services for families, and support for carers.

9. Are palliative care services equally accessible to all who need them?

- Yes
- No ✓
- Not sure

10. From your experience where are the gaps in the provision of service?

Open text—1500 Characters

Currently, due to the limited number of hospice beds in Northern Ireland, it is not always possible for a patient to be admitted to a hospice and some patients are reaching crisis point at home with issues around pain and infection, for example, in an effort to avoid hospital emergency departments because of the difficulty associated with the long waiting times and pressured conditions in emergency departments.

There is also a gap in identifying and supporting palliative patients in hospital acute care settings and emergency departments and this can filter through to unsafe discharges and patients not receiving appropriate palliative care and support in the community.

An agreed pathway for palliative patients who present at emergency departments would improve their access to acute services when needed. This service could potentially be operated by hospital palliative care teams, similar, for example, to the access patients who are in active treatment at Belfast City Hospital (pre-palliative care) benefit from.

In addition, due to caseload pressures, opportunities are being missed to provide support to palliative patients and their families, by hospital social workers. Improved resourcing is required to address this issue.

Finally, the lack of inclusion of hospices in the Encompass programme is reportedly presenting significant difficulties for the voluntary sector.

11. Do you believe barriers exist that prevent equitable access to these services? If yes, please provide examples in the box provided.

- Yes ✓
- No
- Not sure

Open text—1500 Characters

The lack of public awareness addressed in question 8 is a significant barrier in enabling equal accessibility to palliative care services for all who need them. Palliative care social workers practicing in the voluntary sector have reported that patients impacted by poverty and those with poor educational achievement are often less aware of or less able to access services.

Difficult to reach groups include patients with a non-cancer diagnosis, and palliative care social workers suggest there may be hesitancy, due to a lack of awareness on the part of healthcare colleagues in certain disciplines, to refer to palliative care services, particularly hospice services in the voluntary sector. This is particularly an issue for children and young people impacted by a non-cancer terminal illness. There also appears to be fewer services funded and available for palliative care patients with a non-cancer diagnosis than for patients with a cancer diagnosis.

Palliative care social workers working in the voluntary sector also highlight the absence of a clear pathway for palliative patients in hospital settings, with some not receiving onward referrals to community palliative care teams.

12. What additional services could/should be provided?

Open text—1500 Characters

Improved family support and children's services are needed pre and post bereavement for all conditions. Services required include counselling and emotional support, and respite services. These services should be in-house as part of specialist palliative care services and linked into statutory services including children's social care services. Provision of this support must be core to any new palliative care strategy. Central to this must be improved provision of services to support families and children pre and post bereavement for children with any form of terminal illness.

The importance of emotional support, counselling and education, particularly for parents should not be underestimated. Parents are best suited to support their children and if parents are educated and resourced in advance of a family member's death this can ease the need for counselling and professional support for their children post-bereavement. This supportive work is fundamentally a social work role

and is one which requires improved funding, recognition and visibility within palliative care.

There also needs to be an equal focus on the social and medical models of care, with emotional support and social care provision understood as a core element of palliative care, not an optional extra.

13. How well are palliative care services integrated across the health system, through primary, secondary and specialist care?

Open text—1500 Characters

Palliative care social workers report that once patients are known to specialist services they typically receive a high quality of care and good communication and integration between teams and services provided. However. Where patients are only known to primary and /or secondary services, there is often poorer communication and more unmet need, with patients and their carers feeling isolated and unsure of who to contact and where to access support.

Palliative care social workers also note examples of patients identifying that increasing pressures on primary services, for example, GP and pharmacy services, mean that patients find it increasingly difficult to access the support they require. Instances were also reported of difficulties experienced by community palliative care nurses in accessing GPs to address issues around medication for patients.

Core to addressing these problems is the provision of improved options for palliative patients to have access to their GPs.

While there are integrated pathways across Health and Social Care Trusts, there remain areas for improvement including integration of hospices and specialist services into the HSC Encompass programme. Palliative care social workers practicing in hospice settings highlight this as necessary to address silo working arrangements.

14. Should palliative care be a regional service? Please outline your reasons in the box provided.

- Yes ✓
- No
- Not sure

Open text—1500 Characters

BASW NI fully supports the creation of a regional approach to palliative care services. This will ensure there is a framework to build best practice across Northern Ireland and improve services for individuals who move between Health and Social Care Trust areas.

A regional approach to service planning and provision for all patients with a palliative illness will also improve referral pathways and increase integration and communication between primary, secondary and specialist services. This in turn will help improve the identification and referral of palliative patients to specialist services at an earlier stage, improving timely access to the care they require.

15. What can be done to improve integration?

Open text—1500 Characters

As detailed by the 2016 Regulation and Quality Improvement Authority (RQIA) review, a priority for the next palliative care strategy should be to standardise the availability of core services across populations. BASW NI notes that fundamental to this approach should be the designation of a central referral hub for each Health and Social Care Trust for the screening of all palliative care patients.

There is significant need for information and education sessions for health and social care practitioners in primary and secondary services concerning pathways for referring patients into palliative care services. This must include a focus on information for emergency medicine practitioners as often palliative care patients admitted to hospital emergency departments are treated for a singular acute issue, but are not viewed in the context of their palliative issue and are therefore discharged without appropriate follow up or notification to those providing palliative care support.

There is also a need to better integrate understanding of palliative care into social work education, at both degree level and in-work training. This will affect many, if not all areas of social work practice.

Improving understandings of theories of grief and loss would benefit social workers to not only support people with a palliative care need and their families and carers, but also people who use services in many other areas of practice.

16. Do you have any examples of good practice or pilots in palliative care that are meeting the needs of patients and families/carers? If so, is this best practice happening widely across Northern Ireland?

Open text—1500 Characters

BASW NI will defer to our partner organisations representing the views of medical and nursing colleagues to identify good practice examples of palliative care from a healthcare perspective. BASW NI wishes to focus on the example of Marie Curie's pilot which provided education and training to teachers in secondary schools concerning palliative care and bereavement in children and young people.

The pilot reported positive feedback from teachers who noted rising numbers of pupils affected by loss but who had not felt equipped to provide support. Teachers often offer the most significant support to children outside their immediate family, and providing adequate resourcing to make bereavement assistance in schools a reality for children in Northern Ireland should be included in any future palliative care strategy.

BASW NI also notes the many potential benefits for children and young people associated with school social work. Presently, school social work is in its infancy in Northern Ireland, and if resourced for roll out, school social workers would have a key role to play in providing emotional support and counselling to children affected by bereavement.

Bereavement Café initiatives operated by the NI Hospice and Marie Curie are also good examples bereavement support. It is vital these examples of social work led, person centred services are recognised, resourced and promoted via a future palliative care strategy.

17. Do you think that families receive sufficient support when accessing services? Please outline your reasons in the box provided.

- Yes
- No ✓
- Not sure

Open text—1500 Characters

Palliative care social workers note that patients and families are often unsure of who to contact for palliative care support when they are in community settings. This appears to contrast with non-palliative or pre-palliative patients who are in active treatment. These patients are more likely to feel confident regarding who to contact in emergency situations for advice and support. Once patients are deemed palliative, they can feel a sense of confusion about who is delivering their care and lack clear pathways concerning how to access support.

18. Do you think the current funding for palliative care is sufficient? Please outline your reasons in the box provided.

- Yes
- No ✓
- Not sure

Open text—1500 Characters

The current funding for palliative care, as with wider health and social care services in Northern Ireland, is not sufficient. BASW has called at UK level for the introduction of a needs-based approach to funding public services in Northern Ireland to replace the outdated Barnett Formula which has led to under resourcing in the region given Northern Ireland has disproportionate need for service provision.

It is vital the UK Government recognises the disproportionate need in Northern Ireland and resources the region's public services accordingly. It is the responsibility of the Northern Ireland Executive to collectively make this case to the Westminster Government.

19. Is the current model for the funding of hospices, including hospice at home/community care/rapid response support, sustainable and sufficient to meet needs now and in the future? Please outline your reasons in the box provided.

- Yes
- No ✓
- Not sure

Open text—1500 Characters

The services provided by the voluntary sector in terms of hospice provision and other aspects of palliative care support are vital and highly valued by the social workers BASW NI represents. It is, however, utterly unacceptable that voluntary sector organisations providing vital public services are required to fundraise to deliver care to palliative patients. Provision of hospice and other palliative care services by the voluntary sector marks a failure of the state to adequately provide services to citizens.

Where services are directly commissioned from voluntary sector organisations by the Strategic Planning and Performance Group, palliative care social workers practicing in the voluntary sector note the challenges they face in planning services based on one year funding cycles. This could be addressed by the provision of multi-year funding cycles which would improve services for patients and security for staff.

20. Is there a need for a new Palliative Care Strategy for Northern Ireland? If yes, what should it include? If no, why not? Please outline your reasons in the box provided

- Yes ✓
- No
- Not sure

Open text—1500 Characters

In developing a new strategy, it is important learning is taken from the 2016 RQIA review of the 2010 strategy. It found “although many initiatives have been developed to raise awareness of palliative and end of life care, there remains a significant lack of understanding about these services amongst service users and staff. There is a continuing need for a coordinated approach to raising public awareness about palliative and end of life care.” The review also highlighted inconsistency in the services available across NI and noted the priority need “to standardise the availability of core services across populations”.

There must be a clear focus on accountability for delivery and adequate resourcing for service provision, including improved funding for voluntary sector service providers.

It must be recognised that there have been demographic changes in the Northern Ireland palliative population since the publication of the previous strategy. Palliative care social workers note an increase in referrals for younger adults being diagnosed with a palliative illness. It must also be recognised that, post-pandemic, practitioners are operating in a changed landscape in terms of grief and complex grief.

Given limited resources, including hospice beds, there is an increasing need to provide palliative care in the community. This requires improved integration between services to prevent patients and their families feeling unsupported and confused.

21. Any other comments

Open text—1500 Characters

It is difficult to provide a clear answer in response to question 7, “In your view what is the current state of palliative care services in Northern Ireland?” BASW NI opted to select “neither” as the standard of service depends heavily on the area of provision. The Association is aware, via engagement with social workers practicing in hospice settings of the high standards of care provided within hospices operating within the voluntary sector. However, this high standard of care is not in all cases replicated within the statutory Health and Social Care sector.

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