Cross Party Group on **Hospices and Palliative Care**

What role can the Welsh Government's Compassionate Cymru programme play in building capacity and resilience in communities through and beyond Covid-19?

RECOMMENDATIONS

Compassionate Cymru should target action and support where it is needed most by:

1. **Engaging and supporting racialised communities**
2. **Making it everybody's business to care before an expected death and into bereavement**
3. **Caring for families and carers**
4. **Leading a national conversation with the people of Wales about 'what matters' at the end of life**

About the Cross Party Group on Hospices and Palliative Care

The purpose of the Cross Party Group on Hospices and Palliative Care is to maintain and develop understanding and interest by Members of the Senedd of issues affecting hospice and palliative care services, in the furtherance of improving end of life care in Wales.

Cross Party Group Chair: Mark Isherwood MS, Welsh Conservatives, North Wales

Secretariat provided by Dr Catrin Edwards on behalf of Hospice UK

Chair's Foreword

It is clear from the contributions received by the Cross Party Group on Hospices and Palliative Care throughout 2020-21 that Compassionate Communities approaches have tangible benefits to individuals, communities and health and care systems as they care for people who are dying, caring or bereaved.

Never has this co-productive approach to community resilience been more relevant and more needed than now as Wales lives through and, in time, recovers from, the Covid-19 pandemic. Time and again we heard at the Cross Party Group this year of the importance of taking an asset-based approach to supporting communities; people are our greatest assets and what matters to people and communities should be central to the Compassionate Cymru approach.

I am grateful to the communities, charities, hospices and health and care teams for sharing with the Cross Party Group on Hospices and Palliative Care how they have innovated to step up to the challenges of meeting their communities' needs during the Covid-19 pandemic. Some messages from the ground were heart-warming, others were a call to action to address where existing programmes, including the Welsh Government's Compassionate Cymru, are not yet meeting community needs.

With that in mind, I am pleased to share our findings during our Cross Party Group work this year, highlighting the ways forward that a Compassionate Cymru approach should take if we are to empower and build capacity in communities to offer the support needed by people affected by death and bereavement during the Covid-19 pandemic and beyond.

Mark Isherwood MS
Chair of the Cross Party Group on Hospices and Palliative Care

Recommendations

Compassionate Cymru should target action and support where it is needed most by:

1. Engaging and supporting racialised communities

The Cross Party Group were told by BAME community leaders in no uncertain terms that access to existing bereavement care and holistic palliative care support is neither experienced as equitable nor widely known of amongst their own racialised communities. Coupled with this, the CPG heard of no known project in Wales under the banner of 'Compassionate Communities' – funded or otherwise – that specifically addresses the needs of racialised communities[1]. With regards the inclusion of racialised communities in compassionate approaches to palliative care, the CPG was told:

> **'We [BAME people and communities] are an add on.'**
> *Pastor Hadassah Radway, BHM 360*

This gap exists despite the context of the Covid-19 pandemic, which is known to have had a disproportionate impact on BAME people and communities. The CPG heard how the social impact of the pandemic has been experienced differently by people of colour. BAME community leaders noted the particular impact on the bereavement experience of people from BAME communities during lockdown, with many families unable to fulfil "homegoing" or rights of passage that would often involve the gathering of many families in the bereaved family's home over an extended period[2]. This has been compounded by the well-documented higher death toll for people of colour: in England and Wales, men of Black African ethnic background had the highest rate of death involving Covid-19, 2.7 times higher than men of White ethnic background; women of Black Caribbean ethnic background had the highest rate for women, 2.0 times higher than women of White ethnic background[3].

Despite no known formal involvement in Compassionate Cymru projects, BAME communities have independently stepped up their existing community action and compassionate approaches to address the particular challenges of the pandemic. These include culturally appropriate food parcels for people shielding[4] and social media support groups for bereaved families, often locality or faith-based[5].

Tailored services to meet the specific needs of racialised communities, and in particular mental health and acute bereavement care, were highlighted as specific gaps that must be addressed going forward[6]. The CPG was told about the importance of involving people from diverse communities to co-produce services, leading to more inclusive and accessible care. Previous work from hospice Compassionate Communities approaches across the UK have identified the practice of developing BAME advisory groups to steer inclusive service design[7]. However, the CPG was told clearly that engagement between formal services and diverse communities must be accompanied by a commitment to listen and implement change if connections between communities and services are to be meaningful and sustainable[8].

"Engage and then commit to make the change."

Monica Reardon, Marie Curie

What needs to happen next

- Racialised communities should be involved from the outset in coproducing Compassionate Communities initiatives.
- Formal services should proactively engage with the racialised communities they serve and commit to address inequities in access to care.

2. Making it everybody's business to care before an expected death and into bereavement

Working jointly with the Cross Party Group on Funerals and Bereavement, the CPG heard of the significant bereavement needs Wales will face in light of the Covid-19 pandemic, with an estimated 185,000 people thought to be bereaved during 2020[9]. Given the magnitude of this figure, it is likely that every community across Wales will be supporting bereaved families. In this sense, Covid-19 means that bereavement care is already everyone's business.

Evidence from previous studies on bereavement suggests that conditions prevalent during the Covid-19 pandemic – such as social isolation, sudden deaths and limited contact with loved ones – are likely to lead to complex grief outcomes[10]. This is set within the context of the Bereavement Scoping Review, established prior to the pandemic, which exposed the existing gaps in bereavement care services across Wales, including significant waiting times for counselling and regional variations in access to care[11].

The CPG heard that people who were bereaved following a loved one's death from Covid-19 were particularly affected and unable to access timely bereavement support. This has led to online support groups, such as Covid-19 Families Wales, where bereaved families are acting as sources of information and support in the absence of the availability of formal care and support[12]. In response, hospices detailed how the Welsh Government has part-funded hospice bereavement services on a per capita basis, with the aim of ensuring hospice bereavement care reaches people in all areas of Wales. For some hospices this has meant funding to extend their bereavement care to people in areas of Wales who would not otherwise be served by hospice care[13] and extending their care to professionals on the frontline, such as in care homes[14].

Pre-bereavement care was universally championed as a way of building resilience and improving bereavement outcomes. As well as emotional and well-being support, the CPG was told how this approach is holistic and extends to supporting a family's social, housing and economic situation, where these factors are effected by the death of a loved one[15].

Crucially, we heard that a significant amount of support for bereaved families would not be formally recognised as bereavement care.

> **"We think of bereavement care as a service but that's not always the case."**
>
> *Julian Abel, Compassionate Communities UK*

This refers to the informal response of communities in supporting bereaved people as well as the more formal role of Compassionate Cymru, and the Compassionate Country Charter, in ensuring that all spheres of civic life – schools, community centres, care homes among others – are primed to meet the needs of bereaved people. There is an opportunity with the National Bereavement Framework under development to reflect this community response. As part of this endeavour, bereavement professionals noted their role in upskilling and educating non-bereavement specialists from other professions to support bereaved people in community settings. This aspect of the specialist bereavement provider's role was described as:

> **"Making grief everybody's business."**
>
> *Jonathan Pearce, Palliative Care Social Worker, Hospice of the Valleys*

What needs to happen next

- Prioritise bereavement needs following Covid-19 as part of the Compassionate Cymru programme for 2021/22 and take an active steer in shaping the community level bereavement support that follows from the National Bereavement Framework.
- Identify opportunities to strengthen links within communities where professionals in other areas of care (education, social care, GPs) can have a role in facilitating good bereavement outcomes.
- Plan to reach people early by improving access to holistic pre-bereavement care where a death is expected.
- Support and promote open access bereavement services.

3. Caring for families and carers

Covid-19 has placed a significant additional caring burden on families living with someone with a terminal illness or a child with a life-limiting condition. The CPG was told that since the pandemic dying adults have spent 80-90 per cent of their time not accompanied by professionals (and therefore dependent on the care provided by unpaid carers and family),[16] while families with a life-limited child provide around 95 per cent of care under normal circumstances,[17] which has increased further as families shielded vulnerable children. Contributors informed us that there is a need to reflect on the social experience of providing care – including feelings of marginalisation, exclusion (real or perceived) from social groups and employment, and the impact on family relationships – and that Compassionate Cymru has a role to play in this.

Despite this, there are very few initiatives under the Compassionate Community banner in Wales that directly support children with life-limiting conditions and their families. While organisations supporting children are offering appropriate family support, this tends to be within the context of the organisation rather than the wider community. We heard that families with life-limiting children often feel invisible within their communities but that valuable support from their communities could be provided through facilitated schemes that are appropriately resourced[18].

Children's hospices have offered virtual services and online programmes for the whole family throughout the pandemic[19] and the CPG heard of successful virtual offerings from formal services and Compassionate Community projects targeted at supporting carers and newly bereaved carers since the outset of lockdown. These have been varied and creative, including an online bread making course for male carers[20] and activity sessions for siblings.

Despite the clear benefits of virtual support for carers and families, providers were clear that virtual care is no substitute for in-person support.

> **"Covid has taught us we can do virtual but it's a pastiche for face to face care."**
> *Andy Goldsmith, Ty Gobaith*

Respite care – or taking a break from caring while the person cared for is looked after by someone else – was identified as being essential for families, many of whom are at crisis point after a prolonged period of living under restrictions. Face to face respite is being resumed cautiously by many services. This includes children's short break care in children's hospices, face to face sitting services provided by specialists such as hospices, and community befriending initiatives.

> **"I managed to do a full week's grocery shopping and then sat in the car for ten minutes. Wonderful!"**
> *Jo, wife and carer of Nigel. Respite provided as part of the Compassionate Coedpoeth befriending programme by volunteer Vincent*

What needs to happen next

- Initiatives to support carers should consider a blend of virtual and in-person (Covid-19 safe) support.
- Gaps in Compassionate Community support for families with life-limited children should be explored and addressed, involving the partners who understand their specific needs.

4. Leading a national conversation with the people of Wales about 'what matters most' at the end of life

The Covid-19 pandemic has raised the profile of death, dying and bereavement amongst the public consciousness in a way never known before, and yet contributors noted that taboo and a lack of knowledge about death and dying persists.

> **"Dying is not something we all know much about."**
>
> *Lesley Bethell, Chair Compassionate Cymru*

This presents an opportune moment for the Compassionate Cymru programme to engage the public in planning for their own care and mobilising communities to support people affected by Covid-19.

There was absolute consensus among contributors to the CPG that planning for our care preferences at the end of life should be seen as a social, rather than exclusively medical, process, which communities have a central role in facilitating.

> **"Don't over-medicalise death."**
>
> *Prof. Mark Taubert, Clinical Lead for Advance and Future Care Planning*

'What matters most' is an approach that could be helpful in initiating and scaffolding conversations about care planning at a family and community level, throughout the life course[21].

As with many of the issues presented to the CPG in relation to the Compassionate Community agenda, and how this translates at a national level under the Compassionate Cymru programme, the ongoing tension between a 'top-down' and 'bottom-up' approach was explored in relation to this issue. There was consensus that local communities are best placed to hold these conversations but that a national lead and campaign would facilitate local conversations.

In parallel, there was recognition that, despite the preference for a social approach to care planning, the expertise of medical professionals and those trained in Advance and Future Care Planning (AFCP) conversation skills should not be underestimated. The CPG heard of the role of hospice specialists in ACP continuing to upskill care home workers in facilitating ACP for residents throughout the pandemic[22]. Set within the context of isolated cases of inappropriate ACP or Do Not Attempt Cardio-pulmonary Resuscitation (DNACPR) orders for vulnerable people during the pandemic, this specialist role is highly valued[23]. Likewise, within local whole-system Compassionate Community approaches, there is a recognition of the importance of ACP, with the Cardiff South West Primary Care Cluster dedicating one of four strands of work within their Compassionate Community programme to supporting people approaching the end of life.

Contributors to the CPG cautioned, however, that a national conversation as well as local and individual conversations about care preferences at the end of life cannot happen in isolation from the availability of formal services.

"It can be difficult to make promises to dying people about fulfilling their wishes because we can't guarantee that the support they need will always be available, or will be suitable for them."

Lesley Bethell, Chair Compassionate Cymru

What needs to happen next

- Through a national steer, promote community initiatives that support people to take a social model approach to planning for our end of life.
- Consider the role of those with experience in conducting 'what matters' conversations to support non-professionals to engage wider communities

Considerations beyond the scope of the inquiry

Throughout the course of our work on the role of the Compassionate Cymru programme to support communities through and beyond Covid-19, contributors raised wider issues that fall beyond the limited scope of the CPG's inquiry remit.

We recognise that these considerations pertain to the success and implementation of the Compassionate Cymru programme, which in turn frames the potential implementation of the recommendations we have proposed. For this reason, we believe there is merit in outlining further considerations that the Compassionate Cymru programme should seek to address.

While emanating from the end of life care sector, there was overwhelming consensus that compassionate community approaches benefit whole communities. Despite this, there is little understanding beyond the end of life care sector about the meaning of 'compassionate communities', with similar approaches to community action called by different names in different sectors. With this in mind, the CPG proposes that the Compassionate Cymru programme should:

- Improve understanding and promote the work of the Compassionate Country Charter and Compassionate Communities models of care, including through the use of consistent terminology amongst national and regional statutory bodies.
- Ensure that successful models of community action can be recognised and, where appropriate, scaled at pace or rolled out to other areas of Wales.

The CPG also heard of the fragmented nature of funding for Compassionate Community approaches across Wales. Some are entirely supported by volunteers, others are supported through local or national third sector organisations, whilst others have accessed national funding, including the Welsh Government's Transformation Fund. Going forward, the Compassionate Cymru programme should:

- Ensure that approaches under the Compassionate Community banner have access to national funding opportunities.

Acknowledgements

We are grateful to all presenters and contributors who provided evidence to the Group throughout this inquiry and helped shape the final recommendations.

The Group acknowledges the significant contributions of Members of the Senedd in terms of their guidance on lines of inquiry and forming the recommendations. In particular, we wish to recognise the contributions of Rhun ap Iorwerth MS, Dr Dai Lloyd MS and Darren Millar MS.

Secretariat was provided to the Group by Hospice UK.

This report was authored by Dr Catrin Edwards, Hospice UK.

References

1. For example, Professor Uzo Iwobi shared at the meeting on 20 January 2021 that there has been no involvement of Compassionate Cymru or any organisation under the title of a Compassionate Community involved in either of the five Cultural Hubs lead by Race Council Cymru.
2. Pastor Hadassah Radway, 20 January 2021.
3. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/updatingethniccontrastsindeathsinvolvingthecoronaviruscovid19englandandwales/deathsoccurring2marchto28july2020
4. Chris Campbell, working across Torfaen, led a community effort to arrange and deliver culturally appropriate food parcels to families within BAME communities in response to a lack of available appropriate support from statutory sources.
5. The role of WhatsApp and Facebook to unite communities were cited as examples.
6. Patience Bentu, Race Council Cymru, 20 January 2021.
7. Murungu D, Woolf TSS, OA17 Compassionate communities: engaging with communities to support patients at end of life: a Birmingham St Mary's hospice lived experience BMJ Supportive & Palliative Care 2015;5:A5-A6.
8. Monica Reardon, Marie Curie, 4 March 2021.
9. Based on an estimate of each death leaving five people bereaved.
10. Dr Emily Harrop, Marie Curie Research Centre and Cardiff University in presentation on 26 November 2020.
11. C. Ochieng et al (2019) 'A scoping survey of bereavement services in Wales' Marie Curie Palliative Care Research Centre, Cardiff University.
12. Andrea Williams of Covid-19 Families Wales, 26 November 2020.
13. These are areas where NHS services meet local palliative care need. This does not usually include providing bereavement care.
14. For example, hospices are offering bereavement care and supervision to care home workers and Hospice UK's. Just B service, as part of the Our Frontline partnership, provides telephone trauma and bereavement support to all frontline workers.
15. Jonathan Pearce, Palliative Care Social Worker, Hospice of the Valleys in meetings on 23 June 2020 and 26 November 2020.
16. Lesley Bethell, Chair of Compassionate Cymru, 4 March 2021.
17. Andy Goldsmith, Chief Executive Ty Gobaith/Hope House Children's hospices, 4 March 2021.
18. Andy Goldsmith, 4 March 2021.
19. Andy Goldsmith and Deborah Ho, 25 June 2020.
20. Luke Conlon, Compassionate Pembrokeshire, 23 September 2020.
21. See, for example, https://www.whatmattersconversations.org/2020-charter
22. Laura Hugman, Paul Sartori Hospice at Home, 25 June 2020.
23. See, for example the joint statement from the Older People's Commissioner for Wales and the Equalities and Human Rights Commission in Wales https://www.olderpeoplewales.com/en/news/news/20-07-21/Joint_Statement_by_the_Older_People_s_Commissioner_for_Wales_and_Equality_and_Human_Rights_Commission_in_Wales.aspx