

CPG Hospices and Palliative Care Inquiry

Oral evidence session 1: 8-9am 17 January 2018,
Conference Room A, Ty Hywel

Present AMs:

Rhun ap Iorwerth AM, Jane Hutt AM, Mark Isherwood AM (**Chair**), Dr Dai Lloyd AM.

Present – other:

Kathleen Caper (Hospice UK), Tony Curtis MBE (Dreams and Wishes), Sandra Dade (Paul Sartori Foundation), Julia David (Jayne Bryant AM office manager), Dr Catrin Edwards (Hospice UK, Secretariat), Baroness Ilora Finlay (All Wales Clinical Lead), Paula Foley (Jenny Rathbone AM researcher), Dr Richard Hain (All Wales Paediatric Palliative Care Clinical Lead), Steve Ham (Chair EOLC Board), Andy Goldsmith (Ty Gobaith/Hope House), Paul Harding (Marie Curie), Wendy Hobbs (Dreams and Wishes), Tracy Jones (Ty Hafan), Rob Jones (Ty Hafan), Tracy Livingstone (Nightingale House Hospice), Dr Finlay Mackintosh (Paul Sartori Foundation), Iain Mitchell (St Kentigern Hospice), Trystan Pritchard (St David's Hospice), Greg Pycroft (Macmillan), Emma Saysell (St David's Foundation), Kevin Thomas (MND Association), Phil Thompson MBE (Paul Sartori Foundation), Grant Usmar (Hospice of the Valleys), Mike Walsh (City Hospice)

Apologies:

Julie Morgan AM, Jayne Bryant AM (sent representative), Simon Thomas AM, Llyr Gruffydd AM, David Rowlands AM, Jenny Rathbone AM (sent representative), Lynne Neagle AM (sent representative), Cath Thomson (Skanda Vale Hospice), Ruth Chamberlain (Older People's Commissioner's office)

Mark Isherwood AM:

The progress report on the Palliative and End of Life Care Delivery Plan notes that developing Hospice at Home was a priority for 2017 and beyond – what actions have been taken to ensure there is equitable access across Wales?

Steve Ham:

Took over in 2015/16 on the Board – there was unanimous agreement that that was the area that needed to be prioritised. The £910,000 that was invested at that stage has made a positive difference. There is more that needs to be done around Hospice at Home, particularly with the increased need from diseases other than cancer.

Baroness Ilora Finlay:

It is important to remember that we are looking at the number of patients expected to need palliative care, worked out by Irene Higginson. We have applied that formula in Wales to look at need. Some areas of Wales have older or younger populations – East cities have younger populations but larger numbers of people – and the total proportion with any palliative care needs will be slightly less. In those groups the number of people who need specialist palliative care is a small group – around a third, sometimes a half. A Hospice at Home service cuts across all those groups. The funding formula was originally worked out by taking populations of each area. Compensating for age and rurality made calculations complex and cancelled each other out. It then looked at what provision was already invested in – we found a glaring gap – there was no charitable provision (other than a little Marie Curie night service) in Cwm Taf, for example. We worked out what the minimum level of service would need to be in each area in Wales to make sure that should all of the voluntary sector services collapse, we would be sure that everybody in Wales had fair access to specialist palliative care. It also considered what would we do to upskill the generalists across Wales so that if you were on the Llyn Peninsula or in central Cardiff with complex needs, specialist palliative care would be available. That was the basis for the funding formula – it looked at what was currently there in health boards and then made sure that NHS funding was able to fund the core level of specialist palliative care and that meant putting in new people. The next stage was Hospice at Home, using the same formula; it needed to recognise that people in the generalist group were also using this service. It was a question of dividing up that money fairly.

Mark Isherwood AM:

How do you feel that the current distribution of services across Wales affects access?

Baroness Ilora Finlay:

We are the only country in the world that has 7 day services and 24/7 access to advice: calls to Holme Towers have been coming in from across Wales since 1989. At that point, calls from professionals at night and on weekends were quite high. Since we've gone to 7 day service, the number of crisis calls has gone down. For example, in ABUHB, where St David's Foundation run their own advice service, about 50% of those calls are from health care professionals. BCUHB run an advice service. We are leading the way in terms of access at the time of need.

Mark Isherwood:

And of quality and equality?

Baroness Ilora Finlay:

We have outcome measures. Many of the services are using PROMS or OACC – bringing improvement into the specialist services. Also we assess the patient

experience through iWantGreatCare, asking patients and their carers at the time. Scores are consistently high – 9.33 out of 10. We take 6/10 as a warning. Returns vary for different reasons. iWantGreatCare was chosen instead of VOICES because VOICES captures carer perspectives retrospectively – perception and memory can distort scoring – and because of cost. Looking at PROMS scores, they are up with the best in the UK.

Steve Ham:

Refreshed Delivery Plan March 2017, Board has begun work to look at how we measure outcomes. National drive to take forward PROMS and PREMS for national consistency across NHS Wales. Also undertook an audit of hospital services last year around end of life – which compared very well with the equivalent audit in England. We need a conversation about how we take that forward with community based services.

Dr Dai Lloyd AM:

Canmol y llwyddiannau sydd wedi bod yn camu ymlaen ond mae yna ganfyddiad bod pobl sydd â diagnosis nad yw'n ganser – stroc ayyb – yn parhau i gael eu tangynrychioli wrth gael gafael ar ofal lliniarol arbenigol. Cwestiwn i'r Bwrdd, pa gyfeiriad y mae'r Bwrdd yn ei roi ar lefel genedlaethol i fynd i'r afael â hyn? Pa gamau sy'n cael eu cymryd yn rhanbarthol? Beth yw'r rhwystrau?

We should praise the strides forward but there is still the perception that people with non-cancer diagnoses continue to be under-represented in accessing specialist palliative care. A question to the Board, what direction is the Board giving at a national level to address this? What actions are being taken regionally? What are the barriers?

Baroness Iora Finlay:

I've looked at the non-cancer referrals across the HBs – for both NHS and voluntary sector providers – using CaNISC. In the voluntary sector, the provider with the highest number of non-cancer referrals is St David's Foundation, with 30% of referrals from patients with non-cancer diagnoses. That's plateaued and it won't go higher – they are case finding and they are finding all the need too. Non-cancer referrals by HB have also increased. We have also achieved trying to upskill other services:

- Heart Failure nurses are now part of Cardiac Services Teams, so they can manage their own palliative care
- Guidance on renal failure was developed with the National Renal Team Leads
- Respiratory failure support has increased since 2009 with targeting non-invasive ventilation patients in the community

- Around 500 GPs have been educated to date on the short palliative care course, which covers palliative care across the board of chronic disease
- Marie Curie nurses are supporting people dying from dementia
- There is a specific project in Hywel Dda to develop dementia-friendly services

The HB specialist palliative care non-cancer:cancer ratio is about one third:two thirds. I have brought the graphs of the data that shows this.

Steve Ham:

A network of disease-specific implementation leads has been established, i.e. Cardiac, Renal etc. The Coordinator of the End of Life Board meets these Boards to ensure that the work we want to undertake is reflected in their discussions and to consider areas for joint working. We want to be having a shared conversation with them, and we encourage them to be pushing us as well. Joint working also involves GP education about appropriate referral pathways.

Rhun ap Iorwerth AC:

Rydych chi'n disgrifio amgylchiadau darpariaeth gofal lliniarol ar gyfer pobl ifanc yng Nghymru fel storm berffaith? A allwch ddweud mwy wrthym am eich sefyllfa, mewn perthynas â mynediad cyfartal i wasanaethau?

You describe the circumstances of palliative care provision for young people in Wales as a perfect storm? Can you tell us more about your position, in relation to equal access to services?

Dr Richard Hain:

Correction on context – specifically addressing the plight of children or families who've lived with a life limiting condition throughout childhood and then as they approach adulthood, it is often the time when they are also approaching death - there is often rapid decline. You are also transitioning to adult services, with a new set of colleagues and carers. The nature and philosophy of paediatric and adult palliative care is very similar but the operational context is very different and carried out by different people.

Rhun ap Iorwerth AC:

Looking at pre-transition paediatric palliative care we know that we have some shortages – in nursing for example – can you expand on some of the areas where we need to have the sharpest focus in our ability to deliver the services that we want?

Dr Richard Hain:

A good death in children's palliative care requires us to give the choice to the family of the environment in which care takes place – that's the minimum that families can expect from us. Hospices are fantastic and if that's the place that people choose, they're well supported there. If they choose for the child to die in hospital, similarly we have good access and good staffing. If families choose for the child to die at home – which is the most popular choice – then we have a situation where the feasibility of delivery is dependent on what's available locally.

It follows on from comments Steve and Ilora made because it relates to the interface between specialist and generalist palliative care. We've got good specialist palliative care provision in Wales.

There are problems and the main problem from specialist palliative care – and the first focus – is that although we have a specialist palliative care nurse in each LHB she is not yet made available to participate in an all-Wales out of hours advisory rota, which is what was intended.

Despite the appointment of these nurses there are still areas in Wales where the person would not be able to support a child to die at home. That's because of a shortage of Community Paediatric Nurses. These are trained in Paediatric care, but not in palliative care per se. They could be advised by the out of hours specialist nurse, which should be in place.

Rhun ap Iorwerth AC:

What is the block to increasing nursing provision – financial? Competing demands within the health service?

Dr Richard Hain:

Both, and also difficulties recruiting. Sometimes we're able to put together an ad hoc team around the family. They do this particularly well in West Wales. However, even if there is sufficient money to put a team together, it isn't always possible to recruit.

Rhun ap Iorwerth AC:

We could include this under the category of 'workforce planning?'

Baroness Ilora Finlay:

The Today Programme covered the issue of workforce retention, including in terms of workload pressures. Nurses are becoming completely exhausted from the workload. Looking at new models of nursing – like the old SEN grade – coming through may be helpful in terms of the workload. However, we have a few years until these come through the system and we can't recruit out of nowhere.

Rhun ap Iorwerth AC:

Thankfully we have enough young men and women wanting to be nurses still, it's about capacity.

Baroness Ilora Finlay:

Yes, and we need to be supporting them. The all-Wales rota is very much a senior management issue – there needs to be commitment and it must be prioritised by adjusting rotas. 24/7 provision must be there because crises happen very rapidly in children. This is why we had a programme early on to upskill paediatricians in each HB, under Richard's leadership and the Transitional consultant post.

Rhun ap Iorwerth AC:

Rydych yn nodi yn eich tystiolaeth ysgrifenedig bod pobl â diagnosis nad yw'n ganser yn cael eu tangynrychioli mewn gofal hosbis – beth yw'r rhwystrau i ehangu mynediad? Pa gamau y gellid eu cymryd ar lefel genedlaethol neu leol i wella ehangu mynediad?

You note in your written evidence that people with non-cancer diagnoses are under-represented in hospice care – what are the barriers to widening access? What actions could be taken at a national or local level to improve widening access?

Trystan Pritchard:

Mae'n bwysig cydnabod y cynnydd sydd wedi bod dros y ddegawd diwethaf a'r safle mae Cymru ynddi o ran y gallu i gynnig gwasanaethau. Dyw hynny ddim yn cuddio'r ffaith fod yna fylchau o ran sut mae gwasanaethau yn cael eu dosbarthu ar draws Cymru a sut mae gwasanaethau'n cael eu ffurfio – lleoliadau, er enghraifft o ran hosbisau sydd a chleifion mewnol, sy'n anghyson ar draws y wlad. Mewn rhai ardaloedd mae gwasanaethau hosbis yn y cartref yn gallu llenwi'r bylchau ond mae yna broblemau o ran trafndiaeth, ardaloedd anghysbell a gwledig. Mae angen sicrhau ein bod ni'n cyrraedd y bobl yno sydd a'r angen. O ran ein profiad ni, rydyn ni'n gafael allan i ardaloedd Ynys Mon a Phenllyn, ardaloedd Sir Dinbych.

Rhun ap Iorwerth AC:

Mae dweud bod daearyddiaeth yn rhwystr yn We almost expect geography to

rhywbeth i'w disgwyl yng Nghymru. Ai dyna'r unig rhwystr? Oes na elfennau mwy strategol o ran blaenoriaethu gwasanaethau sy'n creu diffyg cysondeb?

be a barrier in Wales. Is that the only barrier? Are there strategic barriers in relation to prioritising services that lead to inconsistencies?

Trystan Pritchard:

Mae'n her i hosbisau – mae'n nhw'n ganolfannau arbenigedd ond yn amlwg mae gallu cyrraedd poblogaeth eang iawn o'r ganolfan yn effeithio ar bwy rydyn ni'n gallu gweithio gyda. Mae yna lot o waith yn gwella sgiliau mewn cartrefi preswyl lleol, er enghraifft. Mae addysgu staff mewn sefydliadau felly yn gyfrifoldeb ar hosbisau sy'n meddu ar y sgiliau a'r profiad arbenigol hwnnw. Mae yna ffyrdd o wasgaru sgiliau. Dyw hynny ddim yn ateb cyflawn i'r heriau rydyn ni'n gwynebu. Mae yna dal achos i ehangu sut rydyn ni'n cyrraedd pobl yn eu cartrefi ei hunain – efallai'n gynharach yn y salwch, pan fydd y teulu a'r claf yn dymuno treulio'i dyddiau olaf yn y cartref. Ond, wrth i'r cyflwr dwyshau, a'r pwysau'n cynyddu ar y gwr neu'r wraig, neu'r teulu agos, mae'r heriau yna'n cynyddu ac mae angen rhyw fath o fewnbwn gan hosbis yn y cartref, neu wasanaeth ysbaid, neu gyfuniad. Yn aml mae hyn i gefnogi'r teulu i godi i'r her ac i roi dewis i'r claf ble i farw.

Rhun ap Iorwerth AC:

Oes gennych chi sylw i wneud ar sut y gallwn ni fynd ati i ehangu mynediad at hosbisau plant?

Do you have any comments on what, in your view, would support widening access to children's hospices?

Rob Jones:

There are a number of things from a strategic level. Firstly a national agreement that every eligible child and young person should have access to hospice care, with agreed funding models. A national agreement on the number of children and young people across Wales who have a life limiting condition.

At an operational level, recognise the increasing complexities of the needs of children with life limiting conditions, which is growing.

The impact of funding to support families at home, who are essentially primary care providers, and face a very unpredictable journey.

A greater understanding of hospice services within the clinical network – understanding what we can provide in the hospice and the community.

I recognise the comments that were made around the challenges around experienced Registered Nurses and geography. We have two children's hospices in Wales but we can only cover some areas and access for families in some areas is very difficult.

Tracy Jones

We need to ensure that families have the services they want, where they want it. Not just about choice of place of death but choice of place of care, which for paediatrics is often a very long journey. The challenges around that do include geography and workforce. It's not just about the numbers of nurses but the number of appropriately skilled nurses – those with palliative care skills. Across the hospices we've got an excellent workforce, but if we try to spread that out across the hospice at home service, which is something we all want to do, it's where do we get that skillset from without impacting on what is also a much needed residential service – the bread and butter for families? Not just about the numbers but also the skillset. We're working to upskill our more generic staff – social care staff as well as health – to be able to support families where they need it.

Geography – how do you provide the hospice at home service in a way that meets the needs of the family but it doesn't put the workforce in the impossible position of needing to drive three hours to cover a night shift?

Rhun ap Iorwerth AC:

Going back to the point of reaching a national agreement on what people can expect, it's largely about capacity to deliver?

Tracy Jones:

Yes, there is an element of that. There's also an element of keeping that balance of how we offer our service delivery. By and large, children's hospice service delivery has been based around holistic care, primarily using a residential model – it's about how we move that out in a way that reaches all the children and families across Wales.

Baroness Ilora Finlay:

I want to draw your attention to what I think is an excellent definition of the hospice movement, which is from the beginning of the Hospice UK strategy,

because it points out that hospice care is delivered by hospices and specialist palliative care in hospitals, in the community, by in-reach and out-reach to primary and secondary care, in prisons and other institutions, and hospice at home. So I think it's helpful to differentiate when we're talking about hospices as buildings, and services and organisations, from hospice care, which outreaches.

One of the big challenges in paediatrics is that some of the children with rare conditions have almost unique needs within a particular area. So it isn't just about having staff, it's about having people who can upskill local staff and train them, and quite often the family's skills in managing that particular child are better than the professionals' skills because they've been looking after the child for many years.

Looking at children with palliative care needs is a very different population from the adult population who have been well, get a disease and then deteriorate. Many of these children are survivors of long term, very serious, life limiting conditions, with a different trajectory as well. The rarity makes it a particular challenge. We've got evidence from North Wales in particular of their staff going out into the hospital with the child, because it may be one or two nurses who are used to that child but the ordinary paediatric ward nurses won't know that child as well. So it is about that integration, which becomes really important if we're going to meet the needs of the individual.

Dr Richard Hain:

One of the key things that isn't necessarily clear is that District Nurses are a valuable resource in delivering palliative care to adults. Simple but obvious things like changing a syringe driver every 24 hours is something that a DN would be able to do. This enables the specialist palliative care team for adults to upskill the DN at the local practice. DNs don't see children. What that means is that we need Community Paediatric Nurses. She will bring the same skill and expertise in caring for the dying or sick child at home that a DN might bring to an adult. Imagine how difficult it would be to deliver good palliative care at home to an adult without a good DN; that's how difficult it is to deliver palliative care at home to children without sufficient CPNs.

Mark Isherwood AC:

Can I welcome Jane Hutt, who has now joined us.

I'd like to add that in the North East we have Clare House and Hope House children's hospices as well, providing outreach and residential services.

Tracy Livingstone:

As a group of hospices we're looking at how we can deliver services in different models. At Nightingale House we're establishing community-led, volunteer-run befriending groups for palliative care patients and also for individuals who are

isolated in their community without a palliative care diagnosis, because isolation often comes as a result of bereavement. Trying to reach many more people through different models across the area. Trying to have impact without that impacting on our resources and the cost to other services as well.

Jane Hutt AM:

I wanted to say how pleased I was to hear about this Inquiry. Interestingly, yesterday we had the publication of the Parliamentary Review into Health and Social Care. That notes the importance of having equitable access across the whole of Wales. Particularly these lines of questioning, for example with non-cancer diagnoses and for children and young people, are important. Shortly, I'll be hosting the annual launch of the daffodil appeal. In my new role, I'll be supporting this CPG.

Kevin Thomas:

In relation to non-cancer patients accessing hospice services, in North Wales the services for people with MND have dramatically improved by working with the hospices and hospice at home because the hospice and the palliative care team are part of the MDT. Hospice and palliative care isn't in isolation from the other services. What I've seen is that those sensitive discussions with the hospices and palliative care team as part of the MDT have led to a dramatic increase in the number of the people accessing those services over the twelve years that I've worked with the MND Association. Integration is important.

Baroness Ilora Finlay:

There is data to back that up, from the GP register for palliative care. I looked back 5 years ago and last year. In every HB there has been an increase. In some the numbers have doubled, the smallest is a 50% increase. So there is greater awareness amongst primary care. They're picking up more patients to put on the PC registers, which means that the MDT meetings in primary care should be addressing things. We have had a targeted programme around MND and neurological conditions. The Association of Palliative Medicine has guidance on the withdrawal of ventilation for people with MND. That has been evaluated; when that guidance is used, deaths are peaceful, gentle and not-prolonged, health professionals are there and people feel comfortable with how it's gone. They have a national audit – Wales is contributing to that. There was also an audit on quality last year by the Royal College of Physicians – for adult services – comparing Wales and England. On the last audit, Wales came out slightly better on some of the markers than England.

The Inquiry might also want to look at a study by ATOS looking at the impact of specialist palliative care on emergency bed consumption, on the likelihood of dying at home and the impact of deprivation on specialist palliative care. 5% increase in specialist palliative care outpatient contact was estimated to result in 1.47% reduction in emergency bed usage for palliative care

Andy Goldsmith:

Can you tell us about plans to improve access to Paediatric consultants in North Wales?

Dr Richard Hain:

BCUHB currently have 1 consultant session in place. This just isn't enough to meet demand. We've put forward a proposal to the Board to increase this by upskilling consultants with an interest in palliative care so that we are able to offer 3 sessions.

In addition to this we are also running joint clinics where I, and colleagues, from South Wales travel to other areas in Wales to see children and families.

Mark Isherwood AM:

We heard earlier that the funding formula supporting independent hospices was designed to ensure that palliative care services in Wales would continue if the voluntary sector completely lost capacity; is that the case?

Baroness Ilora Finlay:

Yes, that's correct. That was back in 2009. We are now in a position where an up to date audit is needed to look at HB contribution to NHS staff and staff employed by the voluntary sector and to look at population need and the impact on services. Because of the expertise in Cardiff and the nature of the population there, C&VUHB is seeing 116% of the expected referral rate based on its population. We need to look again at the numbers. In ABUHB, the voluntary sector is meeting 92% of the expected need.

Mark Isherwood AM:

The Parliamentary Review sets out the case for integrated services and third sector delivery is a key part of the Social Services and Wellbeing Act and the Wellbeing of Future Generations Act. Parity of power between the third sector, communities and the statutory sector is needed for genuine coproduction.

Baroness Ilora Finlay:

We need to build on the Byw Nawr movement, which draws on volunteers and communities. We want to see Wales as the first Compassionate Communities Country.

Dr Richard Hain:

We must remember to consider Paediatric palliative care differently – the Funding Formula doesn't apply to children's hospices and it isn't based on research about the prevalence of need amongst children.

CLOSE

