GTB Hosbisau a Gofal Lliniarol: Ymchwiliad
CPG Hospices and Palliative Care: Inquiry
Oral evidence session 2, 11:00-13:00 16 March 2018, Glyndwr University, Wrexham

Attendance:
Mark Isherwood AM (Chair), Michelle Brown AM, Mandy Jones AM, Darren Millar AM
Dr Sally Anstey, Kathleen Caper, Sandra Dade, Catrin Edwards (Secretariat), Alison Foster, Andy Goldsmith, Dinah Hickish, Tracy Livingstone, Iain Mitchell, Dr Martin O'Donnell, Julie Price, Trystan Pritchard, Fiona Redmond, Mrs Redmond, Dave Redmond, Carys Stevens, Jan Sutherland-Oaks, Sophie Thomas (on Skype), Mary Wimbury.

Apologies:
Jayne Bryant AM, Llyr Gruffydd AM, Janet Finch-Saunders AM, Lesley Griffiths AM, Jane Hutt AM, Rhun ap Iorwerth AM, Dai Lloyd AM, Julie Morgan AM, Simon Thomas AM.
Paul Harding, Rob Jones, Carol Killa, Kevin Thomas, Grant Usmar, Mike Walsh.

Formal evidence gathering

Mark Isherwood AM (Chair):
In this evidence session the CPG is seeking to understand the challenges and barriers that contribute to inequalities in relation to achieving preferred place of care and death, and related issues, from the people delivering that care.

To mark the end of the Inquiry's formal evidence gathering process, we'll turn our focus to solutions by hearing from organisations and individuals delivering projects that seek to improve equality of access to hospice and palliative care.

In terms of the GP experience, what are the barriers to equal access to hospice and palliative care?

Dr Martin O'Donnell (Vice Chair, RCGP Cymru):
Thank you for the opportunity to follow up our written submission.
The main difficulties remain organisational, geographical, but in terms of GPs, most of it is individual and educational. We have difficulty with a lot of colleagues still understanding what palliative care actually is and what services are available.

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We have to understand it's not just Cancer but other Life limiting conditions (LLCs), Cardiac, Renal, Dementia. From a GP point of view, it's extremely difficult to identify those who need to go on to a Palliative Care Register (PCR). Whenever you've got a Life Limiting Condition (LLC) entering a terminal phase it means having a difficult conversation. Some GPs are better at it than others.

There's also family understanding and the level of expectation from families. Sometimes their expectations about the level of support to the individual can be unreasonable. This is often related to the fact that, sadly in today's age, lack of literacy is a major problem. The recent National Survey of Adult Skills in Wales shows 29% still have reading age level 1 or below – worse in unemployed and deprived areas – leaflet/booklets often useless and we give them forms to fill out and they can't do it. They ask for help and we don't always have the time to do it. Social workers are few and far between. Often, the more rural it is, the more difficult it is. Elderly people are very proud, as are the rural community, and are brought up not to ask for help so it's very difficult to persuade people that they're entitled to help – you're able to have this care. We're there to gently push them forward.

We need better communication from hospitals; secondary care discharges are often due to the pressure of beds, sometimes unplanned and unscheduled. They push people into environments that aren't always the best for them. 'Discharge letter to follow' is often useless – it tells the GP nothing. As a GP I can't then organise the right care for the person. Better educated ask for and consequentially get more.

We have major issues with regard to dementia, especially in the terminal phase of life, because people can become aggressive and very difficult to manage at home. We often have difficulty with our care home colleagues who are inundated and amalgamating EMI and nursing residential care, trying to find a bed, wherever it may be, which is often far from family. A recent case in Llandudno ending up in Pwllheli.

Patients are also extremely worried about the affordability of care; can I pay for my funeral? How will my wife cope?

Patients still feel they're not being listened to. The Academy of the Royal Colleges in Wales are promoting the Making Choices Together programme (formerly Choose Wisely Wales) From a patient perspective, 'choose wisely' often meant 'do what the doctor tells you'. Patients need to be part of the conversation, educating secondary care into this will improve the situation. A lot of people feel they have no one to fight their corner, and that's where the GP comes in. If they're on their own and isolated – whether that be in rural areas or even in cities living alone – with a limited number of palliative care beds.

We do have limited contact with Children's Services. Palliative Care Specialist Teams tend to be extremely good and manage the care. But the main issue we have as GPs is transition. Whenever they move from Children's into Adult Services there isn't any adequate carry over. There is often a loss of adequate care for those individuals and medication access is very patchy – it depends where you live – especially in the Out of Hours (OOH) period. Not all medicines are available in all pharmacies so they can be difficult to source.

Mandy Jones AM:

I live very rurally, I can understand the massive difficulties. Considering the geographic aspects of Wales, and rurality, what do you do, and how many people, want to have in-home palliative care at the end of life, including people with dementia or children? Do you offer those services?

Andy Goldsmith (Ty Gobaith/Hope House Children's Hospice):

With regards to children. It is available. As a children's hospice provider we can provide the service for a short period of time. Often the issue is how long the end of life episode lasts. There needs to be a joint approach. What we're seeing (and Jan [from Claire House Children's Hospice] may have a different experience) is for lots of children they aren't known to be in an end of life phase and are often receiving active treatment, are in hospital in crisis. End of life then happens in the hospital. We're not actually getting children out of hospital into the home to provide that care because they're dying suddenly in hospital. From our point of view we're thinking about how can we improve that end of life experience in hospital, rather than at home.

Jan Sutherland-Oaks (Claire House Children's Hospice)

We provide and in-home service. As we've developed, we've picked up on how we can support children dying in hospital, particularly in intensive care and neonatal units, and developed a shared model with SPC, ourselves, we have a rapid response service, commissioned by West Cheshire CCG, in partnership with the local community team. There's a three way partnership and one of those partners will take the lead. The choice for death at home is actually there. For deaths in hospital, when the child can't be moved, we would offer in-reach services from the hospice. It's an integrated model and has made a big difference in terms of offering choice. We know we're not reaching everybody – that's due to capacity, and doctors making those decisions sooner and making those referrals. We now have one of our team working in the neonatal unit and in intensive care in Alder Hey to pick up to pick up those referrals. We do refer on to our hospice colleagues across North Wales as well.

Carys Stevens (RCN and Hywel Dda UHB)

I work in Ceredigion, which is a very rural part of Wales, and we don't have a hospice building in Ceredigion – the nearest one is about two hours away. The model that we have in Ceredigion is an 'all under one roof', one point of access palliative and hospice care service. It's Health Board and third sector providing and we have a hospice at home nursing team and hospice at home volunteers as well, working alongside the SPC. We have over 30% of people who choose to die at home achieving that, or in the care home. We're supporting residential homes as well because that is often the person's preferred place of care. Our service in-reaches into nursing homes as well.

Dr Martin O'Donnell

With regards to the interface between primary care and the palliative care teams it is brilliant across North Wales. When we ask for help, we get it. The difficulty often is capacity – mental capacity of the patient and the ability of the carer to cope at home. Sometimes dying at home isn't the best experience, especially dementia care where the person needs supportive care and 24 hour care. It's often not possible in the home environment.

Mark Isherwood AM

What role do the adult hospices across North Wales play in this?

Trystan Pritchard (CEO St David's Hospice and Chair of Hospice Cymru)

Sefyllfa sydd gennym ni fel hosbisau i oedolion, rydyn ni'n teimlo bod yr arbenigedd sydd gennym ni wedi'i ganoli yn y adeiladau. Yr her yw i wasgaru'r arbennigedd ar draws timau yn y gymuned, cartrefi preswyl a hefyd datblygu'r berthynas sydd gennym ni gyda meddygon teulu. Rydyn ni'n awyddus i sicrhau bood y cymorth yna ar gael yn gynharach yn siwrne'r claf. Dwi'n teimlo i'r raddau helaeth mai'r model sydd angen i ni edrych arni yw pob dim o dan un tô. Ond yr un fath o heriau rydyn ni'n wynebu yng Ngwynedd a Môn o ran sut rydyn ni'n gwasgaru'r arbennigedd dwys sydd gennym ni. Felly rhai o'r pethau rydyn ni'n edrych arni yw sut gallwn ni ddefnyddio'r sgiliau uchel sydd gennym ni yn yr hosbis i weithio'n agosach gyda'r gwasanaeth iechyd – y timau hosbis yn y cartref. Un prosiect rydyn ni'n edrych arni yn Hosbis Dewi Sant ydy cytuno i gefnogi pobl mewn ysbytai cymunedol a rhedeg gwasanaeth hosbis lloeren mewn ysbyty cymunedol. Mae'n golygu ein bod ni'n gallu cael cyfuniad o arbennigedd a'r ochr sydd ddim yn glinigol o ofal hosbis, sef y gofal ysbrydol a'r gofal mwy ymarferol, a chyfuno hynny gyda'r adnoddau sydd gan y gwasanaeth iechyd yn barod. Felly, fel lot o bethau eraill, yr agenda bartneriaethol rydan ni angen. Mae na gyfrifoldeb ar y trydydd sector hefyd i wasgaru a lledaenu'r dylanwad y gallwn ni gael.

Mark Isherwood AM:

What role could better Advance Care Planning (ACP) have in this, particularly when we know people have progressive conditions?

Alison Foster (BCUHB)

ACP gives people an opportunity to think about their wishes and preferences for their future. So it's not just about preferences for care right at the end of life but planning for future care. We've got to be really careful that we make it positive for people to engage in that ACP process because it's a choice and people don't have to do that – it's entirely down to them. There is evidence that engagement in ACP does increase the likelihood of people's wishes, preferences and needs being met. In North Wales we have a particular piece of work that we're leading funded by Macmillan Cancer Support where we have a Project Manager who's leading a three year implementation plan on ACP. It's to encourage the public as well as people who are ill to take time to think about what's important to them and to communicate that information with those that matter to them, who may be their family members or health care professionals. We're keen to have a coordinated approach in North Wales whereby we're encouraging people to do that but we're sharing the information so that when something happens all the professionals involved are aware of what that person wants. There is something about managing expectations; ACP isn't a legally binding document but it stands to good reason that if we can speak to people, give them the opportunity to tell us what's important to them and to record that and share that information then hopefully we can make sure that we plan and coordinate care and services accordingly.

We were talking about being able to support people at home. In North Wales some interesting models have been discussed. Everybody who works in health and social care has a role in supporting people to be cared for at home. It's not just about specialist services. We're aware of the challenges GPs and District Nurses face; but GPs and District Nurses are the mainstay

who allow people at the end of life to be cared for at home. Our specialist services that we've talked about, whether it's our integrated team, our hospice at home teams in North Wales, and the really important partnerships that we have with our third sector partners in hospices, Macmillan and Marie Curie – we're really keen to all work together. Just to reiterate what Trystan was saying that we've got to integrate and work creatively going forward.

Mandy Jones AM

I'm glad to hear that you're starting to work together. Many years ago I was an end of life dementia carer and there was no support out there that we could see, for us or for the family. That was in a very rural areas, Llanuwchlyn. I'm wondering now what support have you got – apart from to families, which seems to be improving because you're now integrating – for your professional carers, including mental health and wellbeing. As carers we used to get really close to our dementia patients and when they died there was no support for us.

Alison Foster

From my area of work, staff who work in our palliative care services are able to access clinical supervision, which is important. It's important for recruitment and retention. We know that in some areas it can be difficult to recruit. And in ensuring safe practice and quality of care for people. Having good team structures and team leadership – we've done a lot of work to be able to improve that recently. The other side of things, is training and education – giving staff the opportunity to learn and reflect on their experiences and how to improve care for the future going forward. So for example with our hospice at home service we have them based within our SPC team so we've got that hierarchy of people who know about that and are able to provide that supportive environment. We have a 'Six Steps to Success' training programme that we deliver to care homes across North Wales, and we have delivered it to other care settings too. It's had a dramatic impact on staff working in care homes – it's improved the level of confidence of those staff. That then means that those staff feel more effective, they get much more job satisfaction, they feel supported because it's also about their managers supporting them and realising what they're doing. Equally that then has a direct positive benefit on patient care, or the care to people towards the end of life because people are much more likely to have the confidence to support them to be cared for in the care home rather than be cared for in hospital.

Dr Sally Anstey (RCN and Cardiff University)

I'd like to take us back, if possible, to the ACP issue and I think that perhaps the position clinically is linked to diagnosis. With cancer we have a very precise dying trajectory where we know someone's life is coming to an end than with dementia, comorbidities and frailty. So I think that one of the issues with ACP, and our research at Cardiff University is proving this, is the timeliness and the appropriateness and, as we've heard, the education of staff. There is still the perception amongst staff and family members of 'voodoo kills'; if you talk about death and dying and planning for death and dying you make it happen. So I think there's a real need to make ACP almost a routine practice for all of us to think about. There are lots of all-Wales strategies that are helping with that but I still think it's down to the public being less fearful of dying.

Mark Isherwood AM

Can I ask the hospice and third sector, in terms of the support for carers, how your model supports families and carers before, at and following the bereavement?

Trystan Pritchard

Un prosiect sydd gennym ni yn Hosbis Dewi Sant, i bigo i fyny ar yr atebion gawsom ni o ran daearyddiaeth a pha mor anial mae rhai o'r cymunedau ry' ni'n gwasanaethu, mae gennym ni brosiect yn ardaloedd Meirionydd a Dwyfor, De Gwynedd, sy'n edrych ar roi Swyddogion Cefnogi Teuluoedd – Patient Family Support Officers. Dydy rhein ddim yn glingwyr, beth mae nhw'n gallu gwneud yw cynnig ystod o lefelau gwahanol o gefnogaeth – o bethau ymarferol iawn mae'r teulu'n gorfod meddwl amdano o ran budddaliadau, o ran trefniadau, a hyd yn oed pwy sy'n cerdded y ci. Rydyn ni hefyd yn edrych ar ol yr ochr emosiynol – dydyn nhw ddim yn cwnsela'r teuluoedd ond yn cynnig clust i wrando a barn bersonol ar y sefyllfa, a mwy na dim byd arall yn tawleu meddwl. Mae hyn yn cael ei wneud trwy gyfuniad o alwadau ffon, dros y we, neu mewn rhai achosion mwy dwys mae nhw'n gallu ymweld a'r teulu. Dyw e ddim ar raddfa eang iawn ar hyn o bryd oherwydd ein bod ni'n ei brofi fo mewn ardaloedd gweldig, ond mae'r neges o gefnogaeth a'r dystiolaeth yno, wedi i'r claf farw hefyd, yn gryf iawn, gyda'r gefnogaeth ymarferol yn enwedig ac i raddau yr elfen ysbrydol hefyd.

Michelle Brown AM

The RCGP have mentioned that continuity of care and the provision of that care by GPs in the community and elsewhere is something that's very important. Would you say that continuity of care is there for the vast majority of patients? What are the challenges in providing continuity of care?

Dr Martin O'Donnell

I think everyone will agree that continuity of care is of paramount importance and although GPs do provide it, they're not the sole providers. The RCGP End of Life toolkit highlights the need for effective communication for those with LLC, proactive care and support planning is seen nowadays as core to the GP's work. It's advocated right in the early training. Last year's winner of the RCGP Wales' GP of the year was nominated with the testimony of a deceased patient's wife. With comments like 'He popped in on his way to surgery or on his way home', 'He gave his personal number'. Patients never abuse that. I was called to be told a patient had died when I was on top of Arthur's Seat in Edinburgh – the family wanted me to know so that I wouldn't be upset when I came back on Monday morning. GPs facilitate and inform family discussion in the planning of care, but also when organising the funeral.

We have difficulty identifying when a person enters into the last phase of life. Continuity of care isn't only for the last phase of life, it's for the lifetime. A GP does that because he has ongoing contact. Nowadays patients are registered with practices – the point of contact may not be specifically the GP. We're developing models with Advanced Nurse Practitioners and there's a model in Rhyl where an Advanced Paramedic Practitioner does all the care homes – goes and visits, gets to know all the patients in the care homes for that practice, which is ideal.

But everyone's got this big worry about certification of death in that in the last days of life; the GP needs to have seen the patient within the last two weeks to be able to issue the death certificate or else there's a discussion with the Coroner. In Northern Ireland it's four weeks, which is a better time. It means a GP can go on holidays!

Transfer for patients to OOH care needs careful planning, including when do you notify them. Because OOHs don't want a list of palliative patients, they want a list of probable deaths. They will be flagged for them. Opportunities arise for a team based approach utilising other skilled personal – community nurses, palliative care team, other condition leads – cancer – as far as the QOF and driving things forward.

From the patient point of view, the number of times I've had to sit down and help sort out finances, DS1500, there isn't a social worker to do it. A solution for people in palliative care is an advocate. Somebody who knows how to go down that road. The third sector does that a lot – that's vitally important in our rural communities. Patients want to know not 'what's the matter with me?' but 'what matters to me' – big difference. GPs listen and we try to work out a care plan, anticipatory prescribing, just in case boxes. The GP electronic record remains the best available source of that continuity of care so that others can access it. Individual Health Records are accessible, in summary form, through the Welsh network for OOH services when they have to do a home visit. But also we can visit, we can advise on local services such as the third sector and national services such as Byw Nawr. Obviously coordination of care through GPs is what we do best.

Alison Foster

Just to echo, there's been a lot of work done over a number of year, not just in North Wales but across the UK, where GPs are developing registers of people who they would not be surprised if they died within the next 6-12 months. That register of patients is discussed on a regular basis with key members from the Multi-Disciplinary Team (MDT) to be able to review that care and the coordination and the planning. And that's really important and I think the point has already been made about the difficulties identifying people to be able to go on to those registers and we need to look to see how we can improve. What's also important, and we've talked about ACP and OOH already, but sometimes when people come into hospital and a lot of the work we want to do, and we are doing, is to support people to be able to care at home if that's their wish. But sometimes people do need to be admitted and need acute care – if they need that then it's important that they get the right care at the right time. We're all aware of the pressures on our acute hospitals at the moment. We want to avoid a situation where people are admitted who really don't need to be there. One of the things we're doing a bit of work on at the moment to look to the future to identify if there's any models we can develop is to see how palliative care can be more active in A&E departments, for example. We want to tackle it before people come in, but equally when people do come in we want to make sure people are assessed and responded to to make sure we're getting the right care, be that in acute hospital or supporting them at home.

Michelle Brown AM

How consistent is palliative care provision across Wales? How good is it?

Dinah Hickish (RCN and St Kentigern Hospice)

For inpatient hospices we work with 7% of people – a small percentage of people who die. Whether that's a good thing or not, it's a measure.

Iain Mitchell (St Kentigern Hospice)

I don't think it is consistent across North Wales or across Wales. It's really dependent on how the funding streams were established in the first place and what was the critical mass of people who contributed to it. For example, if you take my own hospice, St Kentigern, if we relied solely on the Government for funding, we'd only be open 60 days a year. I can't say it's consistent. As a former NHS animal, coming into the hospice environment it's been harrowing to see - there's great work being done but there's inconsistency. I think the reason behind that is legendary and very obvious.

Dr Sally Anstey

Everyone who needs it. Specialist palliative care is available for people who have very complex, comorbidities or problems. I think that the generalist palliative care across Wales is compromised by education and resourcing. It is every professional's business to provide palliative care but it is a group of very skilled professionals providing the bulk of it. There are socio-economic variable that impact on equity across Wales. If we look, historically, hospices were built in areas of high income, middle class, and I think that certainly in the South Wales valleys there are excellent hospices who, for example, have been supported by National lottery funding, but if they relied on the Government, it wouldn't be very much.

Mary Wimbury (Care Forum Wales)

Provision is patchy for people already receiving other forms of support and care. Both in terms of – you talked of the 'Six steps to success' – and that's been welcomed in residential care homes, but in some parts of Wales it is still the case that you can be supported to die at home unless you call a residential home your home, and that's where you've been living. That support in some areas of Wales just isn't available. Equally there are different levels of support for nursing homes providing care and different expectations of the ability to work with domiciliary carers who may already be going in to someone in terms of support and training that can be provided to them to be a complementary part of palliative care. So I think the people who either are already receiving care or leave hospital to go to a care home for palliative care, that service is patchy across Wales.

Mark Isherwood AM

I wanted to mention the Palliative Care Register. From your perspective as palliative care providers, are they working? Are they enabling you to reach more people? Do they enable you to deliver better care? Or do you propose changes to the way they work?

Iain Mitchell (CEO St Kentigern Hospice)

I think that the End of Life Board said at the end of 2016 that numbers were low – that some practices were very good at it and some practices weren't. That is a solution – to have a robust palliative care register. From the All Wales End of Life Board Report 2016, Wales was low in comparison.

Dr Martin O'Donnell

Palliative care registers are useful if they're populated. The problem is populating them. As with other registers, they end up in an envelope somewhere. The reason being, again, people don't want the label of 'the last days of life'. With a lot of the computer systems in general

practice there's inbuilt decision making tools which are used for risk stratification, which populate the register automatically for you. If they're used, one, they're very time consuming so you have to look back when you fill it in, and secondly, you have to use the right read code. If you put in the wrong read code, it won't populate and some people are quite new at it or they don't use the right read code so we're trying to educate our GPs.

The use of ancillary staff, the use of nurse practitioners is improving that because they're much better at documenting and have more time.

The QOF palliative care element says there is need for a register. Some people do that really well and other areas are still working and developing. With all these sort of thing, with regard to palliative care, the area needs an advocate or a champion or a lead for palliative care within a cluster to develop staff.

As part of the register there is a difficulty – you have to have a DNACPR instruction or conversation with the patient. That really is quite difficult for most people to get across; 'when you're going to die do you want us to do everything we possible can'. You have to find the right way to approach it. Some people might want to tell you about their living wills and what they want done with them.

In summary if the palliative care register is to be used in accordance with the End of Life Care Delivery Plan March 2017 there is an opportunity to educate providers of care and carers in general. But the numbers are patchy.

Andy Goldsmith

And for children there is no register. There's no palliative care register for children at all. There's less than a thousand children with life limiting conditions in Wales but there's no single point of reference or source for that.

Michelle Brown AM

Are you going to do anything about that?

Andy Goldsmith (CEO Ty Gobaith/Hope House Children's Hospice)

We're in conversations with the palliative care Board about sharing information better. But there's no database that exists at the moment.

Carys Stevens

As the palliative care team nurse in Ceredigion we go to most of the GP meetings with the consultant and it's just anticipating, identifying and actually sometimes taking patients off the register as well. Having that discussion as a team, maybe one of us has had that anticipatory planning, DNACPR discussion with the person, so it's that care planning, multi-disciplinary team approach across specialists and generalists.

Darren Millar AM

Can I first of all apologise for being late, Chair? Unfortunately I had to go to another appointment first. But I'm very pleased to be here and very interested in that last discussion about the register.

Is it just GPs who use the register, or consultants and other professionals?

Dr Martin O'Donnell

The register I'm referring to is the register held in GP practices identifying patients who are put on the register when they reach a stage where they require palliative support or end of life support. As referred to earlier, some patients will come off of it. I've had the honour of being on and off the register in my practice, because you do need help whenever you're critically ill, and if you manage to get out the other side you can hopefully say goodbye to it.

Darren Millar AM

I know that there are some changes coming to IT systems in our area. Is that going to cause problems with the register?

Dr Martin O'Donnell

There is a decision making tool embedded in it.

Darren Millar AM

I suspect that there is a risk, though, that any new system that GPs, where any new system that makes tasks for GPs more time consuming, will be skipped or missed out as they become familiar with the system.

Dr Martin O'Donnell

It's in the specifications for the new providers that they maintain the interface between NWIS and the templates that are being used, some locally. Because if you're all on different computer systems you won't be able to talk to one another. It's a requirement of the new providers that they incorporate it and we want to make sure it's there.

Darren Millar AM

Can I just turn to the role of nurses then, because much of the front line of what's delivered in palliative care will be by nurses. We heard earlier on that some nurses will specialise in palliative care but of course everybody will need to have some access to resources and materials to enable them to deliver appropriate care, whether that's at home, in a hospital or indeed a hospice. So what's available now within nurse training to make sure that there's sufficient access to that information?

Dr Sally Anstey

At the moment we have a new curriculum across Wales in nursing and midwifery training. I would certainly appreciate your view on having an all Wales joined up approach to ensure that all nurses have a certain level of competence and skills to support people requiring palliative and end of life care.

Darren Millar AM

Is there anything specific within the existing training regime?

Dr Sally Anstey

It's very variable across universities. When I went to Cardiff University palliative and end of life care had half a day and we've now negotiated five days because, obviously, it was very exclusively linked to cancer care. There is quite a lot of cross-curriculum working that needs to be done. This should be an essential skill for all nurses. What we then need is, after qualifying, having a mandatory approach to continuing to educate nurses as part of their CPD. I can give you an example from Cardiff & Vale's strategy where all nurses are encouraged to undertake a module of distance learning, which could be rolled out across Wales. It's aimed at nurses and Allied Health Professionals from all care settings but it's based in practice. And that is mandatory for community nurses and Cardiff & Vales have now said that 10 percent of all staff in acute settings, whether it's A&E or hospital wards, should also attend that module. They're also funding a clinical lead for each care home to attend that module.

Darren Millar AM

What about the other 90 percent?

Dr Sally Anstey

Absolutely. But I guess that 10 per cent is better than it was, which was around 2 percent.

Darren Millar AM

It's a pretty low aim though, isn't it?

Dr Sally Anstey

Absolutely. But the difficulty is releasing staff – with backfill. That's why it's distance learning. People can come, possibly, once a month over a period of six months. Back in the day, we'd do it over six weeks. So it is about release, backfill cost. Particularly for care homes, they are a much more mobile population. You cover all care homes in an area and then the staff moves, so that creates huge gaps. Education is the key.

Darren Millar AM

So we've got to educate people up front before they come in to the profession. Then we've got to re-educate, if you like, those who are already in the profession working on the front line. To what extent do individuals who are working in care homes, nursing homes etc, to what extent do they have access to the training provided by the NHS because that makes your job easier if they're good at their job too?

Dr Sally Anstey

The model that we have in Wales is that Clinical Leads are responsible and are then supporting people back in their care setting to cascade it down. We're looking at an evaluation to see whether that makes a difference. The one thing we don't know about education is whether it makes a difference long term. We know that it makes a difference for the first few

months, because you might have desensitised them, but you don't know whether it's sustained.

Mary Wimbury

My experience again is that it's patchy across Wales. And also there's a relatively high turnover because people come into the care home sector and they're recruited to move into the NHS. It's the releasing of people to take on the training, backfilling behind them and just the pressure providers are under to provide nursing care at the moment. There is within the NHS a shortage of nurses. That is even more the case within the care home sector. So it's the ability to release people for additional training and it is then, even if you can do that, it's the cost of backfilling and providing that care.

Tracy Livingstone (Nightingale House Hospice)

There is access to training from hospices to home care agencies and the ability to use our facilities. We welcome them coming in and using our expertise.

Alison Foster

If I could just share with you a little about what's happening across North Wales? We're delivering the 'Six steps to success' that's predominantly delivering in care homes across North Wales. It hasn't been delivered everywhere yet but there is a plan to. That's an eight month programme. There are champions identified in the care homes, who are the nurses, who participate in the programme. They come to a number of study days. It's not just about the attendance. They're actually required to keep a portfolio that provides evidence of change and quality of care with regards the improvement of end of life care in their setting. That's been quite strict in terms of how that's marked for quality. We've worked in partnership with Wrexham and Flintshire county borough councils, for example, where they've supported us with that programme. From a care standards point of view they've been really ready to help. It's a bit quick but we've seen a dramatic improvement in care.

Darren Millar AM

How many individuals from within Betsi have attended this course?

Alison Foster

We do different training for individuals within Betsi but we have done some pilots on acute wards.

Darren Millar AM

How many people, as part of their CPD, within Betsi as a proportion of the workforce, have had access to specific palliative care training.

Alison Foster

I couldn't give you a figure right now. We've piloted about 12 wards in East and some more in Glan Clwyd. The programme was primarily designed for care homes and what we've been doing is looking to see whether that translates to different care settings. So that work is ongoing.

Darren Millar AM

I'm pleased to hear that work is going on. Most of the complaints AMs receive tends to be about hospital care rather than care homes.

Alison Foster

If I can also share with you, that team on the Bevan ward, have won an award and have won a King's Fund award. The small amount of funding that came from that is to look at how we can roll that out further in North Wales.

Dinah Hickish (RCN and St Kentigern Hospice)

I teach on two days at the Undergraduate degree at Bangor University. This isn't a great deal. For our nursing staff, for them to go on a palliative care degree module, they have to go out of Wales to access that. There isn't a course for them.

Jan Sutherland-Oaks

We should also consider the needs of children in terms of education, for transition. There's an increasing number of children now surviving into adults. Many of these are now finding themselves in nursing homes. They don't always get access to good palliative care because they have very complex needs which adult providers often struggle to provide. That's certainly our experience.

Darren Millar AM

So making sure there's a dedicated approach to training for children who have palliative care needs.

Jan Sutherland-Oaks

We now have the technology to enable children to survive into adulthood and care services need to be ready for them. There needs to be the expertise in primary care and in hospices. Most of these young people will die at some point, but that point is getting later, and they won't be supported by paediatrics. I know that many of our families are really in trouble and they end up in very difficult places – in hospital or in nursing homes. Adult hospices struggle to take them in.

Darren Millar AM

You've effectively got a captive audience if you've got a care home team or a hospital team. In recent years the use of agency staff has been very, very high. How do we make sure that agency staff are also getting access to Continuous Professional Development which supports their understanding of palliative care and how to deliver it well?

Tracy Livingstone

We've worked a lot with agencies. We've had some really positive experiences with local care agencies who've bought training from the hospice for a whole group of staff, from the point of view that they were caring for people at the end of life in their own homes, who perhaps were originally just being cared for for their social needs but then their general condition

deteriorated, the same care staff were looking after them but the funding stream had altered. We've had some really positive experiences where they've contracted us to deliver palliative care courses to groups of staff. That takes a lot of investment on their behalf to release the staff to still deliver the care.

Darren Millar AM

That's great that we've got some who are proactive, what about those who are less proactive?

Tracy Livingstone

We can make it available to them but we can't enforce people to take it up.

Darren Millar AM

Should we be enforcing it?

Dr Sally Anstey

We have mandatory training for things like infection control, health and safety. I think that the one way forward that would make a difference would be if there was a mandatory commitment to say that every nurse, every year does one day on palliative care and symptom control and supporting families. There are ethical issues around Advanced Care Planning so it would be a very full day! But if we mandated that both for nurses and Allied Health Professionals – for some diagnostic groups it's the physio who is the key worker – if there was a bit of teeth from your Committee that said that then I'm sure the RCN and certainly the Nursing and Midwifery Council would take that on board.

Michelle Brown AM

I just want to come back to the supply on the nursing agency side of things, who's responsible for procurement? How is the agency qualified before they're signed on as a supplier?

Tracy Livingstone

It would be Care Inspectorate Wales who regulate the agencies. It would be up to the person contracting out to the agencies to make sure they were compliant.

Michelle Brown AM

Could the requirement for training be placed in the contract? Whoever is procuring the services has the control. If you tell an agency they need to ensure their services have A, B, and C training, they'll do it. The key to that is the contract that you're placing with the agency.

Dr Martin O'Donnell

With regards to nursing and care homes, it has been successful to a degree because what we notice in daytime General Practice and our colleagues in WAST, we've seen a gradual decrease in unnecessary calls. As for timing and when you call, you don't need to get a blue light for someone who's expected to die. That can happen quite a lot in OOH. We notice that those who haven't been trained will call – so the training is important.

Mandy Jones AM

In your written evidence to the Inquiry you note that nursing homes are now providing much more complex care, often funded by Continuing Health Care. What are the main challenges and opportunities this presents to ensuring equal access to palliative care?

Mary Wimbury

I think in terms of the challenges, we've seen the dependency levels of people in nursing homes increase significantly over the past 10-15 years, in part because are people are enabled to be kept at home much longer. That does mean people are much sicker when they're coming in to nursing homes, they're needing much higher levels of care and staff are needing greater training so that they are enabled to keep them out of hospital. I think the opportunities there are that rather than see a patient with a particular need that you might need training for once in a blue moon, you're seeing them more regularly. Therefore that training can be provided. But sometimes it's also about what support is provided as well. We heard right at the beginning about the GPs getting transfer letters that weren't very useful, what will often happen with care homes is that people are often transferred with insufficient information about care needs, about medication, about supplies of medication etc. We've actually reached a point now where I know a number of care homes will not take discharges on a Friday afternoon. Not because they want to discriminate against people who want to be discharged on a Friday afternoon but they have just found that too often the support services are not there, the information is not coming to them, the medication is not coming to them. And therefore they can't provide the level of support they ought to be able to, particularly – we talked about people having to move areas to get an appropriate care home placement – well it may be that you were under one GP and you're moving to another GP and all the documentation needs to be transferred. We see all sorts of problems. This particularly affects people with dementia who haven't got family support who can carry that information forward either.

Mandy Jones AM

Retention levels. Have we got enough numbers of agency staff? What's the retention of full time carers? My daughter is actually a carer through an agency. She says that the turnover is crazy. What are your experiences?

Mary Wimbury

It is difficult both to recruit sufficient staff and to retain vital staff across the care home sector and the domiciliary care sector. I referred earlier to the fact that I think we have people coming in – both as nurses and care workers – for independent providers, being trained and then offered far improved terms and conditions by the health board or, in some circumstances, local authorities. It's those same health boards and local authorities that are commissioning at rates that don't enable independent providers to pay those same rates to retain people. We need to be honest about this. It is a significant issues.

In terms of nurse agencies it would be great if the health board through its contracts started putting out requirements in terms of palliative care training but the supply and demand in the sector is such that it is incredibly hard – in particular with nurses because you've got an even more restricted supply of people to take up that role and to provide cover. We are increasingly hearing of relatively sharp practices in term of someone can have booked planned annual leave, well in advance, and another nursing home has an emergency and their saying 'we'll

pay this and we can provide you with a nurse' and they're phoning in sick to the other provider. We just haven't got enough nurses to provide the care that's needed.

Things are going to change somewhat. With the Regulation and Inspection of Social Care Act – it was referred to about nurses agencies registering – unless they are providing domiciliary care they won't be required to register from April. The nurses individually will be required to register but that change is coming in and it's going to make a difference. At the moment you register either as a nursing home that provides 24/7 nursing care or as a residential home and you might have a specialism in either category. Under the new Act, people will not register in either of those categories but they will have a statement of purpose and they will have to outline the care they can provide. There are challenges and opportunities there. I think we'll see that some people need nursing care but don't need it 24/7 so we may see some care homes providing that kind of service. But equally at the moment we're in a situation where, even if you've got a nursing home and a residential home on the same site if someone needs nursing care, you've got someone in a residential home and calls it their home, goes into hospital and comes out needing palliative care, they can't go back to that residential home unless the provision is put in. It will give us flexibility around those areas. You might be able to provide nursing support in ways that you can't currently. There are opportunities there but it's all going to come down to how it's commissioned and the ability to recruit staff.

Dr Martin O'Donnell

We as primary care get a lot of cooperation from the care homes and the community nursing colleagues in regard to beds in order to stop people going in to hospital. Palliative care element, one of the most notorious elements of that is blood transfusion. Care homes are great at facilitating when they can.

Mark Isherwood AM

To an extent the terms care and nursing homes are used interchangeably, how have those pressures impacted on care homes, as opposed to nursing homes, including palliative care? I've seen palliative care provided in a care home myself. Secondly, we've heard reference to the need for greater integration from statutory and third sector partners but from your sector's perspective, how might we develop that approach?

Mary Wimbury

I talked about the increase in dependency in nursing homes – I talked to one of my colleagues in a nursing home yesterday and she said that since Christmas, they have 50 beds, they have had 21 residents who've come in on palliative care and passed away. That is the level of support we're talking about. Again, what was said earlier about support for staff in those circumstances and the mental resilience is quite important.

What we've also seen of course is the dependence in residential homes without nursing has also increased significantly. I think in terms of providing palliative care there are some great things like the 'Six steps to success'. In those care homes where this is provided people do spend time there and it does become their home.

The Older Person's Commissioner states that people in a care home should have access to the same services as people who are resident in their own homes.

Mark Isherwood AM

Questions now for Betsi Cadwaladr UHB. What are the particular challenges to providing palliative care in North Wales?

Alison Foster

The challenges aren't simply restricted to healthcare. Public awareness of palliative care is poor and even within the palliative care community we need to break the taboo. One way we're doing this is during Dying Matters week in May, and we work with our hospice colleagues on this.

Identifying people with palliative care needs can be a challenge. We've already heard of the prognostic paralysis from colleagues here today. There's also much more work to be done around conditions other than cancer.

At Betsi we're supporting professionals to communicate effectively about palliative care and those difficult conversations.

Our palliative care teams are the experts in this field. We offer training for non-specialists but the challenge is that we can't make people attend.

We're looking more to the compassionate communities model. Our primary care colleagues have a role in delivering on this.

We're also investing in research to improve our deliver of palliative care. For example our CARIAD project, which is looking into the viability of supporting carers to administer medications usually only administered by healthcare professionals at home.

Michelle Brown AM

To what extent do you get to learn from others?

Alison Foster

We're a close community in Wales and we talk with our colleagues across the country. We also have support from organisations such as Hospice UK.

Mark Isherwood AM

Coproduction between the statutory sector and third sector has always been a passion of mine. To what extent is there joint decision making between health boards and hospices before budgets are set?

Iain Mitchell

There has been no clear strategy for us in North Wales. Hospices need to be part of the planning process.

Alison Foster

At Betsi Cadwaladr UHB there's pressure to deliver on the national plan. If there's to be a strategy in place it needs to be a good one.

Iain Mitchell

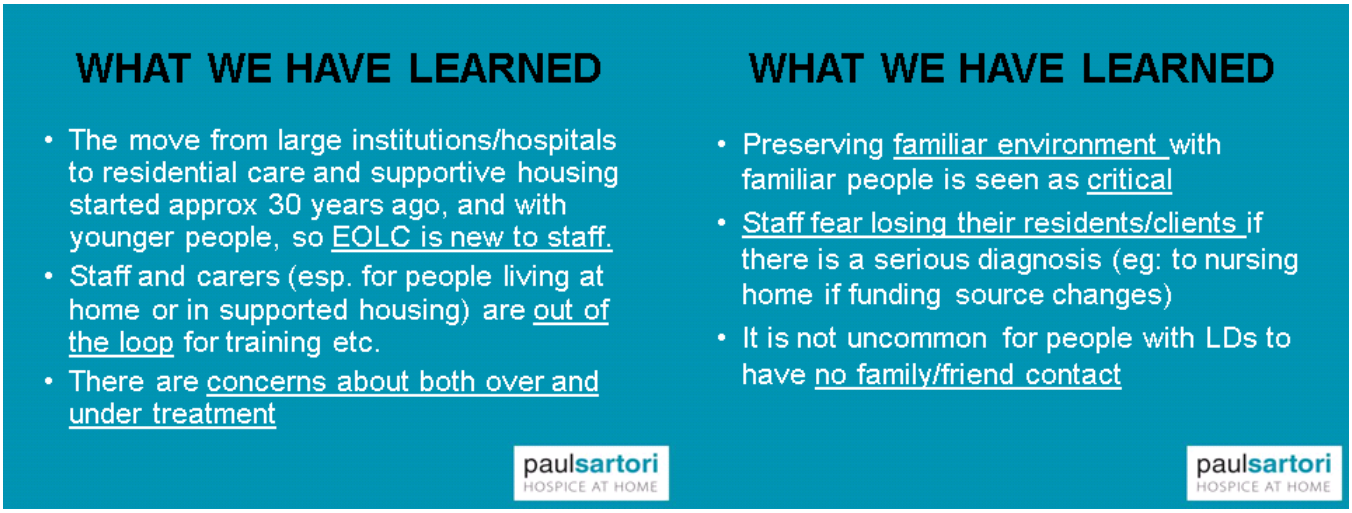
We need to acknowledge the impact of the aging population, plus our work in care homes and social housing.

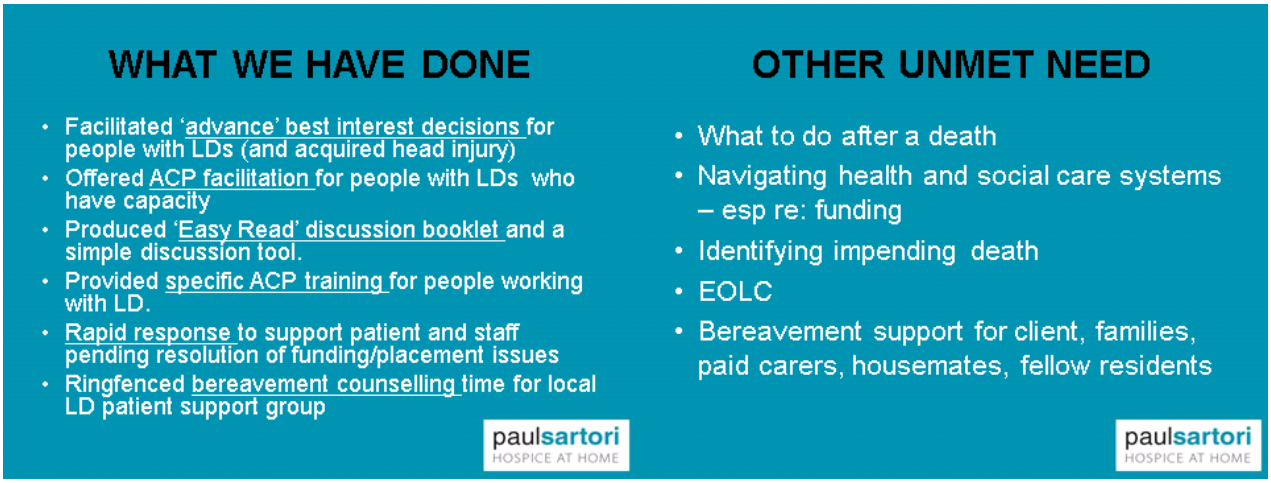
Mary Wimbury

Independent providers also need to be involved in planning at health board level.

Presenting Solutions

Sophie Thomas, Paul Sartori Foundation





Fiona Redmond (independent)

Mobilising The Community in Times Of Adverse Weather Conditions.

Good morning,

I'm Fiona Redmond and this is my husband Dave and I'm here to talk about our recent experience of caring for a dying patient in the recent adverse conditions and our intention to assist in avoiding the situation arising again.

Briefly, I have been a registered nurse for 24 years and cared for palliative patients for the majority of this time, in various stages of their care. My husband is a Medical Technician/Trainer and former Managing Director of a company providing medical cover for events whatever the weather and whatever the terrain. But, this is not why we're here

We're here as the daughter and son in law of an eighty-year-old gentleman, who sadly passed away on 10th December 2017 with his loving wife by his side, in his own bed, in his own bedroom, with a view of his garden which was his pride at joy, with the snow falling. In theory, my father, my mother and our family couldn't have asked for anymore for him. But, as the events unfolded 48 hours prior to passing, I wouldn't wish it on any patient and their family and we can't let it happen again and I speak as a professional with experience in this field.

Diagnosed over 8 years ago with a rare heart condition, my fathers right sided heart failure had progressively deteriorated since May last year but, at the end of November, there were no other options available to slow this down. This led to to a DNR being put in place and the decision to deactivate his ICD was made. Following discussions involving my father, mother, family, District Nurses and GP, it was decided it was acceptable and possible for my father to remain at home to die, with the support of Hospice at home and Marie Curie. The services were booked accordingly, involving two visits daily plus, overnight care by Mare Curie when available commencing on the night of 9th December

As predicted, on Friday 8th December, the snow began to fall. The community nurses were aware of dads deteriorating condition; anticipatory drugs were prescribed. The Hospice Nurses contacted us to cancel the visit, on the Saturday due to the weather but, at this stage, dad was poorly but, we were coping and I knew on the Saturday night, I would have a break, as Mari Curie would be attending. By late Saturday afternoon, it was clear my father was progressing

towards the end of life and at 17:00 hours, I received the phone call, which haunts me to this day. The Marie Curie Nurse was unable to come that night because of the snow! This meant I potentially was on my own, to care for my dying father and to support my 80-year-old mother. Thankfully, my husbands experience of driving in adverse weather conditions, allowed him to get to us. Without him, I don't know what I would have done…my father was becoming increasingly agitated and unable to care for personal needs. By 5am the call was made to out of hours, as my father was now struggling. A trip that usually take twenty minutes, took the nurse and HCWS two hours to get to us but, we were eternally gratefully that they were prepared to try and drive themselves. Dad was given the drugs required to keep him comfortable.

At 10 am the community nurses attended and we were just lucky that the husband of one of the nurses had a 4 x 4 and that was the only reason they got to us. The care they gave him was outstanding.

At 4.30pm, my father passed way.

A lot of reflection has taken place since that time and we can't allow adverse weather conditions have such an impact on patient care. That weekend there were two red cross vehicles assisting the local hospitals, with a 4 x 4 group assisting hospitals in Bristol.

My husband and I are proposing to create a 4 x 4 group of volunteers, who will respond to the adverse weather conditions and ensure patient care continues. We will be responsible for recruiting and co-ordinating volunteers by using social media and liaising with local health boards and charities. We've taken advice from medics and emergency services contacts in the Alps and their suggestion was snow tyres! We tried and tested this, last week and we got out of a village which was cut off to those without a 4x4.

We may not experience adverse weather conditions like some other countries but, the care available to a dying patient, shouldn't be effected by this.

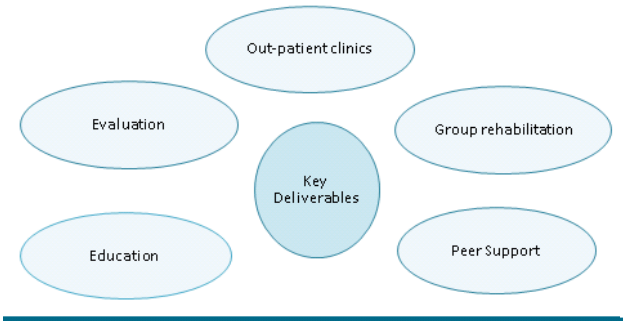
Tracy Livingstone, Nightingale House Hospice

Inside/Out- Integrating Heart Failure Services within Nightingale House Hospice.

- Shared Purpose – Improve access for patients and families living with a diagnosis of heart failure to hospice care.

Partnerships

- Identifying a shared goal and opportunity



The Volunteer Community Resource

Calon Llan

The Heart of the Village
Llandderfel Be-friending Service

The Llandderfel *Calon Llan* (Heart of the Village) befriending service works in partnership with local Health Services to support people with life changing conditions, and where appropriate their carers.

Sustainability for the Future

Keeping it Local!

- **Community delivered**
  - Local Volunteer coordinator
  - Safe referral system
  - Local knowledge
- **Hospice Supported**
  - Governance
  - Recruitment/DBS
  - Induction training
  - On-going training, reflection and support