

Grwp Trawsbleidiol ar Hosbisau a Gofal Lliniarol
 Cyfarfod Cyffredinol Blynyddol
 Cross Party Group on Hospices and Palliative Care
 Annual General Meeting
 17 September 2019

Cofnodion | Minutes

Yn bresennol | In attendance

Mark Isherwood AM	Dai Lloyd AM
Liz Andrews	Dr Idris Baker
Selena Booth	Janette Bourne
Kathleen Caper	Andy Goldsmith
Esther Green	Iwan Hughes
Laura Hugman	Carol Killa
Elin Llyr	Cathy Owens
Harry Thompson	Vanessa Skingle
Gwyneth Sweatman	Judith Thomas
Grant Usmar	Tyler Walsh
Andrew Wilson-Mouasher	Matthew Norman
Tracey Jones	Chris Jones

Ymddiheuriadau | Apologies

Kirsty Williams AM	Jane Hutt AM
Rhun ap Iorwerth AM	Helen Mary Jones AM
Jeremy Miles AM	Adam Price AM
Llyr Gruffydd AM	Veronica Snow
Joyce Bellingham	Rob Jones
Tracy Livingstone	Steve Parry

CCB / AGM

The meeting formally started with the Cross Party Group's Annual General Meeting. Mark Isherwood AM stood down as Chair. The Secretary thanked him for his work. Mark Isherwood was nominated by Dai Lloyd AM for re-election, which was seconded. No other candidates were nominated and Mark Isherwood AM was therefore re-elected as Chair unopposed.

Mark Isherwood invited nominations for Secretary. Kathleen Caper stood down. Kathleen Caper was nominated and seconded. No other candidates were nominated and Kathleen Caper was therefore re-elected as Secretary unopposed.

What Next for Hospices and Palliative Care in Wales?

Mark Isherwood AM

Mark Isherwood AM reminded the audience that the post-AGM meeting was marking a year since the publication of the report on Inequalities in Access to Hospice and Palliative Care, examining progress and further actions that needed to be taken. Mark Isherwood AM also reminded people of the impending Hospice Care Week in October, and of the Hospice UK Senedd event to be held on 9 October 2019 at lunchtime that will commemorate it.

Dr Idris Baker, National Clinical Lead: Palliative and End of Life Care

Dr Idris Baker stated that he often experiences looks of envy from colleagues across the UK about the opportunities that he and colleagues enjoy in Wales. There is a need to make 24/7 palliative care coverage in Wales more sustainable. We need to make the best of the skills that we have in Wales as they can be quite thinly spread, and there is more work to be done in making the most of these skills.

There are opportunities that need to be taken to use technology to make the best of community nurses' time, such as not travelling to get information on paper when it could be made available to them online.

A lightbulb moment from the last decade was that the number of people needing end of life care a year had been falling – but seven years ago this switched and has been going up by about 1% per annum, which compounds year on year.

Suffering from one condition was the norm in palliative care, with two being the exception. However two or more conditions has become far more common and this opportunity needs to be taken to skill up teams in order to deal with the complexity multiple conditions brings.

Carol Killa, Director of Care, Ty Hafan

Carol Killa stated that progress on the report's recommendations was a mixed picture. There still isn't a clear idea of needs of children in Wales. Paediatric element to services isn't always fully understood by professionals in Wales. Funding is a huge concern at the moment, there is no clear mechanism for children's hospices in Wales and we now lag behind England and Scotland. There is a postcode lottery of what families can get across the country. The report stated that paediatric palliative care should be organised on an all-Wales basis. Children's hospices deliver care over a much longer period of time – from diagnosis, potentially from very early childhood, until the child's death, which could be several years later.

The report recommended that gaps in data collection should be filled. There is a new funding methodology in Scotland, which we would like to take forward, but there hasn't been a positive response on this yet. Funding for charitable hospices should be regularly updated to make sure it is based on current population needs.

There is no funding formula per capita for children in Wales. For Ty Hafan, statutory funding has not been updated since 2009, and reduced in one health board. The change in children's clinical complexities mean that the funding is now nowhere near enough, with less than £300,000 annual statutory funding for a cost of over £4m, we are at risk of losing provision at Ty Hafan.

Need to consider a wider nursing model with statutory and third sector providers.

Children should have the same choice about place of death as adults – most would want to die at home.

Ty Hafan has developed two community nurse hubs to develop skills of community nurses – but this does not address the need for more paediatric community nurses. Hospice Cymru has well represented the voice of hospices across Wales, but a paediatric voice is needed as needs are different.

Liz Andrews, Chief Executive, City Hospice

Liz Andrews as appointed to role of Chief Exec just over a year ago. She spoke about funding, and previously worked in cancer research, raising money and then deciding how to spend it. However, in the hospice sector cash flow takes on a whole new meaning, with money often being a real worry. Cost to deliver goes up every year, but money received remains static, so money from health board needs to be topped up with fundraising. But there are only so many gala dinners etc that can be held each year. So inevitably look inwards to make savings. For a charity, that one legacy donation can often mean the difference between making a profit or breaking even. There is also a contrast in funding levels in Wales. One hospice receives 20% of their costs from statutory funds, one receives 24% and another receives 33%.

Regulation is important to hospices in Wales. At this time hospices are not regulated by Care Inspectorate Wales or Health Inspectorate Wales. HIW regulation covers independent hospices. But palliative care does not meet criteria for regulations as not embedded – i.e, there are no overnight patients.

How is this resolved – and when will this situation be resolved? When will we be in a position to be regulated?

Discussion

Selena Booth spoke of her husband's wish to die at home, and her personal experience, describing it as 'horrendous'. She stated that it was fine during the day where they had amazing district nurses and GPs going above and beyond, such as turning up at 5am to administer injections.

However, when the services were needed at night, this was not the case. She came to realise that there was only one nurse in her area working one night a week and two nights a week with her healthcare assistant. She had to experience her husband having seizures. She spoke of the trauma inflicted on families experiencing this, and campaigned to reform out of hours services in her area – but that she was eventually told it would be staying the same. She has started her own service to help on Sundays or at home and they have five terminally ill patients, which they fund through fundraising.

They funded a nurse who comes into the home for a patient – with candles, head massage, doing her nails etc. Selena stated that she wished to change this for everyone – so that people who wish to die at home get the same level of care.

Mark Isherwood AM spoke about funding disparity between hospices. Liz Andrews stated that she wasn't sure why there was a disparity between hospices in Wales, and that comparison could be made difficult due to different hospices providing different services. She highlighted how high the level of service provision was compared to the level of statutory funding, and that unless it was increased more people would have experiences like Selena's.

Selena Booth stated that funding was not the only issue, and that best practice needed to be rolled out right across Wales. She called for a simplification of services.

Carol Killa spoke about how hospices' roles had evolved. Mark Isherwood AM spoke about how statutory funding was often equivalent for one month a year, and that the other eleven months had to be self-funded.

Mark Isherwood AM stated that these conversations had been going on for 10-15 years, and asked if there was any new, more recent evidence that could be given.

Liz Andrews and Selena Booth spoke about death – the need to talk about it more and how it would happen to everyone as an inevitability.

Dr Baker stated that there was a strong commitment to measuring outcomes, and stated that the conversation needed to focus more on a more holistic 'what difference does it actually make?' 'What do families and children actually do need?' He stated that he wanted things that would hold his feet to the fire. He also stated that equity is important, and that places may do things in different ways but there needed to be equity.

Andy Goldsmith stated that he agreed that it was hard to have a quantifiable, qualitative outcome of 'quality of life', but that we had heard today Selena's powerful story of what happens when things have gone wrong.

Selena Booth spoke about her husband's death, where her only option was to call an ambulance – but that she did not want him to go into hospital as he wished to die at home. The palliative nurse stated that she had a meeting and could not come, and the GPs surgery also offered no assistance. It transpired that her husband had suffered a heart attack and died without any end of life care, because he wished to die at home.

Dr Baker stated that it was vital to get better at the measurement, in order to make better decisions. He stated that it is inherently more difficult to gain measurements in palliative care than in other medical fields, but that it was far from impossible.

Andy Goldsmith noted that 53% of children's hospice funding comes from government in Scotland, but they are still working on outcomes.

Kathleen Caper stated that she was keen to understand what the Health Boards report on with regards to end of life. She stated that they had lost some transparency as reports go to the End of Life Board rather than on their websites. Dr Baker stated that he did not know they were unavailable, with Kathleen clarifying that they had not been able to find any for any of the health boards for 12 months.

Dr Baker stated that there had been a focus on output rather than outcome. He stated that output was important, and that it should still be focused on, but that there needed to be a focus on outcome in addition to this.

UFA | AOB

Date and venue of next meeting to be circulated by the Secretary.