

## **P-05-912 Supporting Sudden and Unexpected Death in Children and Young Adults, Correspondence – Petitioner to Committee, 18.08.21**

### **Supporting Sudden and Unexpected Death in Children and Young Adults**

***“We call on the National Assembly for Wales to urge the Welsh Government to provide support for a service in Wales to ensure families, who unexpectedly lose their child or young adult aged 25 years and under, get the support they require.”***

In November 2019, I submitted a petition to the Welsh Assembly which called for a uniformed approach to bereavement support in Wales to ensure that no family is forgotten or unsupported. The petition focussed specifically on supporting suddenly bereaved parents. In 2012, I established a charity called 2 Wish Upon A Star following the sudden death of my one year old son, George, and, five days later, the sudden death of my husband, Paul, who took his life as a result of the death of our son. The charity provides immediate support as well as a range of other services to support those bereaved during the initial aftermath of the death, as well as in the longer term. Nearly ten years on, the charity works with every health board in Wales, are supported by every police force in Wales, has a clear pathway outlined in the Public Health Wales PRUDiC document and, since service delivery began in 2015, have supported over 900 families. Yet, we know that families are still not being referred into our services, are being missed and expected to cope, alone and vulnerable at the worst time in their lives.

The petition was delayed from being discussed in the Assembly due to the upcoming publication of the bereavement survey at the start of 2020, followed by the pandemic and the 2021 elections.

I am extremely grateful to the Welsh Government for publishing the Bereavement Survey of Bereavement Services in Wales in 2020. I appreciate the time and effort such a document takes to collate, am very interested in its content and am keen to ensure that the next steps ensure comprehensive support is available to all that require bereavement support. I am also pleased to be part of the Welsh Government Bereavement Strategy group and have been involved in writing the draft framework on bereavement services, which was recently out for consultation. It is reassuring to know that bereavement is being taken seriously at a strategic level and, as a result, funding is now available for organisations across Wales.

However, upon reading the finalised survey of existing services, I believe it raises more questions than it answers. The content tells us very little about who provides these services and what services they deliver. I have listed below some of my main comments/concerns with the survey and have concluded with further questions, recommendations and final comments.

1. The survey states that there are **25 services in Wales who support paediatric death**. That, across Wales, in **every local authority, there are 6-11 services for paediatric death**. That there are **25 services supporting sudden death and 26 supporting suicide**. That, across Wales, in **every local authority there are 5-10 services supporting sudden death and 5-9 supporting suicide**. Yet, it provides little information as to where these services are, who they are and what support services they are delivering. 2 Wish Upon A Star was founded because there were no support services in place for either of Paul nor George’s untimely deaths. If there are 25 services in Wales for paediatric death and 26 for suicide, then presumably services should have been available at the time of their deaths. The survey states that, in **Rhondda Cynon Taf specifically, there are 8 services for paediatric death and 10 for suicide**. It also states that, across all respondents, 75% have existed for nine years or more. Yet, the policeman who sat with me following the death of

my boys, researching support services on the internet, came up with no services available locally or nationally.

2. Bereavement support has been described by NICE as encompassing three components and the survey collated data in guidance with these components. There is no information on organisations who provide all three components, or all three components as well as 'other' services. Comprehensive support that avoids a postcode lottery approach is paramount and the survey does not identify who is able to provide all-three NICE components across the whole of Wales. As far as I am aware, 2 Wish are the only existing charity to provide services for all sudden and unexpected child death in line with all three NICE guidelines across the whole of Wales. Yet the survey does not acknowledge or, is not able to, dispute this.
3. The survey states that there are **23 services providing support for neo-natal deaths**. In April 2019, 2 Wish reached out to all neo-natal units across Wales to ensure partnership working similar to the pathways in place with A&E, Critical Care and Organ Donation. **2 Wish received 28 referrals for neo-natal deaths** in the remaining eight-month period of 2019, which is the second highest cause of death for the year, second only to death by suicide for which the charity received 49 referrals. If, as it states in the survey, there are **23 services for neo-natal bereavement** support being delivered across Wales then uptake on the service 2 Wish provides would not be so great. The same applies to the referral rate for those who have died by suicide, which is the highest it has ever been despite the 26 services providing services across Wales.
4. The survey states that there are **26 services in Wales supporting suicide and 5-9 services in every local authority which support those bereaved by suicide**. From 2016-19 alone, the referrals 2 Wish received for those who have died by suicide have more than quadrupled; in 2016, 10 referrals were received, in 2019, 49 referrals. Those figures continue to increase because there are so few organisations able to offer immediate and ongoing support, yet this is not demonstrated within the survey results. The 'Talk to me 2: Suicide and Self Harm Prevention Action Plan for Wales 2015-20' contains sixteen priority actions, ordered according to six principal objectives. Objective 3 is "information and support for those bereaved or affected by suicide or self-harm" and the priority action is the "further dissemination of Help is at Hand Cymru". As far as I am aware, of the organisations listed within the resource, none provide immediate and ongoing support for bereavement by suicide in line with all three NICE components across the whole of Wales. 2 Wish Upon A Star do.
5. The survey states that 45.6% of organisations are "unable to meet the demand for service". However, it also states that 62.2% of provider respondents "do not have a waiting list for their service". This contradictory information does not allow for a clear understanding, but only increases confusion. 2 Wish Upon a Star have seen an increase for demand year upon year since service delivery began. Yet the service remains able to meet the demand without a waiting list. That said, the continual increase in demands causes other challenges such as the need for funding to ensure the delivery of services continues to be able to meet its demand.
6. The survey states that a "number of respondents, from different types of organisations, stated that clear referral pathways to bereavement support were lacking". Through this petition, I hope to address this and ensure that a mandatory approach to bereavement support is implemented across Wales. And with training, increased awareness and a strategic approach, support will be available to every individual who lose a child or young person suddenly and unexpectedly. However, until we fully understand what already exists, how can a strategic plan be constructed that includes support for all.

### **Further questions about the Bereavement Survey**

1. What is the bereavement support being provided? A flyer, a phone call, a group? What is the definition of bereavement support? Does an information leaflet and/or signposting count as bereavement support?
2. Who is providing the bereavement support? Who are the organisations, what are their services and where are they delivered?
3. When is this support offered and for what duration? The bereavement survey states that 42% of services provide 'immediate support'. Which services do that? 2 Wish provide support within 48 hours of a referral into our services. In most cases, the referral is made the same day as the death occurred.
4. How are quality of service and outcomes measured across all bereavement services?

**Following on from the bereavement study and with my involvement in the Bereavement Strategy Group, I strongly believe this petition still requires discussion and my recommendations to be considered.**

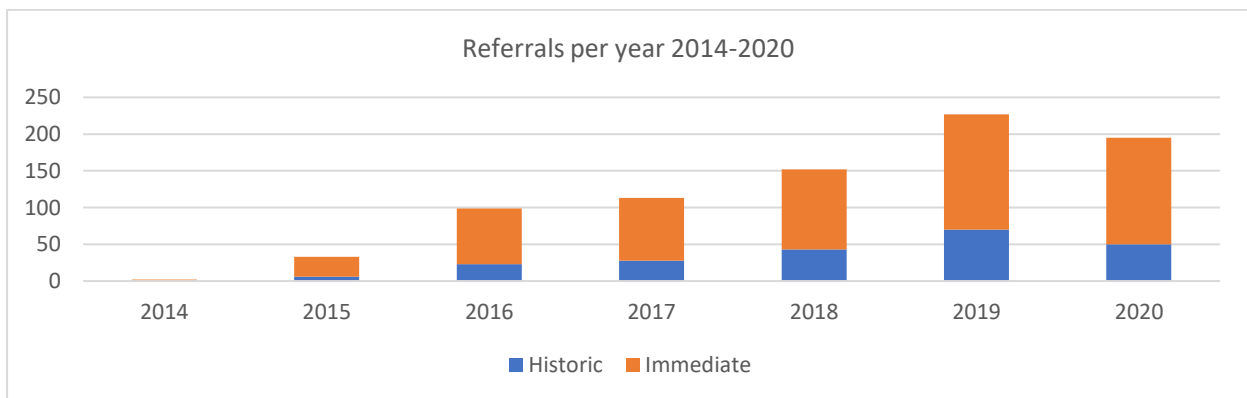
### **Recommendations**

1. **Early intervention to support families who lose a child or young adult aged 25-years-old and under.** This will help avoid long-term intensive support through other services such as mental health pathways. Every single bereaved family needs to understand, accept and be reassured about their feelings.
2. **To ensure professionals in hospitals, as well as all other professional environments, follow an immediate support pathway.** The pathway relieves pressure from the bereaved individual and the emphasis is placed upon the organisation to contact the individual. At the time of death, families should be offered a memory box and, with consent, family details should be passed onto the relevant organisations. This needs to be a mandatory offer of support enforced by Welsh Government. The impact of this pathway not only supports families in a proactive and immediate manner; but allows professionals to feel they have provided all the care and support they are able. The consequential impact this has on staff too must not be underestimated.
3. **An All-Wales, immediate support pathway to ensure all families who lose a child and young adult are offered the same support no matter where they live in Wales.**
4. **Adherence to the 'Talk to me 2: Suicide and Self Harm Prevention Action Plan for Wales 2015-20'.** Objective 3 is "information and support for those bereaved or affected by suicide or self-harm

5. **To provide training to professionals working with suddenly bereaved families.** To initiate conversations around the support families can access, using memory boxes and ensuring referrals are made during what is a difficult time for everyone involved.
6. **Professionals involved in the sudden death of a child or young person can also require support.** There needs to be immediate support pathways to ensure that all professionals have an offer of support when they are involved in the traumatic and sudden death of a child or young person.

**Summary**

2 Wish Upon A star are delivering every single recommendation as listed above and have seen the positive impact of such support on more than 900 families since 2015.



**This petition calls on the National Assembly for Wales to urge Welsh Government to make the offer of immediate support mandatory and ensure that no family, professional or individual is missed or left to cope on their own when a child or young person dies suddenly and unexpectedly.**

Thank you for taking the time to consider my petition and I look forward to hearing from you in due course.

Best wishes

Rhian Mannings