

P-05-912 Supporting Sudden and Unexpected Death in Children and Young Adults, Correspondence – Petitioner to Committee, 28.01.20

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 here in Wales to ensure families who unexpectedly lose their child or young adult aged 25 years and under get the support they require.”

We are extremely grateful to the Welsh Government for publishing the Bereavement Survey of Bereavement Services in Wales. We appreciate the time and effort such a document takes to collate, are very interested in its content and are keen to ensure that the next steps ensure that comprehensive support is available to all that require bereavement support.

2 Wish Upon a Star supports anyone affected by the sudden and unexpected death of a child or young person in Wales. We provide immediate and ongoing support to families, extended family, friends, witnesses and professionals, as well as supporting any historic death. 2 Wish Upon A Star offer support in several ways including memory boxes, immediate support during the initial aftermath of the death, free and confidential counselling, complementary therapy, play therapy, as well as focussed support groups, residential weekends and monthly events.

In November 2019, we 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 and unsupported. We work with every health board in Wales, are supported by every police force in Wales, our pathway is clearly outlined in the Public Health Wales PRUDiC document and, since service delivery began in 2014, have supported over 640 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.

Our petition was delayed from being spoken about in the Assembly due to the upcoming publication of the bereavement survey. We were delighted that a comprehensive overview of bereavement services across Wales was being conducted. However, upon reading the finalised document, we believe it raises more questions than it answers. The content tells us very little about who provides existing services and what services they deliver. We have listed below some of our 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. In 2012, our Founder and CEO, Rhian Mannings, lost her one-year old son, George, and, five days later her husband, Paul. 2 Wish Upon A Star was founded because there were no support services in place for either of their 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 Rhian following the death of her boys, researching support services on the internet, came up with no available services in her area.

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 we are aware, we 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 our second highest cause of death for the year, second only to suicide for which we 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 our service would not be so great. The same applies to our referral rate for 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 suicide**. From 2016-19 alone, our referrals for suicide have more than quadrupled; in 2016, we received 10 referrals, in 2019, we received 49 referrals. Our numbers 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 we are 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 has seen an increase for demand year upon year since service delivery began. Yet we remain able to meet the demand without a waiting list for our services. 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". 2 Wish Upon A Star are trying to address this through our petition; to 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. 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? It states that 42% of services provide 'immediate support'. Which services do that? We 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, we strongly believe our petition still requires discussion and for our 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.

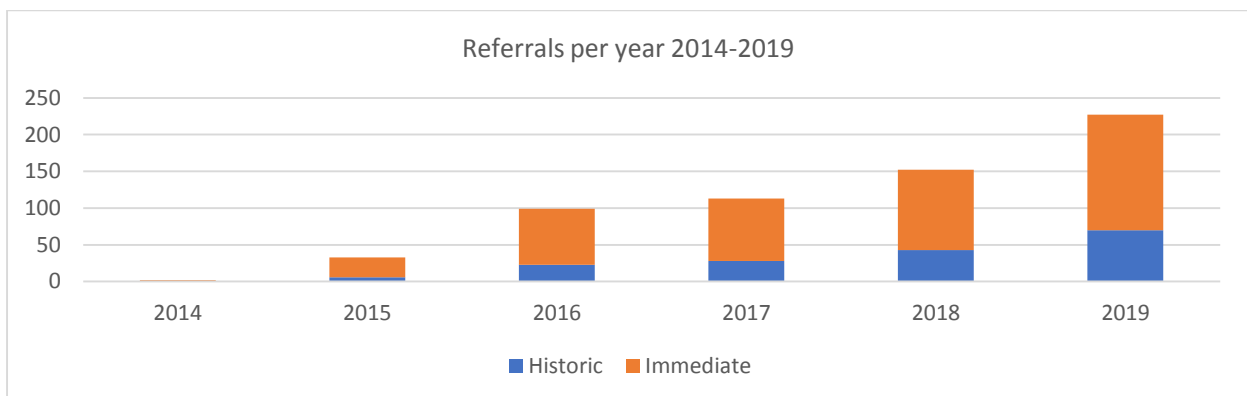
Summary

2 Wish Upon A star are delivering every single recommendation as listed above. Our petition is to call on the National Assembly for Wales to urge Welsh Government to make the offer of support mandatory and ensure that no family, professional or individual is missed or left to cope on their own.

2 Wish Upon A Star

2 Wish Upon A Star strives to be a service whereby the sudden and unexpected deaths of **all** children and young people aged 25 and under are referred into our organisation. We have worked tirelessly to develop and maintain strong professional relationships with the hospitals, police forces, GPs and mental health services across Wales to ensure referrals are made, and we have made significant progress; however we are still not receiving some of the referrals and this results in those families not receiving the support they deserve.

2 Wish Upon A Star remain a predominantly self-funded charity and, despite our ever loyal and passionate community of fundraisers, this model cannot continue to support the inevitable growth of the charity. We welcome discussion around bereavement support in Wales with inclusive content of sudden and unexpected death, which historically has been underpinned by organisations providing End of Life, Palliative and Cancer Care. The sudden and unexpected death, particularly of a child or young person, can be the most traumatic experience of an individual's life. The services provided and the time scope available to ensure immediate support in the aftermath is extremely limited due to its unpredictable nature. Therefore, services need to be funded and a multi-agency approach undertaken to ensure support can be delivered Wales-wide and severe, long-term consequences can be reduced. As the following table demonstrates, the demand for our services continues to increase with each year and we cannot continue to meet the demand within our current financial parameters.



The survey states that the “results of the survey have been used to identify parts of Wales that may be experiencing gaps in structured bereavement care services, as well as gaps and challenges in the provision of comprehensive bereavement support in Wales” However, it does not give a clear indication of whether the services that do exist, are fulfilling the need of those who use them. Before gaps can be identified for areas which may be lacking, it is imperative to better understand the services that do exist; is their model suitable to bereaved individuals and are their services more comprehensive than a flyer and/or signposting. 2 Wish Upon A Star advocate for a mandatory and uniformed approach to

bereavement support across Wales. We feel we are an example of best practice with regards to child and young person death; however we acknowledge we cannot provide support for all types of death and hope to be part of a multi-disciplinary, strategic approach that allows for any bereaved individual to receive the offer of immediate and long-term support for the death they are grieving for.