

Annex 1 - Consultation Response Form

Please return this form to reach the Welsh Government no later than **15 January 2019**.

The email address for responses or queries is:

lonelinessandisolation@gov.wales

Postal responses should be sent to:

Loneliness and Social Isolation Team
Welsh Government
Cathays Park
Cardiff
CF10 3NQ

Your name:	James Cooper
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Email Address:	james.cooper@togetherforshortlives.org.uk
Your address:	Together for Short Lives New Bond House Bond Street Bristol BS2 9AG

Responses to consultations may be made public on the internet or in a report. If you would prefer your response to be anonymised, please tick here:

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Question 1: Do you agree with our definitions of loneliness and social isolation? If not, what would you propose instead?

YES..... NO.....

Comments:

We call on the Welsh Government to define social isolation as both poor quantity and quality of social relationships. An individual's social relationships have the potential to achieve a range of outcomes for a person, including those relating to their health and wellbeing, and not just the extent to which they feel lonely. Therefore, we ask that the Welsh Government takes this into account.

Question 2: How can we help people to understand the trigger points for loneliness and social isolation and to build emotional and psychological resilience to enable them to take steps to avoid or reduce these feelings?

Comments:

Children with life-limiting conditions and their families often have to engage with up to 30 different professionals and provider organisations spanning health, social care, education, housing, welfare and leisure services. It is crucial that these services joined-up around families to provide the support pathways that these families require.

There are a number of potential points at which parents of children with life-limiting conditions might become lonely:

- When their child's condition is diagnosed or needs recognised.
- When their child is born.
- If/when there is a transition from curative to palliative care.
- When their child dies.

[Research carried out by Together for Short Lives](#) has found that:

- 84% of families caring for a child with a life-limiting or life-threatening condition have felt isolated and alone since their child's diagnosis
- 90% said their relationship, social life and interactions with friends had been adversely impacted since their child's diagnosis
- 74% said the same for their relationship with their partner
- 87% said the same for their relationship with their immediate family
- For bereaved families, over 50% said their relationships with family and friends had been adversely impacted by their child's death.

Families of children with life-limiting conditions face a number of challenges that mean they are vulnerable to becoming isolated and lonely. Together for Short Lives found that common reasons for becoming isolated include feelings of social exclusion and the sheer exhaustion of caring for a seriously ill child. Other families talked about how hard it is to engage with everyday social conversations or talk about anything trivial when your life revolves around caring for a seriously ill child.

Families cited access to a community of families experiencing similar challenges as being a hugely beneficial resource. As one respondent said: "I feel like I can only share my true thoughts and feelings with parents who have had a child with a similar condition. I'm part of a private Facebook group run by Together for Short Lives, and the people there lend an empathetic ear and a shoulder to cry on."

It is crucial that local health boards (LHBs), local authorities and other agencies work together to establish care pathways to meet the needs of these families. We call on the Welsh Government to guide them and hold them to account in doing so.

Question 3: How can the Welsh Government foster the right environment and create the right conditions to build resilient communities?

Comments:

Children with life-limiting conditions – and their families – rely on frequent short breaks for respite to enable them to relieve this stress, spend time as a family and do the things that other families do.

When caring for a child with a life-limiting condition, 64% of mothers and 24% of fathers will need to give up work and this, combined with the extra costs of caring for a seriously ill child, means that many families may live in poverty. This cuts families off from the communities they may have previously been a part of.

Research conducted by Julia's House Children's Hospice and Bournemouth University found that 74% of parents rated short breaks provided by children's hospices as having a direct, positive effect on their relationship with a partner, giving them rare time together as a couple. Others used short breaks to spend time with their other children or just enjoyed time to themselves, regaining some balance in their lives, ultimately benefitting the whole family.

We call on the Welsh Government, local health boards and local authorities to work together to:

1. Plan and fund children's palliative care services which offer families caring for seriously ill children a range of short breaks (respite) when and where they need them; we ask the Welsh Government to make it clear to LHBs and local authorities that they are responsible for planning and funding short breaks - and to hold them to account for doing so.
2. Produce a guide to LHBs and local authorities develop strategies to tackle isolation among families caring for seriously ill children.
3. Work with Together for Short Lives and other voluntary sector organisations to deliver awareness campaigns to make sure that the public better understand and are more willing to help families of seriously ill children.

Question 4: How can children and young people be better equipped with the skills to establish and maintain meaningful social connections?

Comments:

Question 5: How do we ensure that schools can better support children and young people who may be lonely and socially isolated?

Comments:

Question 6: What more can the housing sector do to reduce loneliness and social isolation? How can the Welsh Government support this?

Comments:

Question 7: What more can the Welsh Government do to support the improvement of transport services across Wales?

Comments:

Question 8: How can we try to ensure that people have access to digital technology and the ability to use it safely?

Comments:

Question 9: What experience do you have of the impact of social services on addressing loneliness and isolation
Comments: <p>Some of our members have reported that, since the introduction of the of the Social Services and Wellbeing (Wales) Act 2014, some children with life-limiting conditions and the families they work with have experienced increasing difficulty in accessing an assessment. This can mean that children and families do not receive the care and support they need - or receive it too late. This can have a profound impact on their feelings of loneliness and social isolation and also increases their risk of needing to access acute, unplanned and expensive NHS care.</p> <p>We ask that the Welsh Government does more to hold local authorities to account to make sure that assessments are carried out when families need them, so they are not left vulnerable to isolation.</p> <p>As we set out in our response to question 3, we ask the Welsh Government to make it clear to LHBs and local authorities that they are responsible for planning and funding short breaks - and to hold them to account for doing so.</p>

Question 10: What more can the social care sector do to tackle loneliness and isolation?
Comments:

Question 11: What more can we do to encourage people who are at risk of becoming lonely and isolated to get involved in local groups that promote physical activity?
Comments:

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Question 12: In what other ways can health services play their part in reducing loneliness and social isolation?
Comments:

Question 13: What more can the Welsh Government do to encourage people to volunteer?
Comments:
We ask the Welsh Government to help encourage the public to:
<ul style="list-style-type: none">• Reach out to families caring for seriously ill children in local communities by being a supportive neighbour or offering a helping hand with day-to-day activities, such as gardening, shopping or housework – whatever is needed. A friendly smile and a conversation could make families feel less isolated.• Share information about local support so families know help is out there; for example, by sharing Together for Short Lives’ helpline information on social media or in local GP surgeries.• Find out how they can volunteer to support seriously ill children in their community via their local children’s hospice or palliative care service.

Question 14: How can the Third sector play a stronger role in helping to tackle loneliness and social isolation? What can the Welsh Government and other public bodies do to support this?
Comments:
<u>We were delighted to be awarded funding by the UK Government and the Big Lottery Fund to tackle loneliness in families in England looking after a seriously ill child.</u> The grant from the Building Connections Fund will be used to grow our support with families, including our

free helpline and online family support group that helps connect families caring for seriously ill children. The funding will help Together for Short Lives reach out and support the growing number of families in need of vital care and support.

We call on the Welsh Government to initiate a similar fund for Wales.

Voluntary sector providers, including children's hospices, bring social value to communities. When local NHS organisations and local authorities remunerate these charities for the children's palliative care they provide, the funding is matched and exceeded by charitable donations which also contribute to running services. Local volunteers also help to provide children's palliative care which are part-funded from statutory sources, further adding value.

Despite this, our members feel that too many LHBs and local authorities are failing to recognise the role that the voluntary sector can play. Our voluntary sector members are not receiving equitable and sustainable funding from local health boards and local authorities for the palliative care they provide.

Our voluntary sector members also feel that they are reaching children and their families too late in the course of their illness, because assessments that would allow for these lifeline services to be accessed sooner are being carried out too late.

We believe that this is caused, in part, by local authorities and LHBs not being clear about their responsibilities to work together to plan, fund and deliver children's palliative care services. This is particularly true in terms of short breaks for respite for children with life-limiting conditions and their families, which are both a health and social care service. We ask that the Welsh Government produces statutory guidance to clarify these responsibilities, and to hold local authorities and LHBs to account to make sure that they work together to jointly plan and fund children's palliative care services.

Question 15: How can employers and businesses play their part in reducing loneliness and social isolation?

Comments:

Question 16: What more can the Welsh Government do to support those who experience poverty alongside loneliness and social isolation?

Comments:

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Question 17: What more can we do to build community resilience and support communities to combat loneliness and social isolation?
Comments:

Question 18: Do you agree with our proposed approach? Yes If not, what would you otherwise suggest?
Comments:

Question 19: Are you aware of examples of successful interventions within Wales, or beyond, that you think we should be looking at?
Comments: We call on the Welsh Government to consider the impact that providing short breaks for respite for children in Wales with life-limiting conditions has upon the extent to which their families feel lonely and isolated. These services are provided by Ty Hafan and Hope House Children's Hospice.

Question 20: Are there other ways in which we can measure loneliness and social isolation?
Comments:

Question 21: We would like to know your views on the effects that our proposed approach to tackling loneliness and social isolation would have on the Welsh language, specifically on opportunities for people to use Welsh and on treating the Welsh language no less favourably than English.

What effects do you think there would be? How could positive effects be increased, or negative effects be mitigated?

Comments:

Question 22: Please also explain how you believe the proposed approach could be formulated or changed so as to have positive effects or increased positive effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language, and no adverse effects on opportunities for people to use the Welsh language and on treating the Welsh language no less favourably than the English language.

Comments:

Question 23: We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to report them:

Comments: