



Northern  
Ireland  
Children's  
Hospice

# SAY WHAT.

**CONSULTATION WITH SIBLINGS  
OF CHILDREN AND YOUNG PEOPLE  
WITH LIFE-LIMITING CONDITIONS.**



WESTERN  
HEALTH AND SOCIAL SERVICES BOARD

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# FOREWARD.

The Western Health and Social Services Board is pleased to have supported the development of the 'SAY WHAT' Consultation, in partnership with the Northern Ireland Children's Hospice.

Improving outcomes for life-limited children and their families is a major objective for the Board. This has helped shape our planning and investment priorities through the Board's Review of Palliative Care in partnership working with the Board's multi-agency Palliative Care Forum.

The Board welcomes this consultation and commends the approach adopted, which has clearly embraced meaningful dialogue with young people with life-limiting conditions and their siblings. These young people have openly shared their views and personal reflections on their own needs and perceptions of how they are 'seen' in the eyes of others.

Together with the Northern Ireland Children's Hospice, we have taken tremendous strides in developing Paediatric Palliative Care Services for children and their families in the West.

I look forward to extending our partnership with the Northern Ireland Children's Hospice into the new commissioning arrangements in the future.



**DOMINIC BURKE**  
CHIEF EXECUTIVE WESTERN HEALTH

# INTRODUCTION.



The 'SAY WHAT' consultation was facilitated to give the opportunity to siblings to have 'their say'. The consultation included a structured focus group session, and music and art workshops, designed to be fun and to offer peer support in an age appropriate, supportive environment.

This report is a record of the consultation and includes recommendations to guide approaches to sibling support and participation in service development.

The young people who participated in the 'SAY WHAT' consultation are to be applauded for their participation, honesty and forthrightness. The song, which is one of the outcomes, is a moving tribute. I am impressed by their selfless attitudes and support of their ill brothers and sisters. They are a credit to their parents and families.

Northern Ireland Children's Hospice looks forward to working with the brothers and sisters of the children in our care to develop services in partnership which reflect the issues raised in this report.

I would like to take this opportunity to thank the WHSSB for supporting and funding the 'SAY WHAT' consultation.

**PROFESSOR JUDITH HILL**  
CHIEF EXECUTIVE OFFICER  
NORTHERN IRELAND  
HOSPICE

# SAY WHAT.

## WHO WAS INVOLVED?



The 'SAY WHAT' consultative discussion and subsequent report was carried out by an Independent Consultant under the guidance of the Youth Participation Project on behalf of the Western Health and Social Services Board (WHSSB) and the Northern Ireland Children's Hospice. Music and art therapists from hospice facilitated the workshops.

# WHO WAS INVOLVED.

## WHSSB & NORTHERN IRELAND CHILDREN'S HOSPICE.

### HOSPICE SPECIALIST PALLIATIVE CARE SERVICES ARE PROVIDED BOTH IN THE COMMUNITY AND IN HORIZON HOUSE.

#### WESTERN HEALTH & SOCIAL SERVICES BOARD (WHSSB)

The Western Health and Social Services Board (WHSSB) covers a wide geographical area including five urban centres with large rural settings. It is charged with the responsibility for the health and social care provision for its population of c.282,00 one third of which is under 18 years and includes c.134 children with life-limiting conditions. The WHSSB has an active focus on paediatric palliative care and facilitates and chairs the area Children's Palliative Care Steering Group.

Accordingly, the Board acknowledged and recognised a marked lack of understanding by health and social care professionals regarding the needs of siblings of children/young people with life-limiting conditions and a dearth in specific services. The Board's Paediatric Palliative Care forum identified a need to review services for siblings. Consequently the Chair commissioned the Northern Ireland Children's Hospice to facilitate a consultation process to identify specific needs of this cohort, encourage user and peer participation and inform interested voluntary and statutory health and social care professionals.

#### NORTHERN IRELAND CHILDREN'S HOSPICE

The Northern Ireland Children's Hospice is a voluntary organisation which provides palliative care services to children and young people with life-limiting conditions and their families throughout Northern Ireland.

Horizon House is a purpose built unit in Newtownabbey offering; short breaks for children young people and their families, symptom management and 'end of life' care. Facilities include: family rooms, hydrotherapy pool, multi – sensory room, den, art room, music room, soft play area, living room and dining room, catering facilities, outdoor play park and landscaped gardens. Care, although nurse lead is provided by the multidisciplinary palliative care team and includes, nurses, doctors (GPs), nursing care assistants, social worker, physiotherapist, artist in residence, complementary therapist, music therapist, chaplain and activities coordinator.

Community services are provided throughout Northern Ireland and are led by a team of Children's Hospice Nurse Specialists (CHNS) and Social Workers supported by the Children's Hospice at Home service, which includes trained

nurses and nursing care assistants who support children/young people and families at home. The Hospice at Home Service was pioneered and developed by a partnership between the Children's Hospice and the WHSSB. Community services offered include: emergency and planned respite, symptom management, nursing care, 'end of life' care at home and bereavement support.

Children are not treated in isolation. Care encompasses their families: parents, siblings, grandparents, and includes helping them to come to terms with life-limiting and life-threatening illnesses. Caring for a life-limited child is physically and emotionally draining. The demanding care generally rests with one, or a limited number of family members, unremitting 24 hours a day, often causing social isolation.

The Children's Hospice aims to provide the highest standard of care ensuring the best quality of life for children, young people and their families, both in the hospice and the community.





## YOUTH PARTICIPATION PROJECT

The Youth Participation Project (YPP) was established in 2004 as a cross border project funded from EU investment. The aim of the project is to develop a systematic and sustainable framework for the participation of young people in the planning and design of health and social care provision in the north west of Ireland.

YPP support best practice and operational models to promote the participation of young people at the centre of service plan delivery. The project uses a range of capacity building initiatives, such as conferences, peer led training, residential and policy development.



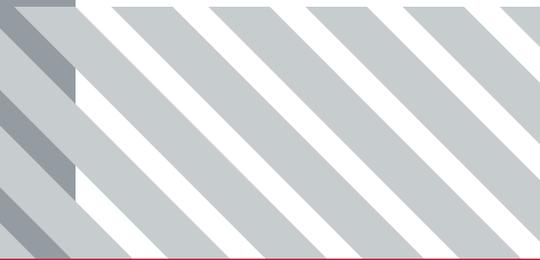
You don't know  
what it's like  
when people stare.  
We want to be equal  
and treated fair.

# WHY WE DID IT.

## 'SAY WHAT' CONSULTATION / WHO WAS INVITED?



It's your lack of understanding and lack of care. Showing your prejudice you stop and stare.



### WHY WE DID IT

The overwhelming impact of a life-limiting condition is recognised and well documented for the parents of the child affected however the effects on siblings are also significant but are less well acknowledged.<sup>1</sup>

It was considered important to promote the participation of siblings in the planning and delivery of children's hospice services.

Collection of the information was for purposes of service development and user participation therefore no formal request for research ethics approval was required.

### 'SAY WHAT' CONSULTATION

Taking part in the consultative discussion gave the siblings an opportunity to express their views regarding services.

The aim of the consultation was to:

- Acknowledge the needs of siblings and listen to their views, opinions and experiences.
- Provide a forum in which they could meet others in similar circumstances.
- Allow siblings to self report, express themselves and suggest improvements to services that would benefit them and others in a similar situation.
- Consider the possibility of setting up a support group.

### WHO WAS INVITED?

The participants in the consultation included seven siblings, from all four Health and Social Services Boards in Northern Ireland. All participants were siblings of children with life-limiting conditions, who had received care from the Northern Ireland Children's Hospice.

Parents were informed of the nature of the consultation and with their permission, siblings were sent an invitation, inviting them to take part.

The invitations were designed to have particular appeal to young people, hoping that the 'SAY WHAT' image would enthuse and encourage siblings to become involved in the consultation day.

Information with regard to the nature of the consultation and its intended outcomes was also provided. Before taking part in the consultation written consent was obtained from parents and sibling participants. Northern Ireland Children's Hospice was responsible for the contact with siblings and parents and provision of the venue.

<sup>1</sup> Barlow, J.H. & Ellard, D.R. (2006) The psychosocial well-being of children with chronic disease, their parents and siblings: an overview of the research evidence. **Child: Care, Health & Development. 32(1).**



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# DESCRIPTION OF THE DAY.

## WHAT SIBLINGS TOLD US.

### DESCRIPTION OF THE DAY

The consultation day was intended to be enjoyable and entertaining, where siblings could meet and interact with other young people who experienced similar situations to themselves. The day began with the consultation and discussion which took place at Horizon House and lasted one hour. The siblings shared their views, opinions and experiences. Following the consultation the young people looked over all they had said and prioritised and grouped themes to underpin the planned music and art workshops.

The music workshop facilitated by the music therapist, supported the group to identify the most significant issue raised at the 'SAY WHAT' consultation. They unanimously agreed that attitudes of others to their brothers and sisters with disabilities were their key concern. They then composed and recorded a song depicting their feelings regarding people staring. The song is called **'IN OUR SHOES'** (see attached).

The art workshop lead by the Hospice artist in residence, also focused on personal issues such as identity, isolation and support.



### WHAT SIBLINGS TOLD US

#### THE POSITIVE

Being the sibling of a child or young person with a life-limiting condition had both positive and negative effects. Positive effects were reported as closer family ties, unique family bonds and greater respect among family members.

**'We respect each other more.'**

The siblings stated that they enjoyed spending time with their brother or sister and appreciated having them in their lives.

**'I appreciate my brother is alive, and what I have, as he almost died!'**

The experience also enhanced positive characteristics siblings demonstrated that they were caring and supportive towards their ill brother or sister. Other positive aspects included a greater tolerance towards and enhanced knowledge of children and young people with life-limiting conditions.

**'The experience makes you mentally stronger and you have more knowledge.'**

Siblings also appreciated the benefits of good health and were compassionate, sensitive and non-judgemental.

**'You don't stare at people in wheelchairs, you are used to it.'**

#### THE NEGATIVE

Siblings were concerned about the general lack of awareness and understanding that existed about children and young people with a life-limiting condition. Their brothers and sisters experienced frequent prejudice and negative attitudes. Dealing with such attitudes made them feel upset, angry, frustrated and stressed. They felt there was a need for greater acceptance, more open discussion and better understanding of their situation and the needs of their ill brother or sister.

Siblings struggled with the emotional demands of having a brother or sister with a life limiting condition. Siblings reported constantly worrying about their ill brother or sister, feeling fearful and anxious about what the future may hold, experiencing and dealing with anticipatory grief, this made them feel sad and upset.

**'You worry that your brother or sister could die.'**

**'It's hard when they are admitted into hospital as you don't know what's going to happen to them.'**

The care of their ill sibling was also of great concern to them, particularly with regard to their parents well being.

**'When you think of the future you are upset to think about what might happen to them.'**

#### STARING (ATTITUDES OF OTHERS)

Most siblings deal with challenges other children do not have to. One of the biggest challenges that siblings have to cope with is feeling hurt, embarrassed, even angry, when people stare at their brother or sister in public.

The prejudicial attitudes of others and the perceived lack of understanding had a considerable negative impact upon siblings. They felt stressed, paranoid and upset.

The way in which people responded to their ill brother or sister was a major concern and they perceived it on many occasions as a form of harassment and/or psychological abuse.

**'The worst thing is that my brother has special needs and I don't like the way people look and stare at him whilst we are shopping or on holidays. I get upset by this.'**

**'When people stare or look in a derogatory fashion we feel angry, feel like hitting them. Feel paranoid. It is very stressful.'**

**'I get upset when people stare.'**

**'You get annoyed; you get a bit paranoid too.'**

**'Makes you angry because you know people are looking at you and saying something derogatory.'**

YOU DON'T KNOW WHAT IT'S LIKE  
TO BE EQUAL AND TREATED FAIR / IT  
AND LACK OF CARE / SHOWING YOU  
STARE / CHORUS / STOP AND THINK  
YOU ANGER WHEN IT'S AT ITS PEAK  
LIKE OR HOW IT EFFECTS / ALL WE  
ANGRY AND FRUSTRATED THAT YOU  
WITH THESE ATTITUDES EVERY DAY  
ISSUES BOTTLED UP / CONTROLLING  
ERUPT / CHORUS / STOP AND THINK  
YOU ANGER WHEN IT'S AT ITS PEAK  
LIKE OR HOW IT EFFECTS / ALL WE  
SPEND YOUR LIFE POINTING AND  
KEEP FROM SHOUTING / IF YOU STOP  
THEN YOU MIGHT START SEEING US  
/ STOP AND THINK BEFORE YOU SPEAK  
IT'S AT ITS PEAK / YOU DON'T KNOW  
EFFECTS / ALL WE ASK IS A LITTLE

WHEN PEOPLE STARE / WE WANT  
IT'S YOUR LACK OF UNDERSTANDING  
YOUR PREJUDICE YOU STOP AND  
THINK BEFORE YOU SPEAK / CHANNEL  
THINK / YOU DON'T KNOW WHAT / IT'S  
WE ASK IS A LITTLE RESPECT / WE'RE  
YOU TREAT US THIS WAY / WE DEAL  
WITH IT / WE GOTTA KEEP ALL THESE  
THINGS OUR TEMPERS OR WE MIGHT  
THINK BEFORE YOU SPEAK / CHANNEL  
THINK / YOU DON'T KNOW WHAT / IT'S  
WE ASK IS A LITTLE RESPECT / YOU  
ARE PROUD / IT'S ALL WE CAN DO TO  
SPEND A DAY LIVING IN OUR LIVES /  
LOOKING AT YOU WITH DIFFERENT EYES / CHORUS  
THINK / CHANNEL YOU ANGER WHEN  
YOU DON'T KNOW WHAT IT'S LIKE OR HOW IT  
FEELS / WE ASK IS A LITTLE RESPECT.

# FAMILY LIFE.

PARENTAL INVOLVEMENT / HELPING OUT AT HOME / SOCIAL LIFE.





## FAMILY LIFE

Siblings mainly reported strong relationships with their parents and strong bonds with their ill brother or sister. They were able to discuss their feelings with their family and friends and found them supportive. Sharing experiences with other siblings in a similar situation was also supportive and helpful.

**'I talk to my Mum and Nan. My friends are supportive too.'**

**'I am close to Mum.'**

**'We always involve my brother everything we do.'**

Adapting to and accepting the diagnosis for the sibling of one young person was difficult initially.

**'It was hard to accept as he wasn't born that way. It was due to an accident!'**

Adjusting to the family situation understanding and communicating with their ill brother or sister proved challenging.

**'It wasn't that life changed but it was hard to communicate with him. I wasn't sure what to do and was afraid of doing something wrong.'**

## PARENTAL INVOLVEMENT

Whilst parental involvement and attention was evident siblings mainly reported limited family activities and altered family dynamics.

**'I think that when we were younger we missed out on things, because Mum and Dad had to look after my brother.'**

## HELPING OUT AT HOME

Siblings helped with household duties and with the personal care of their brother or sister, they also spent time communicating with and entertaining their ill sibling. Some found this challenging at times.

**'It's hard looking after him at home, it is very tiring, he keeps walking around.'**

**'I would take brother out to give mum a break.'**

**'I would help with housework.'**

## SOCIAL LIFE

Having a brother or sister with a life-limiting condition encroached upon some of the siblings social life, limiting their social activities and time spent with their friends.

**'I can't go out with mates because my parents can't collect me. My parents need to care for my sister.'**

## THEIR NEED FOR INFORMATION

Understanding their ill brother and sisters' condition was important to most of the group. Information was provided by parents, grandparents or a care worker. Siblings sought information about brother or sister's life-limiting condition by accessing the internet. One sibling read books and information leaflets provided by his mother or those available at the Children's Hospice.

**'I would read books that are lying around the house regarding my brother's condition.'**

**'I was 4 or 5 when he was born but mum explained more to me as I got older.'**

One sibling shared experiences with friends in a similar situation and stated that taking part in voluntary work with children with special needs also provided relevant information and practical insight.

## SIBLINGS MAINLY REPORTED STRONG RELATIONSHIPS WITH THEIR PARENTS AND STRONG BONDS WITH THEIR ILL BROTHER OR SISTER.

# NORTHERN IRELAND CHILDREN'S HOSPICE.

## WHAT SIBLINGS WANT.

### **'PROVISION OF ORGANISED SOCIAL ACTIVITIES AND A CHANCE TO MEET OTHERS IN THE SAME BOAT'**

#### **NORTHERN IRELAND CHILDREN'S HOSPICE**

Northern Ireland Children's Hospice and its 'Hospice at Home' service had a significant impact on the lives of siblings. They stated that they felt secure in the knowledge that trained staff were looking after their brother or sister.

**'Hospice home care helped, knew how to go about it, could go to cinema, swimming, before that I didn't have a lot of chance to go out.'**

They stated that Hospice provision offered specialist care to their ill brother or sister and provided them with information which helped them to understand their ill siblings' condition. The Children's Hospice provided their families with much needed respite allowing siblings to spend more time with parents and other family members. Siblings appreciated the help and support provided by the Hospice.

**'We couldn't go on holidays, as there was no medical backup. We go now with the support of the Children's Hospice.'**

**'I get to spend more time with Mum like, shopping, going swimming and going to the cinema.'**

**'When you come to the hospice you get more in depth knowledge of the situation. The people at the Children's Hospice are specialists.'**

**'My brother got help from the Hospice. They provide a break for you!'**

Siblings also perceived respite care as a welcome break for their ill brothers and sisters which provided them with a change of scenery, an altered routine, and a healthy nurturing environment.

**'Hospice gives them a break from the same scenery.'**

Those who had quite a distance to travel to the main regional centre requested a hospice closer to home. Another felt that there could be increased flexibility as they felt three months was too long to wait for respite care in Horizon House. One sibling suggested the age limit should be raised allowing young adults to access the hospice over the age of 19 years.

**'I think they should put the age group up so that he can use the Children's Hospice for longer instead of having no hospice service after 19 years of age.'**

#### **WHAT SIBLINGS WANT**

- \* To be provided with organised programmes and social activities providing an opportunity to meet young people who experience a similar situation to themselves.
- \* To create greater awareness in order to reduce prejudice and negative attitudes towards children with a life limiting illness and their siblings.
- \* To raise issues around a perceived general lack of care and concern towards children with a life limiting illness and their siblings.

Siblings agreed that it was important to talk about their experiences with other children in similar situations who understand their experiences.

They felt that there was a general lack of understanding of the issues associated with children with a life-limiting illness, they suggested addressing this lack of understanding by raising greater awareness in schools and youth clubs, not just by paying lip service, but by introducing appropriate programmes of educational interest and relevance.

**'Raise the profile of children with different needs'**

**'Raise awareness in an effective way.'**

**'I would like to see a variety of issues covered.'**

One sibling acknowledged that most schools address the issues relating to children and young people with special needs and that there are pupils with special needs in mainstream education. However he felt the message delivered was not strong enough.



We're angry  
and frustrated  
that you treat us  
this way. We deal  
with these attitudes  
every day.

akphoto

# QUALITY OF LIFE.

## RECOMMENDATIONS & CONCLUSION.



We gotta keep all these issues bottled up. Controlling our tempers or we might erupt.



## RECOMMENDATIONS

### IMPROVE THE QUALITY OF LIFE FOR SIBLINGS BY

Creating a peer support group for the siblings of children who attend or have attended the Northern Ireland Children's Hospice. Providing siblings with an opportunity to meet each other in a relaxed, informal setting, to listen and discuss the needs of siblings, supporting them in expressing their views and taking their views into account.

Providing a programme of social activities where they can meet siblings with similar experiences.

Encouraging and empowering siblings to make representation to Health and Social Care Trusts to have their message heard and to inform policy makers.

Assisting siblings in becoming involved with groups facilitating youth participation in the planning and design of health and social care services. One such example is the Youth Participation Project which may lead to the creation of a sibling youth group to highlight issues relevant to them and to educate, inform and create awareness, in relation to their needs and those of their siblings.

Highlighting the need for further research into the needs of young siblings since it is a greatly under resourced area.

Assess and respond to each individual sibling's needs.

Provide coordinated and planned services for sibling support.

## CONCLUSION

The report is the outcome of a consultation with siblings in an attempt to identify those issues specifically relating to the needs of siblings of children and young people with a life-limiting condition and an opportunity to offer opinions on services.

The resultant 'SAY WHAT' consultation process provided some insight to the challenges of everyday life of a sibling with an ill brother or sister, and provided some understanding of their needs. Whilst the consultation process provided siblings with an outlet for their concerns and the opportunity to voice their opinions, it also enabled them to spend time with young people from similar circumstances and to access peer support.

The 'SAY WHAT' consultation exercise enjoyed considerable cooperation from the siblings and they made a significant and positive contribution which highlighted the effects and challenges both positive and negative of living with a brother or sister with a life limiting condition. The strongest message to emerge from the 'SAY WHAT' consultation was the negative effects on siblings of the attitudes of others towards their ill brother or sister, particularly when people stared at them. This message was so strong it formed the theme for the siblings' workshop, where they composed and recorded a song. The song is included in the report in CD format. Readers should find this a powerful message which provides considerable insight into how siblings feel.

Indeed siblings self reports were very important and allowed them time to talk about their fears, anxieties, emotions, perceptions and experiences.

The 'SAY WHAT' consultation highlighted the general disposition of the siblings to the extent that it was apparent they needed to be encouraged and given the opportunity to discuss the impact on them of having an ill child in the family.

It was important to seek the opinions of siblings in order to thereafter more proactively engage with them to address their needs, inform service providers, improve service delivery, and involve them in the decision making process.

The findings from the 'SAY WHAT' consultation challenge voluntary and statutory agencies to work together in a proactive manner to address the many and varying needs of siblings which require attention; including emotional and practical support, information and advice and strategies for coping with and understanding their situation.

# IN OUR SHOES.

## OUR SONG.

You don't know what it's like when people stare  
We want to be equal and treated fair  
It's your lack of understanding and lack of care  
Showing your prejudice you stop and stare

### Chorus

Stop and think before you speak  
Channel you anger when it's at its peak  
You don't know what it's like or how it effects  
All we ask is a little respect

We're angry and frustrated that you treat us this way  
We deal with these attitudes every day  
We gotta keep all these issues bottled up  
Controlling our tempers or we might erupt

### Chorus

Stop and think before you speak  
Channel you anger when it's at its peak  
You don't know what it's like or how it effects  
All we ask is a little respect

You spend your life pointing and pouting  
It's all we can do to keep from shouting  
If you spend a day living in our lives  
Then you might start seeing us with different eyes

### Chorus

Stop and think before you speak  
Channel you anger when it's at its peak  
You don't know what it's like or how it effects  
All we ask is a little respect



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# APPENDIX 1.

## SAY WHAT.

### METHODOLOGY.

The participants in the consultation included seven siblings, from all four Health and Social Services Boards in Northern Ireland. All participants were siblings of children with life-limiting conditions, who had received care from the Northern Ireland Children's Hospice.

Parents were informed of the nature of the consultation and with their permission siblings were sent an invitation, inviting them to take part.

The invitations were designed to have particular appeal to young people, hoping that the 'Say What' image would enthuse and encourage siblings to become involved in the consultation day.

Information with regard the nature of the consultation and its intended outcomes was also provided. Before taking part in the consultation written consent was obtained from parents and sibling participants. Northern Ireland Children's Hospice was responsible for the contact with siblings and parents and provision of the venue.

The aim of the consultation was explained to siblings by the facilitator at the beginning of the discussion. Siblings were informed that they were able to withdraw from the consultation should they have wish to do so. A verbal confidentiality agreement was also elicited from siblings.

The Young People then chose key themes from their discussion to use in the workshop with the music and art therapists. A key theme unanimously identified as being the most significant to them was used as the basis for the song they composed and recorded.

To further support the siblings and to offer the opportunity to meet again they were invited to attend a further workshop at the children's hospice to design and produce a short animated DVD to accompany their song. The workshop was facilitated by the Hospice artist in residence and a member of Studio On.

# AUTHOR.

If you spend a day  
living in our lives.  
Then you might  
start seeing us  
with different eyes.

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