Signs of Hope

Signs of Hope:
Deafhearing Family Life

By

Donna West

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by Donna West

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For Martin Hughes and Winifred Joyce Hopkins

What use is a book without pictures and conversations, what use is research without image and story?
—Hedy Bach, 2007

As long as we have deaf people on earth, we will have signs
—George Veditz, 1910

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FOREWORD

In lots of ways
it was quite good
not knowing she was deaf
when she was little
    Whereas Christian
        being deaf
    Knowing that from
    immediately
        It was different
        because we already were a deaf family
    Y'know   a *deafhearing* family
(Brigit)

This book tells a story of a narrative inquiry into deafhearing family life. It involves three families, who, over approximately four years, taught me about their lives. We embarked on the inquiry together as an act of political counter-narrative (Andrews, 2002; 2004) to commonly held, mainstream assumptions about, and hegemonic discourses of, deafness, of sign language and of family-life experience. In doing so, spaces were created that respect and acknowledge human beings—adults, children, deaf, hearing—as storytellers and that recognise narratives potentially as political and performative resistance to marginalisation, prejudice and ignorance. With a nod towards Deafhood and Deaf Theory, and a feminist-orientated, culturally sensitive methodology of collaborating with participants as equal, agentic and creative, this book re-presents stories of family life framed largely as resistance narratives. Deafhood (Ladd, 2003) seeks to address the power of discursive systems in which deaf people are talked about as broken and requiring normalisation, integration or cure, and draws parallels with postcolonial theory and minority cultural studies in order to counter the dismissal of deaf lives as lacking, impoverished and pitiable. Deafhood also celebrates deaf people's cultural strategies of collective, artistic, performative and political resistance to what is often perceived as the never-ending campaign of science to end the 'scourge' of deafness. Deaf Theory (Bauman, 2002) casts a philosophical lens over the deaf body to acknowledge sign languages as textual, and the deaf person as a visual, tactile being with an alternative sensory orientation to the world. Narrative inquiry, as a postmodern methodology, opens up dynamic spaces for deaf and hearing people to tell stories and to construct meanings woven from their personal and collective biographies, histories and cultures. The narratives at the heart of this book reveal not only the ways in which damaging and hurtful definitions of, and discrimination towards, deaf people and signing deafhearing families is troubled, destabilised and resisted, but also how pride in, and celebration of, deaf lives and sign language are affirming and essential for family life, together with a desire for this intimate, cultural, social and political re-visioning of deaf/deafhearing life to be heard.

For many of us, deafness represents loss, silence, being without, becoming lost. For others, being deaf is a genetic quirk or happenstance, an opportunity for learning, for spiritual adventure and reward. For yet others, it is the most natural thing in the world; a coming-together of generations of deaf people, a connection to a genealogical layer of signing ancestors, the continuation of a culture and way of being. Today in the UK, the majority of deaf children attend mainstream schools (some with specialist teaching, resource bases or communication support), have cochlear implants surgically fitted when they are very young, and will have little or no contact with deaf people (Mathews, 2010). There are however deaf children born every year into families who are curious about sign language, who have the resources and/or capital to investigate and pursue alternatives to medical intervention, who feel morally, philosophically and spiritually compelled to embrace ‘difference’: families where sign language is learned and used in the home, where generations come together to celebrate what a deaf child can teach her siblings, parents and cousins, where the arrival of a deaf baby is not met with grief but with a strengthened sense of connection and continuity. Amid the noise of the normalising disability discourses of the medical and popular media, the snail’s-pace and tokenistic recognition of sign languages and the legislation concerning embryo screening, diagnosis and (non)selection, there are family voices demanding to be heard—whether spoken or signed—that challenge or reject audiological and surgical intervention, that call for scrutiny and critique of ‘inclusive’ pedagogical practices, that rail against the marginalisation of members of minority cultures and ‘muted’ groups.

Within the majority of empirical research on deafhearing families, a distinct, medical/disability chronology—diagnosis, confirmation, intervention, communication, education placement—is detectable. A great deal of attention is usually paid to the period of time immediately following the diagnosis of deafness in young children, the early experiences of (hearing) parents, and the subsequent ‘coping’ strategies that are employed (Calderon & Greenberg, 1993; Feher-Prout, 1996; Roots, 1999). Reactions to a diagnosis of deafness have often been described in terms of loss and bereavement (Kurtzer-White & Luterman, 2003; Vijialakshmi, 2010; Valente, 2011). So ingrained is the assumption that (hearing) parents will grieve, become angry, go into denial and then accept their child’s deafness, that according to Gregory (2004), mothers in particular who do not go through these stages are often viewed by medical and educational professionals as pathologically deviant.

Due to the relatively recent implementation of nationwide newborn hearing screening programmes (NHSPs) (Young & Tattersall, 2005), deafness is now usually diagnosed and confirmed within ten weeks of birth (Young, 2008). Intervention measures are then put in place before the child is six months old. Screening by medical professionals usually takes place in a hospital setting; the family becomes ‘medicalised’ (Valentine & Skelton, 2003; Mathews, 2010). The thinking behind such early diagnosis is that it is a good thing to know your child is deaf as early as possible, in order that adaptations can be made, and services put in place. However, as Young (2008) highlights, there is an assumption that any grief experienced (if at all), will be less the earlier parents find out. This is countered, however, by the risk of harming the bond between new mother and father and their newborn (newly diagnosed deaf) baby and does not acknowledge the experiences of deaf parents.

Confirmation of deafness marks the next stage for parents who become intense targets for professional advice (Henderson & Hendershott, 1991; Densham, 1995; Lane, 1995; Luckner & Velaski, 2004). According to Gregory (2004), medical and educational professionals tend to presuppose that there is a right way to do things, and that by not following advice, parents are viewed as having failed (Fletcher, 1987; Adams, 1988). Other studies have uncovered a perceived failing in those professionals, not only to provide comprehensive, non-partisan advice to parents (Young, 2003; Luckner & Velaski, 2004; Young, Jones, Starmer & Sutherland, 2005), but also in their attitudes towards deafness and its management (Beazeley & Moore, 1995; Elewke & Rodda, 2000; Mathews, 2010). Hearing parents become overwhelmed with seductive advice that lacks both relevant, unbiased information and choice (Young, Carr, Hunt, McCracken, Skipp & Tattersall, 2006; Mathews, 2010). There is also evidence that deaf parents, largely overlooked (Nelson, Bougatsos & Nygren, 2008) and further marginalised by early services, feel that certain choices are withheld from them (Young *et al*, 2006; c.f. Boone, McBride, Swann, Moore, & Drew, 1998). Despite 21st-century ideologies of parental choice and inclusion (see Evans & Lunt, 2002) there are suggestions that certain provisions for deaf children, particularly signing deaf children, are considered disproportionately expensive; that individual rights, communication requirements and inclusive social responsibility do not comfortably co-exist (see Mathews, 2010). As Young *et al* (2006) propose, this is in fact less about individual, informed choice and more about the framework within which deaf children are conceptualised.

While researchers are beginning to elicit from hearing parents their experiences and constructions of parenthood (Mathews, 2010), there is still a general paucity of qualitative research with families, with siblings (Tattersall & Young, 2003) or with deaf children themselves (Fillery, 2000a/b; West, 2002). Furthermore, the deaf community, deaf parents (with deaf and hearing children) and sign languages have received little positive attention. Deaf people are *still*, it seems, viewed by the medical/educational hegemony as members of an 'alien' cultural group to which you are in danger of losing your child (Henderson & Hendershott, 1991; Dolnick, 1993; Roots, 1999; Mathews, 2010). Studies of language input from deaf parent to hearing child and the resulting need for 'intervention' (Schiff & Ventry, 1976), as well as comparisons with language-disordered populations (Orlansky & Bonvillian, 1985) within linguistic and psychological frameworks define much of the interest. Henderson and Hendershott's (1991) exploration of the impact of sign language within the hearing/deaf family reveals the weight of the 'stigma' of deafness and the way in which family sign-language use merely exacerbates the child's *deviance*, while Mathews (2010: 369) records the fact that parents (specifically in the Republic of Ireland) are still advised, "No sign language if you want to get him (sic) talking." This despite research that has highlighted 'successes' among deaf children with (signing) deaf parents compared with those from hearing (non-signing) homes (Easterbrooks & Baker, 2002). This despite the identification of sign language use in the deafhearing home as an indicator of 'healthy' family life (Luckner & Velaski, 2004). This despite the ever-increasing numbers of hearing people enrolling for sign language classes and the growing popularity of Baby Signing classes (the philosophy of which is to improve communication and to progress the *hearing* infant's language development—Woll, 2008).

Deaf children are a defining family issue. Yet, there are many other unexplored avenues of inquiry. How do deafhearing families interact and negotiate roles and meanings? How do they come to terms with and embrace hearing and deaf cultures within their family? How do they find their way, given the reported lack of non-partisan advice, information, resources and support? What are deaf parent's experiences of raising deaf and hearing children? How do biographies intertwine in deafhearing family life? How is the deafhearing family shaped over time?

By asking for stories, I tap into and make connections with the rich oral tradition of deaf communities, whose fragile, unwritten heritage is transmitted through signs. By asking deafhearing families for stories, I also step into the world of interrupted and shifting cultural transmission, where very few deaf stories get passed directly from parent to child and where deafhearing family life embodies the vibrant and complex intersection of identities, languages and cultures. These stories—many of which are included here in this book—range from deaf childhood memories of entirely fingerspelled conversations around the dinner table, through becoming lost in the deaf-education system and fighting for access to school curricula, to imagined futures where everyone signs, where all deaf children learn in, about and through sign language, where they grow up to be parents, teachers, MPs, travellers, writers.

The re-presentation of the family stories as poetic texts is deliberately and sensitively mindful both of deaf people's varying and unconventional relationships to written text and of hearing people's (mis)understanding of sign language. The aim is for the words to leap from the page; to breathe life back into the stories in the re-telling.

Take the chapters in any order. The enforced chronology of a paper-based book should not deter you from reading only certain pages; nor should it deceive by giving an impression of a coherent, neat and tidy, step-by-step inquiry that adhered strictly to a research plan. The truth is, like life, research is messy, unpredictable and mostly off the page. These stories layer and lay alongside a thousand other stories that extend and spiral through time. Wherever you choose to start, you will gradually come to know the families while encountering historical interruptions, or *intertexts* (c.f. Lather & Smithies, 1997) along your way.

I have provided a map of sorts. Bring a compass.

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And Jim, my compass—words cannot express …

From the Prologue, *Brave Smiles*, *Knowing Maisie*, *The Third Question*, *Banging On*, *A Complete Unknown*, *Opening Up the World*, *Clever Person*, *Pull Together*, *Not Thinking*, *Nice Belt*, *A Real Person* and *Strong Together* were originally published as: West, D. (2009). “Strong Together: Poetic Representations of a Deaf-Hearing Family Narrative.” In *Poetic Inquiry: Vibrant Voices in the Social Sciences*, edited by M. Prendergast, C. Leggo and P. Sameshima, and are reproduced here with thanks to Monica Prendergast and Peter de Liefde, and permission from Sense, Rotterdam.

From Chapter Four, *H/FEA/R*, *Pontificating*, *Fucking Selection*, *Sorrow at the World*, *Screening*, *The Baby’s Deaf As Well!* and *Blessed* first appeared in West, D. (2011). “Deaf-Hearing Family Life: Three Mothers’ Poetic Voices of Resistance.” *Qualitative inquiry 17* (8): 732-740, and are reproduced here with thanks to Ted Faust and Norman Denzin, and with permission from Sage Publications.

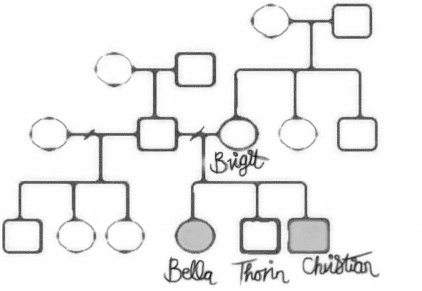

Image 1. Family tree: Brigit, Bella, Thorin and Christian

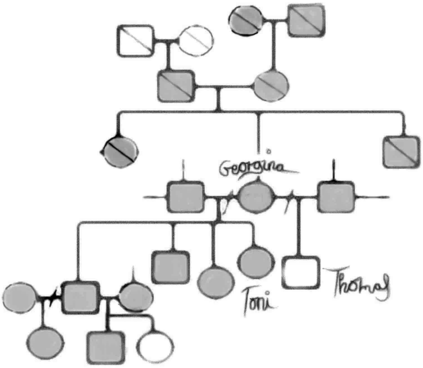

Image 2. Family tree: Georgina, Toni and Thomas

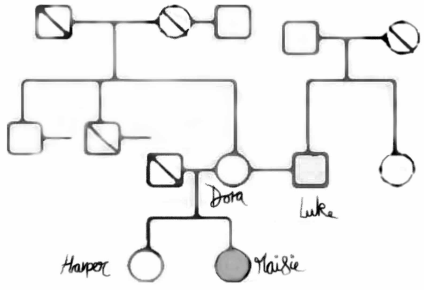

Image 3. Family tree: Dora, Luke, Harper and Maisie

PROLOGUE

> People are like, "Oh wow, how *on earth* do you cope with a deaf daughter!?" and I'm like, "I'm deaf, hello, I'm still a real person!" It's not like trying to control a … lion! (Maisie).

Dora, Luke, Harper and Maisie are my *bookends*; we visit them again in Chapter Four and once more in the Epilogue. We began working together in 2006, although we have been telling each other stories for much longer. It formally started with an e-mail exchange between Dora and me. I had contacted her to ask if the family might like to tell me their story on film for a research project I was about to embark upon. Dora replied:

> I can say what I have found over the years and it is this. Most of what I have read is looking at young children, diagnosis and early language and as such tends to focus on the parents and their decisions. Most of what Luke, Harper, Maisie and I have been living in recent years has been by feel, instinct and learning by our mistakes—there have been many of those and I am not compliment-seeking when I say that!
>
> Having Maisie has meant we have adjusted how we live in almost every aspect and we have learnt as we go along. There is an enormous impact on siblings. Harper's life has been altered to accommodate areas that we would never have been aware of and her home life is quite unacknowledged by her peers. Bright young women though they are, they cannot see it. She has to deal with her (inappropriate) guilt every time she goes out and behaves like a teenager because she knows she has opportunities that realistically are not going to be there when her sister reaches the same age. Harper is a sensitive girl and it is a struggle.
>
> You know us very well and you know what we think. I think if you asked our wider family you might get a very different picture of how they see our lives. I suspect some think I "bang on" about deaf stuff—so dull and difficult for family harmony. I have often been told that nobody has a perfect school when I have tried to explain what is on offer for Maisie. Well get real! It makes me very angry that people cannot get it. Others find it easier to give the whole thing a wide berth and ignore it. There are others such as Luke's sister, her husband and their children who have embraced BSL and as a result us… Dora x

Deafhearing family life: (Not) beginning at the beginning

Dora, Luke and I are sitting in the kitchen. We are ready to begin, yet words, strangely, fail us. There are so many memories, anecdotes, performances and stories, we've forgotten how to have a conversation. As the kettle gently bubbles on the stove, the usual way we have with each other has evaporated, and we falter. We've come adrift in the middle of an enormous, choppy sea of family history. Dora produces a drawing. It is an incredibly complicated, almost incomprehensible family tree; a bewildering scrawl, spaghetti-ed across the page. As she attempts to unpick the partnerships and friendships, the losses and loves, we unwittingly catch a breeze. How has Maisie's arrival, now over fifteen years ago, impacted on extended family relationships? Dora is on the left, with Luke on the right.

BRAVE SMILES

I think
I mean a deaf member of the family
particularly a child
        As adults
        we're responsible for the children
        It affects absolutely everything that we do
And not just on a superficial level either
In everything
It affects us
And then
        that can make it sound simple
But it complicates life hugely, just
Socially
        with other members of the family
        with other friends and family
When she was little
it wasn't the case
because she was little
and little children tend to kind of fit in and
they're much-
there's much less need for them to be socially interactive
But as she's got older
I think probably
We always knew the teenage years were going to be the challenging ones
(Not just because teenagers)
but because she's a real person now

And there was a tendency for her to be treated like
as sort of
rather an attractive little pet by members of the family
Isn't she cute?
Yeah she is cute
And grandparents still do
Yeah
But that has carried on
you know
And
An ornament
Yeah an ornament
and they fail to see her as an emerging adult
which is what she is
Or even a person
Because if you can't communicate
you've got no idea who someone is
So it's a bit like a nice fridge
You can look at it, and say
"Nice fridge"
and that's about it
Yeah
And to them
having her there
It's rather like the inclusive argument for schools
Having her there makes her included
Well it sure doesn't
It actually completely excludes her
in a bigger way than if she wasn't there
cos you know there's like a bit kind of you know
It's just
It's there
It's the elephant sitting in the room
and people
It's very easy for people to carry on and not acknowledge
because she's not y'know
Some children who have great behavioural issues
and things like that
You know'd be kicking up a storm
and you'd have to take notice
But the tendency is
well she's there, so she must be happy
because she's sitting there with a brave smile on her face
And I know
and Luke knows
that actually she's hating it

and she's feeling horrible
she's feeling really horrible
It's fine when you're four
and all the kids come round
and play in the sand pit
But as soon as you're not
the gap increases as you get older
The teenage years
the gap is much bigger
So when people are here
if you don't sign
Maisie takes herself off
She might
she'll just go and watch a film
or take the pudding away
or help us do the main course
And it just gets
<LESS AND LESS>
But that isn't the sum total of the effect
her taking herself away
We're sitting there going
"Ugh I can't relax and enjoy this"
cos I know she's feeling horrible
and there's this kind of racking of your brains thinking
"How can I work this out
how can I make this work?"
And the answer is actually
you can't
We have solved it a bit
We just don't create any of those
situations
so you don't have any other family around
So
when my colleagues all do Sunday lunches
I don't *we* don't
cos it would be unfair
Why should Maisie sit for four hours
with other people's kids running around
talking to their parents
and be excluded?
Or
If you know there are other teenagers around
they're doing whatever teenagers do and
talking about whatever teenagers talk about
which she can't get involved in
Or it then transfers the responsibility to Harper

and it’s a burden then
And I didn’t want to … so I stopped myself
but it *is* a burden
It’s a huge kind of y’know
So it’s something that you kind of carry along with you
and it’s very hard to explain it to people because
they just think we’re kind of difficult
Awkward and
making problems where there aren’t any
Anti-social
Yeah
or making an issue out of it
“She’s fine look at her she’s lovely,
she looks perfectly normal”
Yeah, “nice fridge”
But then that’s a horrible thing because
she’s so bright
that she goes
“I make your life difficult”
And what, *what* do you say to that?
She makes it **different**
not difficult
Yeah
Maybe she can’t see the distinction

No … she said I make it more difficult

KNOWING MAISIE

People are often kind of sympathetic
and see it as a terrible shame
and I’ve always kind of railed against that
No it’s *not* a shame
You don’t have to be sorry for her
So that’s trying to put the positive spin on it
where actually it is difficult but
it’s not a shame
It’s *not* a shame
It’s *not* a shame
It’s not, erm
but it’s very sad
You know you said before
that people don’t know her
Mmm
Y’see cos we think she’s hilarious

she's really funny
People don't know that
Practically no-one can know that

THE THIRD QUESTION

I met a colleague
at the interval at a do at Harper's school
and I did kind of do a double take when I
saw him in the queue
And so
The *third* question is
"Where does your other daughter go ..?"
You know
"Got any other kids?"
"Do you have any other children?"
And
That
changes the rest of the conversation
You can hardly say … (laughs)
I suppose I could say no! (laughs)
But yeah, so I say
"Yeah I've got a daughter of fifteen"
"So, is she at the same school?"
"You'll be sorry you asked me that"
And you go
"No cos she's deaf
She's at a residential special school"
And then
quite a few people kinda go <JAW DROP>
and the rest go
"Ooh, so can she hear anything?"
"Got an implant?"
"Does she speak?"
"Does she speak does she lipread?"
"Does she lipread?"
And and then
if you actually answer those questions
you miss the second half
And so it's very difficult
You pick your opponent don't you?
I mean
that women we met at-
(the neighbours had drinks one Christmas)
Who

The *third* question was
"Where does your other daughter …?"
And I said
"Deaf, deaf school"
And she said
"Ooh … who looks after her here ?"
I said
I said
"*She's not ill!*" (laughs)
We do!
We do!
She lives with us
Fuck off! (laughs)
I said
"She's not ill"
then she …
and then she kind of
moved on to somebody
who was easier to talk to

BANGING ON

The banging on thing is very limiting
because you
you might not wish to go into
That Area of Conversation
You might rather talk about … Rugby
But it's also used as an identifier
I know that people say
"Oh yes you know Dora
She's got a deaf daughter"
And they go
"Oh yes I know who you mean"
But, I mean
in you know
in a restaurant
and you know you can *hear* people
coming up to you in the street
in the shop
Every
Every
Transaction
"*Oh I've always wanted to learn to sign*"
You know (sigh)
"I've got something to do, thanks"

We got given a Braille menu at Pizza Hut …
(laughs)

A COMPLETE UNKNOWN

I don’t know if you knew
but I had no idea at the start of
you know
When I first knew that Maisie was deaf
I had no idea what the future was
No
Not a clue
Not a **clue**
And I don’t think I even particularly thought about it
You’re so busy dealing with the day-to-day
that if anybody said
you know
“Imagine her as a fifteen year old
sixteen year old
thirteen year old”
I couldn’t do it
No
The picture I would have painted
would not have been the reality
Would you have been able to
paint a picture?
Probably not
No
No
I mean
it feels like it would’ve been
much more of
A Complete Unknown
Yes
I mean
We would have had
various imagined futures
for Harper
Yes
you could see sort of
what was going to happen
Cos we’ve been there
Yes
Very similar to

to our lives if you could picture it

I remember the teacher for the deaf
when she first came round saying
        "*Now, thinking about school*"
And I was thinking
(holding baby)
        School?
        What are you talking about?
        This is a *baby*, she's not going to *school*! (laughs)

OPENING UP THE WORLD

But that's the thing you see
That's what I meant about it
opening up this world
The world was there
we just didn't see it
and it would have been very easy
to kinda go along that rather
        narrow
                little
                        path
I don't know who we would have been
I suspect we might not
                                        We wouldn't have been
                                        straightforward
                                        I don't think
No but it would've been easy to do that
So Maisie's made us really stop
and Look. At. Us.
Look at ourselves
I don't know if she'll ever know that
        I wonder if she'll ever know that
                when she's older

Two weeks later, Maisie and Harper sat down on the sofa in the living room, ready to tell all, relishing the opportunity to pay tribute, to shout, to joke, to complain. They needed no prompt; it was simply a case of who would start. Maisie is on the left, Harper is on the right.

CLEVER PERSON

I asked mum
what was his reaction
when they found out I was deaf
I was always asking that
        How did he feel?
And she said
Of course
he was shocked
but you know
Shocked
Not panic-stricken oh-my-god-quick-cochlear-implant-and-all-that
But. Very. Practical.
Like
What do we need to do?
I mean
it was all new to him
the same as mum really
                                        And I always think that
                                        how people react to the deaf thing
                                that's part of how we judge
                                what they're like   as people
                                And I think if they're a good person
                                a nice clever person
                                then they'll understand

PULL TOGETHER

We're very close
And I don't think that's to do with
deaf   and   hearing
I don't think so
it's just
                                        Our family
                                        we're very close
                                Very tight-knit
                                and I think that's to do with
                                Mum's family
                                and they are all very close too
                                        And I think that's had
                                        a big influence on our family
                                                definitely
                                        So we're a strong family anyway
                                        and I think that's really important

that sense of togetherness
But
but also
the deaf hearing thing
I think it’s a very different experience from my friends
It’s forced us to have to pull together
Maybe
I don’t know
It’s difficult to judge how that affects …
What do you think?
Do you think that’s right?
Working so closely together almost forces-
I don’t know …
Well I don’t know!
If I was hearing
I don’t know what our relationship would be like
It’s impossible to know
But trying to imagine what it would be like
that’s really difficult
If I was hearing
what would our relationship be like
you can’t
So …
It made me think about our holidays
and we always plan for the four of us together
and that becomes
more and more important
and whereas other families do stuff
separately
we never do that
that wouldn’t work for us
There’s the communication issue
I feel
I agree
it affects the whole family
The way we choose what-
The way we choose to use our time
We realise how it important it is
to do things together
the four of us
It doesn’t even have to be a family thing
Maybe it’s hearing friends
asking if we want to go bowling
so we’d go
but then go less
and *less*

And then just stop. going. altogether.
because I’d be sat there
twiddling my thumbs
and every time it would be the same
sat there bored and left out and
Harper’d have to interpret everything everyone said
and mum and dad would be
worried all the time about us
        How we’re feeling
        Are we comfortable?
        Having a good time?
And we weren’t
so we just felt
well …
We decided to stop doing that
and that’s why we’ve become so close
And mum and dad would always feel guilty
saying
We don’t want to go because of Maisie
So now I feel really guilty
I stopped them from going out!
So I think that’s become the reason
One of the reasons why we’re so close
        Maybe … (smiles)
                                                                        Our **guilt**! (laughs)

NOT THINKING

                                                When we visited-
                                        When we visited our grandparents
                                        two weeks ago   and
                                we were prepared for a difficult situation
                                        But it was really difficult
                                because I had such a huge responsibility
                                to interpret everything
                                But actually we got on really well
                                no getting at each other at all
Normally when we’re with them
we’re at each other all the time
        You know
because the days are so stressful
that by evening time
we’re really having a go at each other
And that’s been because
I’ve felt she hasn’t done a good enough job interpreting for me