



Our Aims

- support anyone affected by the death of a baby;
- work in partnership with health professionals to try to ensure that bereaved parents and their families receive the best possible bereavement care;
- promote and fund research that could help to reduce the loss of babies' lives.



Our Structure

- **Head office**
central services for the organisation
- **Over 100 Groups**
support meetings, telephone helpline, email, links to local hospitals
- **7 Networks**
Scotland, N Ireland, Wales,
North, South, East and West England



Barriers to accessing our service

- Image
- Language
- Geography
- Support meetings – location and venues
- Equality & diversity in practice?



Making Sands more accessible

- Media & publications
- Identifying the gaps
- Volunteer recruitment
- Cultural awareness training
- Developing links with other organisations



Supporting Women at Higher Risk of Infant Death
Pudsey – 26th September 2013

**Culture and the experience of grief
...when a baby dies**

Roopal Shah - Leicestershire Sands

Culture

You cannot “guess on the basis of community or group in which they live or grew up, their way of life, their socio-economic status, religion or personal circumstances – what any parent will feel or want when their baby dies”

Schott, Henley & Kohner 2007

Culture and the *experience* of grief...

Research indicates that grief is experienced in similar ways across all cultures

Culture and the *expression* of grief...

“Unconscious cultural conditioning and social norms strongly determine the ways in which people express or do not express grief”

(Murray Parkes 1985)

**Understanding different
religious rituals for the dying
and the mourners**

What are the barriers to accessing bereavement support...?

- Language?
- Awareness and education?
- Tight-knit supportive families?
- Stigma - a taboo subject?

Comment from parents who have accessed our support...

"I needed help... I didn't get it from the family..."

"I read your story and felt inspired..."

"I was scared to come, but my husband wanted to – he needed to talk and have his feelings validated"

"I am fed up of people telling me this is "God's Will" – it isn't... How can God do this?"

In Summary...

1. Importance of not making assumptions!
2. Listen to them and
3. Try to empower the parents with choices
4. Reassure parents they should do what feels right for them...
5. And that support is available!



Asian Outreach Project

Research Questions

- ❖ Where do bereaved Asian parents find support? Does it meet their need?
- ❖ What barriers do they face in accessing support?
- ❖ What support and information would be most useful?
- ❖ How can Sands work with others to most effectively provide that support?

Tentative Findings in 4 areas

Small group discussions

- Your feedback and ideas
- How does all of this relate to your bereavement support work?

Raise awareness of the issues and of Sands support in Asian communities

- Market Sands better in areas of high Asian population & in more accessible formats (translations?)
- Encourage public discussion to breakdown stigma/taboo eg radio
- More guidance needed from major religions of South Asia on practices around the death of a baby

A befriending service that meets the needs of Asian parents

- Recruit and train Asian befrienders
- Offer helpline befriending in Urdu, Hindi, Gujrati & Punjabi
- Can we expect all befrienders to have some understanding of how grief *may be* expressed in Asian cultures and religions But no assumptions!
- How to respond to parents who want faith-based support?

What can local Sands groups do to become more accessible to Asian parents?

Encourage and assist groups to offer support which does not exclude anyone (time, place, mixed sex setting)

- Important to stress confidentiality
- Opportunities to build trust with one befriender before joining a group

Working with midwives and other HCPs

- Encourage midwives, interpreters, link workers, hospital chaplains to call Sands in when a baby dies
- Provide HCPs with a Sands leaflet or postcard (translated?) to give parents
- Build understanding of HCPs on culture & grief (professional guidelines training)
- Perhaps a video of bereaved Asian parents experiences?

What happens next?

- We still seek Asian parents to interview
Please refer people to us if you can
- Project finishes November. Sands will then decide how to take findings forward
- Meanwhile we need your ideas on how Sands, & others, can provide more inclusive services