

main course

waiting at the bottom of the mountain:

Waiting respectfully with children with disabilities and their families.

AIM

To explore the experience of waiting through our remembered Bibles and the experiences of families with children who have disabilities.

Approach to the Bible

In this Bible study we will use Remembered Bibles (or RB), a technique of retelling bible stories developed for use with people of all ages and abilities. We will do this because:

- not everyone can read the Bible;
- we want to include as wide a range of experiences as possible
- the remembered bible is the one in us, the one we use in our everyday encounters: it's good to use it to build up our confidence;

Not all Vision4life Bible material uses RB. You may want to try it, or you may want to avoid using it, for different reasons. If you want more information about RB please visit the website.

The Theme

Waiting is a common experience. In Bible study, it can be coupled with familiar stories from the Bible in which we meet people who wait: Abraham and Sarah, the prophets, John the Baptist, Mary, are some that come to mind. In this Bible study we will revisit the theme of waiting but we will use a Bible story not usually associated with waiting and experiences often marginalised in our communities to see if it helps us understand waiting in a new light.

You will need

- To encourage people to work in pairs or threes informally during the 'talk about it' parts of the Bible study;
- Be ready to listen to what is going on, feeding this back to the wider group if you can;
- Be prepared with the story 'Downhill to Jerusalem' if you decide to use that to close the session. It is best not to read this out, but tell it in your own words. Better still get someone with the experience of parenting children with disabilities to tell their story this way (note that the story is based on the real experiences of such families).

Getting started

Ask people to talk to each other about waiting in difficult circumstances. This is not a long detailed conversation but a brief, short moment of buzzing gossip. Remember to encourage people to listen to each other (and not to be too loud so as to drown each other out). What ordinary experiences of waiting have they, or those close to them, had in the last week/s? Some folks wait a long time in circumstances which can draining: energy ebbs away when 'the system' seems unable to respond to their particular need.

Some ideas might be

- Waiting for a hospital appointment or operation;
- Waiting to be made redundant or complete a job contract;
- Waiting alone or with a relative or friend for particular news, good or bad;
- Waiting with someone with a life-limiting illness.

Try to use real everyday examples like these, hearing some ideas from the whole group of what it felt like to wait?

Remembering the Bible

This Bible story from the ministry of Jesus is found about half way through the written down version of Mark's Gospel. It begins with Jesus going up a mountain with three of his disciples. At the top of the mountain we hear about the exciting, mysterious, alarming and unusual things that happen to the. Meanwhile lots of people are waiting at the bottom of the mountain. This includes the family of a boy with epilepsy whom have come to see Jesus.

Do you remember this story?

Try to remember it with the person next to you.

What did it feel like to wait at the bottom of the mountain for those who were there, particularly for the family of the boy with epilepsy (refer to your previous discussions at this point)?

Hear some ideas from the whole group.

Waiting at the bottom of the mountain

Not every experience of waiting ends in celebration. As we think about waiting let us hear from some folks who are waiting at the bottom of the mountain. For families of children with disabilities, that mountain might be a waiting list for specialised medical treatment, for an appointment with a therapist, or a chance of a new educational opportunity or it might mean going into a hospice for some respite or end of life care.

You may want to use some of the examples given from a recent study that are quoted at the end of this document, or you may have direct experiences that you can refer to in your own community or you can find other website on which parents share their experiences [www.scope.org.uk; www.ican.org.uk; www.epilepsy.org.uk for example].

You may want to reflect on the needs of children with disabilities like epilepsy when they belong to faith communities (there is a note about epilepsy at the end of this document)

Refer back to the examples that have been shared and ask: In what ways can we wait respectfully with families of children with disabilities?

Ask people to talk about that together and then hear some of their ideas. It may be that some members of the group have a personal testimony to give about their experiences relevant to this story: try to provide an opportunity for this to be heard. Or you may want to conclude the session with a version of the story 'Downhill to Jerusalem' and some time for prayer.

Prayer

Speaking is just one way
of communicating,
both human and divine.
May we who are Jerusalem bound,
looking for the signs of the times,
remember and respect
both verbal and silent ones,
for the part both can play
in the building up of your kin and kindom.

Janet Lees

Time to use this

This material could be used in Lent or at the Feast of Transfiguration, or at a time of year when we are asked to think about people with disabilities, like Epilepsy Action Week.

Evaluation

Please try to answer these questions for yourself and for others who will use this material:

1. What was the most helpful thing?
2. What was the least helpful thing?
3. What would you like to try now?

Additional material for this Bible study

1. Downhill to Jerusalem

Our son had been going downhill for sometime. Since his early childhood, as other children were learning things, he seemed to always be finding things more difficult. He would have these moments when he seemed not to be himself: his eyes would roll and his limbs would shake. Sometimes this happened for just a few moments, sometimes much longer, every time it seemed to me like a lifetime. Afterwards he would be sleepy and slow, he would stumble and dribble and gradually come back to himself. But over the years these moments took control of his life, more frequent and longer, the effects lasted and meant he learnt less and less. What he had learnt he forgot or seemed unable to do anymore. We were losing him and we didn't know how to stop it happening.

My husband tried to ignore it at first. He told me I was making a fuss and that there was nothing wrong. He wasn't there to hold him during the shaking attacks or clean him up after he messed himself. My friends and family were embarrassed for me. They wouldn't speak about it. Strangers would express their opinions. 'What sinners you and your husband must be' one told me once. Many told me 'It is the will of God' and how I hated their God who had this awful will to blight this little life and mine too.

I had cried so much over the years there was nothing left in me; no tears, no love, no life. I had dried up and just went on waking and sleeping through habit, nothing more. The boy too seemed empty. There was nothing left of him either. There was nothing he could do for himself; I did it all for him. And yet still he lived, if you could call it life.

Someone in my husband's family told him about a teacher and healer from Nazareth and convinced him to try to see him. I was surprised. In all this time my husband had shown little or no interest in the boy, let alone any concern about whether or not he could be helped. But people said this healer had done wonderful things and there were many stories about him going around the neighbourhood. So we went to the place where he was said to be. My husband arranged everything. I just went along, in the cart, holding my son in my lap, but when we got there the healer was not there.

It seems he had gone up a mountain with some of his followers. No one had any idea how long he would be gone, but we were not alone in waiting for him at the bottom of the mountain. There were some who tried to help us as we waited. One woman held my son for me as I got down from the cart. Another got us some water so I could wash him and also shared some bread with us. A few came to listen to our story. My husband told them we wanted to see the healer because our son had this strange illness that came on him and made him shake for no reason. They said little but clearly didn't know what to do. I said nothing.

Eventually we had word that the healer was coming: coming down from the mountain with his friends. A buzz went around the group and the buzz grew into a roar. As he got nearer some went up to him, tried to touch him, screamed for his help. My husband and I watched amazed. We didn't move. The women who had helped us, and the men who had listened, brought the healer over to us. 'This is the family who wants to see you' they said. 'We didn't know what to do'.

His face was bright and warm. I looked at him and for the first time in all of this I dared to let my heart hope a little. He sat with us and listened to my husband who was by now very distressed. I had never seen him like that but it was as if all the waiting had finally brought to the surface everything he had never allowed himself to think or feel or say in all those years. He was crying as he told the story of how our son had changed from being like any other child to this helpless and almost lifeless individual who could only shake and dribble and shit.

'Only believe' the healer said. What did it mean? My husband looked at the hand on his arm and then at the healer's face. 'Oh, I believe' he said, and surely he was as faithful a person as anyone you might meet. 'I do believe' he repeated, 'but help my unbelief'. These last words were just a groan.

Then the healer looked at me. He didn't ask me anything and no words passed between us. He just looked at me as I held the boy in my lap and as he looked it was as if he knew the whole story, as if he understood how the tears had dried up, and why, and how my life had been turned into an empty husk. 'This is his mother', one of the women said.

I understood that he wanted to hold the boy himself. He sat as I had been sitting on the ground and took him on his own lap. Very few people ever held him. He would go very stiff if you held him wrong or if he didn't take to you, so mostly it was just me that held him. I wondered what would happen as I put my son in his arms, but the boy did not stir. He sat with him in his lap, just like I did myself most days, just sat there for quite some time. Gradually my husband stopped crying and looked up.

As we all sat there together, I felt myself relax. People started to move away and some from his group began to get a meal together. We remained where we were, the three adults and the boy on the healer's lap as life went on around us. After a while my husband took his sleeve and wiped our son's face, moving the hair off of his forehead gently with his fingers. He had not done that in a long time. I moved closer to my husband and we both looked at our son lying there relaxed and seemingly content – at least not agitated like he was quite often.

The next morning the group got up ready to go on. They were going to Jerusalem we heard, but we knew we couldn't go with them. We climbed back onto the cart. The healer put my son back into my arms and waved to us as we started back to our village. Eventually he turned around and began walking downhill to Jerusalem.

So, you'll be wondering how that changed anything, anything at all. As if it could. As if a trip to see a magic man could make a difference to such a hopeless situation. Well it did. My husband was changed by it. He would talk now, about his son, about the time we saw the healer, and he would help me. He would even hold the boy, like I did, like the healer had done, and help me with the things that our son needed. Our son was changed: he would still shake and moan at times, but generally he seemed calmer. I had changed. I remembered the eyes of the healer as they looked into mine. I remembered him holding my boy just like I did. I remembered him listening, just listening. It had changed us all. We could work together. We could be together.

As for the healer, I didn't hear about him for sometime. It was long after Passover, when a story started going around that something terrible had happened in Jerusalem that year. The healer had been arrested, tortured and crucified. Someone said they'd even seen his mother holding her son's lifeless body.

I knew just how she felt.

This is an edited version of pages 109-112, of *Word of Mouth* by Janet Lees (Wild Goose Publications, 2007)

2. A note about epilepsy

I have been asked about my interpretation of this story as 'a boy with epilepsy'. Whilst it is very difficult to read contemporary understandings of disability back into the biblical text, I call this boy, the boy with epilepsy because

- epilepsy is a common neurological condition that has effects like those described in the Bible story;
- it is known in all human cultures and has been known since prehistory;
- it has long been and still is often the subject of stigma, prejudice and misunderstanding;
- I know more children with epilepsy than with evil spirits.

Indeed I believe that faith communities need to do more to understand the experiences of people with disabilities and their families, including epilepsy, not only because of the stigma, misunderstanding and exclusion that can arise from ignorance but because it can also be dangerous. In his report of the Victoria Climbié enquiry into the death of that child, Lord Lamming noted that faith communities, and faith leaders, were often ignorant about child abuse and neglect. Moreover he noted that it was potentially dangerous to label physical, mental, communication or learning difficulties, with the label 'evil spirits' as had happened to Victoria (her guardian said this about her and took her to a faith community and told them this too), because this often meant the child fails to receive the support and attention of health, education and social services. Whilst recognising that dis-ease may have spiritual links, children with physical, mental, communication and learning difficulties must have all their needs treated respectfully by faith communities.

I have also been asked why I do not treat the story 'as if it was a miracle as the written text suggests'. I think I do treat the story as a miracle: a miracle in which the family is made new by the experience of meeting Jesus is none the less a miracle. When using the remembered method, try to look between the lines for what might be hidden ready to be uncovered.

3. Parenting disabled children

A recent study of religious families (Horwath and others, 2008) included the experiences of some parents of disabled children. These families, Christians, Muslims and Hindus from the north of England, were taking part in discussions about how religious beliefs and practices influenced parenting.

Families had mixed experiences of faith communities:

'As a Christian and as a faith person, I always think that autistic children are far better off in faith communities because there's that support there but sometimes it's not there, sometimes it's judgmental'.

'Sometimes it [faith community] is judgmental: sometimes [the attitude is], they [disabled children] must behave like us.'

They concluded that: 'Parents with experience of raising disabled children felt in principle that faith communities should be a positive asset for families. However, they expressed mixed views about whether sufficient support was provided in practice. Not all parents felt able to take their disabled child to their place of worship and others had felt their faith communities were too judgmental and intolerant of the way their children behaved'.

This comes from: J Horwath, J Lees, P Sidebotham, J Higgins and A Imtiaz (2008). 'Religious parents want what's best for their kids': RELIGION, BELIEFS AND PARENTING PRACTICES: A DESCRIPTIVE STUDY. PROJECT REPORT FOR THE JOSEPH ROWNTREE FOUNDATION available from www.jrf.org.uk in December 2008.