

Simon and Carol Whyte, one of the couples in our spiritual community, have recently given birth to Katelyn, a baby girl with Down Syndrome and a major heart defect. This will mean that their journey will be both similar and different to that of parents of a child without down syndrome. We as the eldership team of this community want to surround them with love, support and encouragement at this time. Although we will do our part, we know a lot of the loving and supporting comes from you – the family. Here is some information we think would be helpful to keep in mind as you go all out to love and bless this new family. We are confident that Katelyn is sure to be a delight to us all and we celebrate this precious life as we would any other.

Some of the unique and different things the Whytes will face are:

1. Katelyn will undergo a number of different tests by the cardiologist and paediatrician and will probably only come home from the hospital after Carol.
2. Development will not take place at the same pace as other children. Katelyn may have to be taught many things that another child would do naturally. Simon and Carol are likely to enroll her in an early intervention programme, which has been highly recommended by parents of children with Down Syndrome, from as early as 6-8 weeks.
3. Katelyn is likely to go for a heart operation before she is 6 months old. Almost half of babies with Down Syndrome are born with heart defects but many overcome these difficulties over time with medical intervention. Simon and Carol have already met some of the best doctors in this regard so Katelyn will be in great hands!
4. Katelyn may feel “soft”. This is because of low muscle tone which basically takes their strength away, making it harder for her to hold her head up, sit up, suck, speak etc. The good news is that muscles can be strengthened by working them and so it is likely that Simon and Carol will be actively involved in developing their baby girl’s muscles as recommended by physio, occupational and speech therapists.
5. Feeding may be challenging as Katelyn is likely to have a weak suck. Moreover, babies with heart/other medical problems may tire more easily which may impact feeding. However, babies with Down Syndrome experience extra special benefits from breastfeeding as it improves mouth and tongue coordination which helps with speech development and provides protection against infections and bowel problems which are more common in babies with Down Syndrome. While there are certainly fantastic milk formulas available for Katelyn, Carol is going to give breastfeeding her best shot given the developmental advantage this will give her baby.
6. Katelyn will initially communicate through facial expressions, gestures, smiling and pointing. She will most likely have speech therapy from an early age and may learn sign language to assist her communication.
7. Katelyn may be prone to sleep apnoea which would affect her breathing patterns at night. However, these challenges can usually be medically treated.

We can help Simon and Carol raise their beautiful baby girl by:

- Celebrating the birth of their baby girl and enjoy this precious life with them
- Supporting them practically as we would any parents with a newborn (help with meals, babysitting, offering to pick up something for them on our way over to their house)
- Actively engaging with Katelyn and contributing to her stimulation and development. Let's celebrate with them as they reach every milestone. Albert Einstein said "there are only two ways to live your life; one is as though nothing is a miracle, the other is as everything is." Another said "the only true disability is a crushed spirit".
- Being gracious with them as they find their feet, especially during the first year of Katelyn's life

We've also had some input from Mark and Debbie Rossi, past members of CGC who are blessed with a little girl called Isabella, who too has Down Syndrome. Their insights and input have been very valuable. Here's what they say:

"It is very tough for parents to deal with a person coming up to them saying "Shame, we are so sorry". Treat them like you would any couple with a new baby – be excited and congratulate them. Love them a lot - they are going to need it. Support them practically; cook them meals, do their shopping. It is their first child, so much of this is new territory. Carol will probably struggle to breast feed due to the heart defect. If there are moms who can rally around her and just support her with this, it would be super. This was the most testing for Debs. Very, very importantly is that people must not say they are going to walk this road with them unless they are really really going to do it. People think it is the best thing to say when emotions are high but when the emotions fade they forget about the commitment. Simon and Carol are not going to forget that. We had that and out of about 20 couples that said that we have about 3 that are still around.

The heart surgery is going to be tough on them. They have the best heart surgeon in the world working on the little one, so there is not much to worry about, but emotionally they are going to be on a rollercoaster. Keep in touch with them, try visit and just truly show them you care. Also be very real to them - don't make out as if you know what they are going through because you don't - unless you have had a child like this. One thing is for sure – having a little girl like this in your community is going to change your church!"

There are two practical ways we'd like to help Simon and Carol in these first few weeks:

- Preparing meals for them so they don't need to worry about cooking
- Blessing them with a hamper of baby gifts/ food items/ spoil items

Please contact Louise Gibbon louisegibbon@gmail.com if you would like to assist in one of these ways.

