

Praying with Disability

Come and enter my multi-sensory world,
a world where nothing is quite as you see ...
a magical world I'll show you,
full of surprises, come enter with me!
A world where forest green
... is the scent of a 100-foot fir tree;
where winter white
... is the wind when it bites through your clothes;
where cobalt blue
... is the warmth of a pool.
I can swish my legs and splash like a shining seal.
Look at me!
I am free!
I can swim like a shimmering fish in the sea!
I may be blind but can you see
gazing with my secret eye,
my world is very multi-sensory ...
What's your world like?
~ Katriona Goode ~

This poem was written about our disabled son, Matthew, when he was only about 7 years old. It was published in a book produced by the children's hospice Helen House in Oxford. Matthew has had a challenging life journey. Following five months in hospital when he was two years old, he was accepted for respite at the hospice. Prayers were an important focus throughout that time. Matthew's name means 'God's gift' in Hebrew and that is exactly what he is to us every day of our lives. Now a young man of 19, he lives at home full time with care support. He is a member of our local church in the

Scottish Borders and has affirmed his faith in God in a bespoke service themed 'I have the joy of the lord'. Prayer has been hugely important in our lives as a family. We have prayed and prayed for healing, for miracles, for getting through the day and night, for Matthew's survival. Without God in our lives, I just don't know how we would have got through our journey together, for the road has been very rocky indeed. Matthew's story is quite remarkable. He has severe disabilities: cerebral palsy affecting all four limbs, making co-ordination very difficult – any movement is hard for him to control. He uses a wheelchair and cannot walk. He is non-verbal but often very joyfully vocal, especially during the hymns in church! He is cortically blind and is fed by a gastric tube. He has complex needs. He loves music and has learned to control his voice, vocalising at the appropriate times within the service. Only by regular attendance and understanding the shape of the worship has he been able to develop this skill. He has always gone to church since he was a wee baby. We, his parents, have done everything in our power to help him develop whatever skills he can. One very key skill is pressing a switch. Matthew has a communication aid called a BIG MAC (it looks a bit like a large red smarty). We record our voice onto the switch and then Matthew can press it to share his news. For he loves to communicate. We have used it so that he can say 'hallo' and introduce himself, to tell his news from home and school, or to join in with a phrase in a song or a story. It is a most simple and joyful piece of equipment. It has taken years to teach Matthew to use this switch consistently. I have been writing prayers for our local church for some

time now. When we decided we wanted to all worship there together as a family, it was because we wanted Matthew to become known in our village and to be an active member of our community. So it wasn't long before I came up with idea of him using this very switch as an integral part of the prayers. It has revolutionised our worship as a family and greatly enriched the church congregation. It has helped break down barriers in disability, and meant people now come forward naturally to speak with Matthew, as they have learnt how to communicate with him.

I specifically write the prayers with a response. Matthew has the key role to press at the right moment, leading the response of the prayers and triggering the congregation to follow him.

I also use sound as a way of prayerful expression, taking the multisensory approach and bringing the world of nature outside into the church itself. We use birdsong and small toys that reflect our local countryside: sheep bleating, cows mooing and birds tweeting, their sounds becoming a focus of thanks within the prayers. I have also made prayers in an Iona format, and I have even played seawash in the background once. My prayers are always very Celtic influenced, because of the wonderful Borders countryside – it is inspiring to see God around every day, as I look out onto the hills from our home. Usually I take a theme from a reading or a hymn and include that within the prayers. Here is an example of some opening prayers we made together in June 2016: Matthew is going to help with the opening prayers today.

So when Matthew says:

Lord as the sun and stars shine,

The congregation responds:

May we shine with Your love.

Lord, so often in our day-to-day lives,
everything becomes very fast;
we forget to take time to stand and stare,
to be still.

We don't find time to notice the beauty of Your world
in the warmth of the early summer sun;
in the bright white light of a moonlit night; in the glory of the millions of
stars that pinprick
the night sky;
in the moon and stars that guide our way through
the darkness.

Lord as the sun and stars shine,

May we shine with Your love.

Lord we need to take time to be still and to know
that You are God;
to feel Your Holy Spirit, around us every day
and within us;
to feel Your presence now, as we gather together
here in this church.

Lord as the sun and stars shine,

May we shine with Your love.

We thank You for this time to feel Your peace
and calm upon us.

We thank You that we may worship and praise
Your holy name in safety and peace without
fear of persecution.

Lord as the sun and stars shine,

May we shine with Your love.

As we are gathered here together in this place,
open our hearts to feel Your love;
open our ears to listen and hear Your word;

open our minds to understand what Your spirit
is telling us.

Pour out Your spirit onto us all today,
so that we may draw closer to You.

Lord as the sun and stars shine,
May we shine with Your love.

Disability is very challenging. It can be limiting,
frustrating. It can close many doors. With Matthew's
help, the church door has been opened to accept him. He has learned to
demonstrate his spirituality through
prayer connecting to God's Holy Spirit with his joy.

We thank God for that every day. This is how Matthew
has taught us to pray.

Written by KATRIONA GOODE