



Series 2. Episode 18
Turning *Little Stones* show notes.
Listen to a conversation with Fran
Clarke.

Episode 18
Going for GOLD! Living well
with DS
with Fran Clarke

This podcast is aired to coincide with 2024 Paralympic Games. It is worth a listen at ANY time!

We welcome Fran Clarke who talks to me about her 20 years' experience of supporting her daughter to in many ways, not least to achieve a host of swimming medals. Truly inspirational... living well... with Down Syndrome!

Fran is an experienced secondary school maths teacher. She is also a mother of three children. Her youngest, Helen was born with Down Syndrome 20 years ago. This podcast is a celebration of the richness Helen has brought to the whole family – and beyond.

Fran shares her story, with honesty and shot through with humour.

What is Down Syndrome?

Down Syndrome is a genetic condition. Children are born with an extra chromosome (21). Typically, those with the condition may have heart abnormalities, poor muscle tone, distinctive facial features, a larger than normal tongue, auditory processing difficulties (affecting memory) and often with *good* visual processing **abilities**.

Myth busting

Fran explains that there are many erroneous assumptions made about people with Down Syndrome. She counters each one:

'They are friendly' – *"it depends on whether they like you!"*

'They are happy' – *"she experiences the full range of emotions... she can be grumpy, sad, happy, cross...although her whole face likes up when she smiles."*

'They are shy' – *"confidence comes with social skills. Helen has great social skills!"*

'They can be stubborn' – *"They're NOT! Because their language skills are less developed...they just need more time and simple choices..."*

Each person with Down Syndrome is different and unique (just like anyone else).

They are however vulnerable, generally more trusting with a lower awareness of danger.

Infancy – the early days

Helen's condition was diagnosed at birth. Although Fran was accepting and straight about her condition from day 1, the early years were "tough emotionally... especially coming to terms with seeing her not achieve the same milestones as other children".



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She had welcome support from a physiotherapist, whose interventions helped Helen to learn to sit unaided, move about to reach and stretch to get toys etc. She also benefited from an early support adviser, whose help was invaluable – reassuring with regular visit to give focus on what next steps to work on.

Not least, Fran’s family (notably her parents) gave constant, appropriate, practical, and emotional support throughout. The relationships they all now enjoy with Helen independently is testimony to this! (Listeners may also wish to refer to Turning Little Stones Podcast Series 1; episode 16... ‘Active Granny’).

Nursery & primary years

Fran’s direct approach led her to learn as much as possible about Helen’s condition. Significantly this led her to the charity Down Syndrome Education International <https://www.down-syndrome.org/en-gb> (DSEI) which provides “fantastic information and resources”.

She also decided to retrain in early years and worked in a Montessori setting. This approach was helpful as the teaching style was perfect for Helen’s needs. The clear diagnosis given at birth meant that Helen had a ‘statement’ (now known as EHCP), giving her access to 1:1 support for some of her time at nursery and into primary school.

Fran celebrates the place of Makaton for any child with auditory processing difficulties. It helped her communicate before she could talk and continued to be useful when referencing more abstract concepts, such as time.

Using the resources from DSEI, Fran set about making Helen-specific picture/word matching activities and books. This helped Helen learn to read before she could talk. Visual skills were her strength and using these resources she learnt to read, aged 3!!! Helen went onto learn phonics at primary school, but she remained in the top set for literacy into year 3 at primary school.

Fran celebrates the primary school Helen attended, particularly her Year 1 & 2 teacher, who “always thought how to include Helen in any activity”. In fact, Helen remained in that class for half-days into year 3.

In year 4, Fran investigated local special schools for children with moderate learning difficulties and Helen moved to one at the end of year 4. There were pros & cons... “she fitted in, made friends, did not need 1:1 support...” Conversely, her friends were not local and she lost access to some of the creative activities she was beginning to enjoy.

Fran continues to celebrate the vital part her whole family played throughout these years... Helen’s siblings, their friends and her parents.

Extra-curricular interests

Fran recalls this piece of advice,



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Imagine your child is an einsteinium (seriously gifted). You would expose them to as much as you could (music, literature, sport....). For a child with Down Syndrome, the need to do this is even greater!

Embracing this idea, everything that the family did, Helen did too.

This included cooking. She has always cooked at home with the family and is now at a residential college studying Hospitality and Catering. (Listen to Helen at the end of the podcast explaining her signature dishes!)

Aged 10, her brother taught her to swim on holiday. Fran then found a local swimming club for people with disabilities. There, her talent was recognised, and Helen now competes in Para Galas, even breaking world records in 2019. She proudly shows us her array of medals. Now Helen competes alongside younger able-bodied swimmers. Fran explains that here she is more visible, “a trailblazer” as she travels to compete around the world. And her family celebrate her successes!

Family is the strong thread woven through this story.

Last words from Fran...

Fran’s advice to anyone who finds themselves on a similar journey (and their family, friends, teachers) is unequivocal...

“The first thing I would say is CONGRATULATIONS!... Have faith in them...treat them as people...have a great sense of humour... it’s such fun!!”

This family is living proof that we can all play a part to support and celebrate,

‘Living Well... with Down Syndrome!

And Helen, perfectly signs the podcast out!

Further information, practical guidance and advice are available through,

Turning Little Stones

Delving a little Deeper

See website for details.