

# by Dr Jude Opolski

Does the person with Down syndrome in your life talk out loud to him or herself? Maybe they carry out a running commentary on their activities, talk to toys or objects, chat to imaginary friends or have two-way conversations with themselves. If so, they are not alone! Around 90% of people with Down syndrome, young and old, use self-talk.

Hi, I'm Jude Opolski and my son Rohan's self-talk has been the background soundtrack to our family's life for most of his 33 years. My fascination with his constant chatter led me to research self-talk and Down syndrome for my PhD. My study involved over 100 South Australian families who generously shared information and anecdotes providing me with fascinating insights into the variety, functions, and importance of self-talk for individuals with Down syndrome.

#### What is self-talk?

Self-talk can be described as any audible speech that is not directed towards another person. It is a normal part of child development, usually beginning around three years of age. Initially, children use self-talk as a commentary on their actions and to chat with their toys as they play. Later self-talk becomes a useful tool helping them to plan and organise, and to learn new skills. Typically, audible self-talk is gradually internalised and fully replaced by silent thought by the age of eight to ten years.

Of course, occasional audible self-talk is quite common in people of all ages: we mutter to ourselves about tasks that challenge us; consider the pros and cons of decisions; commentate our actions; or swear when we hurt ourselves. Whether we have Down syndrome or not, self-talk can aid our thought processes, task completion, and decision making in very positive ways. Usually, however, those of us without Down syndrome don't self-talk when other people can hear us — we have learned to both internalise our speech and to conform to social rules. We know that talking to ourselves in the presence of other people is not generally thought to be acceptable.

For people with Down syndrome however, self-talk often remains a persistent, sometimes lifelong, behaviour and can be of concern to parents. Generally speaking, self-talk is a developmentally appropriate behaviour for individuals with Down syndrome of all ages and there is usually no need to worry about it. However, there are some situations in which self-talk might not be desirable or appropriate, and in some cases the tone or content of self-talk may indicate underlying difficulties in the person's life.

# The study

For my study I interviewed a focus group of professionals, sent 300 questionnaires to families in South Australia, and interviewed eight parents of teens and adults with Down syndrome.

I received information about 104 people with Down syndrome; 59% were female and 41% were male. They ranged in age from 8–45 years, with the majority aged either 8–16 years (42%) or 17–23 years (44%).

The use of self-talk reported was 90% – an incidence that is consistent with previous studies. The majority (71%) were reported to self-talk several or many times a day. Or, in one case, 'constantly!'

Almost all (98%) of individuals were reported to self-talk when they were alone while 51% did so when other people were close by and 19% self-talked during social interactions. Many self-talked when alone *and* in situations where others could hear them; but nearly half (47%) were reported to self-talk *only* when they were by themselves.

Most people (88%) talked to themselves, 62% talked to toys or objects, and 39% talked to imaginary friends. Over a quarter (27%) used only one type of self-talk, while 36% used more than two types of self-talk, (e.g. to themselves and to imaginary companions), and 27% used all three.

Different styles of self-talk were reported, including: narration of events and activities; acting out scenes from TV or movies (often the same show over and over); saying lines of favourite TV shows or videos while watching them; role playing or fantasy play (often using toys or props); and two sided conversations with themselves (this is the self-talk that my son engages in very frequently – in fact I can hear him doing it in his room right now!).

### Parental attitudes to self-talk

The level of concern reported by parents was quite low. The vast majority said that they were either only a little or not at all concerned. Most parents believed self-talk to be developmentally appropriate (regardless of the age of their child) and many said they felt it was a very useful behaviour. Several parents said that listening to their child's self-talk (particularly the end-of-day 'debrief') was one of the best ways they had of knowing what was happening in their child's life.

When parents did report concerns, their main worry was that if their child used self-talk in public places they might be seen as 'different', judged negatively, or considered to be mentally disturbed. A few parents expressed concerns that their child's self-talk was an indicator of loneliness. A couple said they were concerned about the content of their child's self-talk or worried that an aggressive, angry, or sad tone might reflect serious problems in the person's life or indicate mental health issues.



# **Purposes of self-talk**

The responses in my study strongly suggest that self-talk has a varied and important role in the lives of many people with Down syndrome, including:

- debriefing typically occurring in the individual's bedroom at the end of the day
- developing and practising practical, language, or social skills
- processing requests from parents, teachers etc. This
  can involve two-way conversations (with the self, toys
  or imaginary friends) during which they reason with
  themselves to reach a decision.
- · escaping cognitive or social demands
- providing 'time out' if feeling overwhelmed or unsure, such as being stressed in class due to sensory overload, tiredness, or being unable to do certain tasks
- · avoiding tasks, issues, or interactions
- self-entertainment such as singing
- fantasy play which can involve simple imaginings, or be lengthy and elaborate undertakings using props and complex scenarios
- processing emotional issues
- · talking repeatedly about upcoming events
- · planning and task execution.

#### **Emotions**

Self-talk commonly has an emotional content. For example, talking to toys or imaginary companions to discuss issues that have upset the individual, incidents that have happened recently or to recall enjoyable memories. Self-talk can also be used to reassure themselves when faced with stressful events or circumstances, or to cope with fears or anxiety.

It is not uncommon for people with Down syndrome to have difficulty in expressing their emotions, articulating their anxieties, or explaining what has caused them to be upset. This can make it difficult for parents to know what might be affecting their child's behaviour. How often we wish that we could see inside their heads to find out what's going on!

Listening to self-talk can be a useful way to gain insights into the issues or situations that are troubling or upsetting, getting an insight into their emotional state, or just catching up on what's important in their life (usually a girlfriend update at our house!).

### **Imaginary companions**

I was surprised by how many of the people (including adults) in the study were reported to have imaginary companions. Some were completely imagined entities, while others were cherished toys. Sometimes they were real but absent friends from activities, school or work.

Most commonly people had one or a few imaginary friends but some had lots (one boy had 'hundreds of fairies'). Some remained constant over time (one man has had the same imagined friend for several decades), while others changed, were forgotten, or possibly even died. Some imaginary companions were ordered around and blamed for bad behaviour, 'X made me do it!' For others their imaginary friend acted as a respected advisor or trusted confidant.

To 'construct' an imaginary companion seems a really useful thing to do. People with Down syndrome sometimes have limited opportunities for interaction with real friends and peers or may be isolated by communication problems. Having a companion, who always 'understands' them and can provide companionship and comfort, seems to be a positive activity to me.

## When self-talk can be a problem

There are some circumstances in which self-talk can be problematic such as when it is loud, very frequent, or intrusive in social situations. It can be annoying for those living with the person, or peers at school or work. Self-talk may become more problematic as individuals age as it can become more entrenched and pervasive.

Self-talk can sometimes interfere with social functioning to the extent that it decreases or excludes interactions with friends, family or peers. For example the individual may not want—or be able—to disengage from fantasy, and indulges in that instead of engaging with those around them.

#### Self-talk and mental illness

Self-talk is rarely symptomatic of mental illness but I did have reports of it being misinterpreted and 'pathologised' by some disability and health care professionals. As misdiagnosis can lead to inappropriate treatment, including medication, this is an important issue.

Self-talk, particularly fantasy-play or talking to imaginary companions may *appear* similar to symptoms of schizophrenia or delusions; but rarely is.

However, it can be difficult to distinguish between the self-talk of fantasy or pretend play that is common and 'normal' for people with Down syndrome, and self-talk that suggests mental health problems. To an uninformed observer, behaviour such as talking to objects or imaginary people might appear abnormal but actually it is just something that people with Down syndrome commonly do.

Jude and Rohan





Rohan on holiday in New Zealand

However, it is important to be aware that changes in the quantity, topic, or tone of self-talk – particularly if there are self-berating comments (for example; 'I'm stupid, I can't do anything right') – or a scared or angry tone, might be indicators of underlying mental health issues. The information that is contained in self-talk can play an important role in determining if an individual is experiencing conditions such as anxiety or depression.

For more information on this topic McGuire and Chicoine's, Mental Wellbeing in Adults with Down Syndrome (2006), provides an excellent overview of mental health issues.

# Should we try to stop self-talk?

This is a question I am commonly asked by parents. There is no simple answer but there are a number of factors we need to take into consideration. Is there a compelling reason to change or try to stop the self-talk? Would it actually be possible for the individual to modify their self-talk? And, equally importantly, if the person's self-talk is a useful coping tool, what might the person lose if it is suppressed?

My belief is that that unless there are pressing concerns it is probably best to not interfere.

However, when self talk:

- intrudes on the person's social interactions
- impedes their education, or interferes with their work
- negatively affects the person, for example they are ridiculed or punished for it
- has concerning content or a negative or aggressive tone, an attempt at intervention might be warranted.

If intervention does seem justified there are some prerequisites that must be in place for it to be successful.

My research suggests that an individual needs to have a range of skills and understandings in order for them to be able to moderate their self-talk. General cognitive and social maturation can be a significant factor in our teens and adults developing awareness of their own thoughts and behaviours and an understanding of social rules. As cognitive skills continue to develop throughout life, a degree of self-talk regulation may evolve over time.

Factors that might influence an individual's ability to learn to moderate their self-talk:

- Does the person self-talk only when alone, when others are present, or during actual social interactions?
- Are there situations/environments in which the self-talk doesn't occur?
- Does the person show in any way that he/she can control the amount or volume of self-talk if requested?
- Has the style, content, frequency or other aspects of the self-talk changed over the years?
- If the person is able to read, can she/he read silently?
- Is the individual motivated to change their self-talk?
- The degree to which the behaviour is pervasive or habituated – in terms of neural 'fixedness', degree of functionality, reliance etc.
- The behaviour may have multiple, common triggers (including external situations or internal states) which may be difficult to eliminate or control.

It should be noted, however, that many people with Down syndrome may never be able to regulate their self-talk to a significant degree; and this is quite normal. As long as it isn't causing major issues, 'leaving well enough alone' may be the best attitude.

Self-talk can be a little hard to live with some times (at our house at least!) but it can also offer a window into the often shrouded internal worlds of people with Down syndrome, and can provide fascinating and useful insights into their thoughts and emotions.

If you have any questions, would like information on ways to assess your child's readiness to start moderating their self-talk, or would like to share your own experiences please feel free to contact me at <a href="mailto:jude.opolski@gmail.com">jude.opolski@gmail.com</a>

At the age of 22 Jude became the mother of Rohan, who is 33 years old. She has been involved with Down Syndrome SA since his birth, serving on the DSSA Board for more than 20 years, including six years as President, ten years as coordinator of the new parent visiting program, and worked on resource development projects. Jude also served for two years on the Down Syndrome Australia Board.