



Doctors need to look beyond Down syndrome

By Dr Michael Freeland MP

For many years I have cared for children and now adults with Down syndrome. There have been significant improvements in longevity and quality of life over the last forty years. Life expectancy has increased from around 30 years in the 1960s, to now around 60 years of age.

We know that people with Down syndrome are at risk of certain health problems such as hypothyroidism, ear infections and glue ear, and early onset dementia. However, we should not forget that, like the general population, people with Down syndrome can also suffer from the health problems that we all suffer as we get older, partly because of our sedentary lifestyle.

I have seen a number of people with Down syndrome, obesity, and type 2 Diabetes. Obstructive sleep apnoea can also be an issue in children and adolescents with Down syndrome because of the anatomical problems of a short neck, small midface, and obesity.

Because, as paediatricians we have tended to concentrate on developmental issues, it is my view that some other long term issues can be overlooked such as growth, weight gain, the need for regular (yearly) vision and hearing checks, bone health, and lack of exercise.

Some health professionals can find dealing with someone with a longstanding disability such as Down syndrome to be very complex and time consuming so it is important to find a general practitioner who understands the issues involved and wants to be involved in the long term health care of a person with Down syndrome.

It is also very important that the patient themselves feels confident in the doctor they are seeing, as communication sometimes takes extra time and care. They may or may not want a support person with them during a consultation with a nurse or doctor, and they should always be given the option.

Sometimes they may want to discuss issues such as sexuality but may find this difficult because of expressive language difficulties and may require some degree of advocacy, often from a parent or sibling.

Unfortunately, assumptions about people with Down syndrome can lead to investigations and treatment options being overlooked.

Generally, I find that parents know their children the best and if you feel your concerns are not being addressed, you should always question the doctor. If not satisfied, seek a second opinion. Sometimes families of people with disabilities feel their concerns are not being met. I feel it is always worthwhile talking to the doctor about the concerns before seeking another opinion. Often discussing the issue with other families who have a child with Down syndrome can help with finding a more involved General Practitioner (GP). Most paediatricians are often able to help and support in suggesting a GP who has an interest and skills in this area.

It is sometimes best to go and see a new doctor beforehand, just to ascertain his or her skills and interest in supporting a person with an ongoing disability, and it is usually best if both parents can attend. Many doctors, like myself, appreciate the opportunity to understand parental concerns, particularly as their child with a disability gets older, and often we need to be educated about the family's concerns.

The NDIS is a significant opportunity to improve the life of many adolescents and adults with Down syndrome by helping with access to lifestyle-improving activities such as sport, exercise, transition to work, and community engagement. Families sometimes need help to access these issues through the NDIS but they will lead to significant ongoing improvements in health, longevity and quality of life.

Inclusion and understanding are the two most important factors in ongoing improvement in the lives of all people with disabilities. If I have learnt nothing else in the last 40 years, at least I have learnt that including people with disabilities in our way of life enriches us all.

Dr Michael Freeland MP is the Federal member for Macarthur for the Australian Labor Party and has been a paediatrician in Campbelltown for 32 years. Mike presently sits on a number of Parliamentary Committees, including the Standing Committee on Health, Aged Care and Sport and the Standing Committee on Social Policy and Legal Affairs. In addition to these, Mike is also member of a number of Labor Caucus Committees, including the Committee on Health Care.

