



COMMUNICATION

Communicating with Parents and Carers of a person with Down syndrome

Many people who have a disability will require the support of others (family members, friends or paid support workers) to access and participate in the medical /health consultation and follow through on their management recommendations.

To support the person with Down syndrome achieve the best health outcomes, there are number of considerations when communicating with parents and carers.

01

Use positive respectful language to prevent undue stress and humiliation.

02

Ensure equal access to medical investigations as you would another individual of the same age and gender without Down syndrome.

03

Use clear, accurate and reliable information that can be accessed by the non-medical or lay person.

04

When providing information include possibilities and strengths, not just deficits (what they will not achieve).

Positive vs. Negative Language



Person with a Down Syndrome	Downs/disabled/retarded
Person without a disability	Normal
Person who uses a wheelchair	Wheelchair bound
Person who is successful	Heroic / Brave

05

Take extra care to explain what is happening the HOW, WHEN and WHY to reduce added distress for parents/carers.

06

Listen to the parent's /carer's concerns and observations and include them in conversations.

07

Family members usually have an extensive knowledge of the person's history, personality and function. They are a valuable source of information.

08

Respect the contribution parents, family and carers make to the consultation through their areas of expertise. Do not assume medical knowledge.

09

Recommendation for management of the condition of the patient should be written down clearly to accurately communicate this to all those involved.

10

Regular review of the management recommendations is important to ensure that they are being achieved and prevent undetected incidents.

11

NOTE: Some individuals may not live with family and are in supported accommodation facilities. These individuals are supported by Disability Support Workers who have training in working with people with a disability, but usually do not have any health training. *Usually, the staff member accompanying someone to a medical appointment knows them well, but sometimes this is not the case. Support Staff will usually have a Health File with them containing the person's health history. If more information is required, ring the House Supervisor.*


Acknowledgement

DSWA gratefully acknowledges information gained from Centre for Developmental Disability Health Victoria in the development of this document.

A State-funded project - Department of Communities WA Advocacy Grant "My Voice My Health".

Disclaimer

The information in this resource is general in nature and does not constitute advice. Down Syndrome Western Australia will not be held responsible for any decisions made as a result of using this information. The contents of the resource do not constitute medical and legal advice and should not be relied on as such.

 (08) 6253 4752

 office@downsyndromewa.org.au

 www.downsyndromewa.org.au

 32 Burton St Cannington WA 6107

 PO Box 833 South Perth WA 6151



Down Syndrome
Western Australia