
Personal Health Record

for adults with
Down Syndrome

A project funded by the Queen's Trust of Australia

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Personal Health Record for Adults with Down Syndrome
was funded by a grant from the Queen's Trust of Australia.

Our thanks go to all of those adults with Down syndrome,
their families, carers and doctors who participated
in the preparation and trialling of the format.

Further copies of the **Personal Health Record**
can be obtained from the website of:

Down Syndrome NSW
PO Box 2356
(31 O'Connell Street)
North Parramatta NSW 1750

Phone: 02 9683 4333 Fax: 02 9683 4020

www.dsansw.org.au
(download PHR in .pdf)

email: info@dsansw.org.au

or contact the Down Syndrome Association in your State.

Sydney, 2000

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Personal Health Record for Adults with Down Syndrome
was fully funded by the Queen's Trust of Australia. Under the
terms of the Queen's Trust Grant it may be freely distributed
for use by adults with Down syndrome and their carers, but it
may not be sold on a commercial basis for profit.

- Contents -

SECTION FOR PARENTS AND CARERS 4

Notes for Carers

Some background information about people with Down syndrome

Practical Advice for the Care of Adults with Down Syndrome

PERSONAL INFORMATION 8

My Details

Medical History

Medical Alert Information: (Contacts/Hospital)

Skills Profile

SECTION FOR DOCTORS 19

Key Points about People with Down Syndrome

Abnormal Results

Medication Record

Medication Record

Weight Chart

Period Chart

Useful Contact Numbers

SECTION FOR PARENTS AND CARERS

This personal health record (PHR) has been developed to provide the foundation for good health care throughout the life of the person with Down syndrome. It is meant to support the independence of the adult with Down syndrome by offering a life long medical history that will not depend on the memory of the patient nor the presence of a family member or carer at every visit to a doctor or health professional. This PHR is the property of the person with Down syndrome and should remain with the person in the same way as a birth certificate, Medicare card, passport etc. The format of the record is to allow for easy photocopying so that a copy can be stored separately from the original if desired..

It is very important that a life history of the individual with Down syndrome, as well as the family medical history, are recorded in the PHR while you, who have that information, are available to record it! So please ensure that all the questions on pages 8 to 18 are filled in because this will provide the necessary information for good preventative medicine in the future.

Parents/carers are asked to assist the person with Down syndrome to fill in the relevant sections in this booklet and to encourage the use of this PHR for all visits to the doctor or other health care providers (e.g. dentists, therapists, psychologists). The function and use of the PHR should be carefully explained to the person with Down syndrome so that it will be taken to the doctor/ health professional at every visit. Where possible the person with Down syndrome can register a monthly weight (page 29) and become aware of the need for any regular check-ups that they might have. An appointment card file is provided in the front jacket for follow up appointments.

Notes for Carers

The success of this booklet in improving the health care of people with Down syndrome rests largely with you. The ability of the person to fill in the necessary charts will vary greatly, and whatever that ability, it is likely that you will have to assist to some degree. It would be of enormous benefit if the people in your care adopted the habit of registering their weight on the first day of every month (page 29) and menstrual details (page 30). It is hoped that the benefit of having such a record will far outweigh the difficulties that you might experience in recording this information. The booklet is to be taken to the doctor or other health professional at every visit so that the record can be updated thus allowing for continuity of care over the years.

Your efforts to support this step to improve the general health of people with Down syndrome is very much appreciated.

Some background information about people with Down syndrome

It is as impossible to generalise about adults with Down syndrome as it would be about any other adult group. Each individual is influenced differently by upbringing, and adult lifestyles vary enormously. However it is true to say that the major limitations for older adults with Down syndrome arise out of the low expectations for their future and the poor standard of educational and medical intervention during their childhood. Younger adults have largely benefited from early intervention programs, better health care and wider educational opportunities in an environment which is more accepting of disabilities. Thus the medical, social and educational backgrounds of the adult population with Down syndrome diverge widely.

One common important factor is the self esteem and emotional well being of the person with Down syndrome which is particularly vulnerable. Expressing personal hurts or difficulties, subtle slights and not so subtle slights is well nigh impossible for many people with Down syndrome where both the emotion experienced and the language of expression is complex. As a result, the person's self esteem may suffer with resulting changes in behaviour such as withdrawal and increased anxiety. Sometimes this can be remedied by careful listening, a show of support and love or a long term program to teach the skills that will enable the person to express their feelings. There is a section on feelings and self esteem in the personal development manual for women and girls with Down syndrome "Talk to Me" (published by the Down Syndrome Association of NSW) which would provide an excellent base for developing these skills.

Practical Advice for the Care of Adults with Down Syndrome

Skin

Dry scaly skin is a common problem which does respond to long term care. It is recommended that a dermatologist be consulted if the condition is causing discomfort.

- **Avoid** things that worsen dryness of the skin, for example:
 - Bathing or showering in very hot water – it is better to use lukewarm water
 - Soap, particularly scented soaps. Use a mild baby soap on the most soiled areas. If the skin is particularly dry, sorbolene cream is a good alternative to soap
 - Bubble baths
 - Dry environments such as heated rooms in winter or air conditioned rooms in summer
- Chlorine in swimming pools. This does not mean that swimming should be avoided. A shower after the swim, followed by application of Sorbolene cream with 10% glycerine will help to reduce the dryness.

- Use of oil in the bath can help to reduce dryness (e.g. QV™ or Alpha Keri™, available from chemists).
- A good habit to promote is the application of Sorbolene after the bath or shower every day.
- Evening Primrose Oil Capsules (1000 mg) are recommended by some members of the Down Syndrome Association as having greatly benefited their child's skin condition in the long term.
- Experience tells us that hypoallergenic sunscreen is essential because of a high prevalence of allergy to some chemicals commonly used in sunscreens. Brands which do not contain PABA which may cause allergic reactions, are recommended.
- Lips are particularly susceptible to cracking so that the daily use of a lip balm containing a sunscreen is useful.
- Any sign of skin infections should be treated promptly.
- Fungal skin infection in the crotch area can be easily and quickly resolved with anti fungal creams.

Dry itchy scalp and cradle cap are sometimes evident. An occasional overnight application of Sorbolene lotion or Olive oil will solve the problem.

Feet

Lots of easily treatable conditions can exist.

- Good foot support at all times is essential if the foot is not to collapse due to the poor muscle tone. Thongs are not recommended. A podiatrist will give advice on the best shoe support and may recommend orthotheses to prevent deterioration of the posture. It is a very useful area to pursue as the long term effects of poor foot support may well be chronic back pain, inability to walk any distance due to sore feet, and hip or knee dysplasia.
- Fungal infections of the feet are common. When present it is advisable to disinfect the bathroom to eradicate the fungus and to introduce an antifungal treatment. The whole household should be checked to avoid an ongoing problem. A useful habit to encourage is the careful drying of the feet after washing and perhaps the daily use of a mild antifungal powder.
- Weekly toe nail trimming is a good habit. If there is evidence of irritation due to toes rubbing together or corns forming, a trip to the podiatrist is called for.

Ears

The ear canal can become blocked by a build up of skin and wax. This can be avoided by using ear drops which dissolve wax. Such drops can be purchased over the counter at a Chemist. Any sign of reduced hearing should be checked by a doctor.

Neck

It is useful to know the signs and symptoms of subluxation of the spine which does occur infrequently in adults with Down syndrome either from neck injury or after a fever. Should any of the following symptoms appear it is important to consult a doctor as soon as possible.

- Stiffness and/or tenderness of the neck
- Head tilt
- Difficulty in walking
- Incontinence
- Spasticity of the lower limbs
- Persistent headache

Healthy lifestyle

Good nutrition and exercise are as important for people with Down Syndrome as they are for everyone in the community. It is suggested that the Australian Dietary Guidelines be followed and that regular exercise of at least 30 minutes be undertaken for 3-4 days a week. It is important that the person with Down Syndrome does activities which he or she finds enjoyable. These may be walking, riding a bike, swimming or dancing. Walking short distances instead of riding in a car, and using the stairs instead of the lift or escalators are also easy methods of keeping active.

Person

Place a photo of yourself here

My name is:

This photo was taken when I was aged:

PERSONAL INFORMATION

My Details

Name

Male / Female

Phone: _____

Age: _____ D.O.B. ____/____/____

Date this book started: _____

My interests and activities. Please tick those activities you do every week and indicate how many times per week. e.g. Swimming (4)

Social Club

Ten Pin Bowling

Gymnastics

Cooking

Gymnasium

Walking

Music

Cycling

Cooking

Dancing

Netball

TV

Sewing

Videos

Exercises

Movies

Aerobics

Swimming

Any other activities?

Are you still at school? Yes / No

Which School?

Are you a student at TAFE? Yes / No

What subjects are you studying?

Do you have a job? Yes / No

Where do you work?

Do you do voluntary work? Yes / No

What do you do?

Where do you live ?

- at home with your family? _____
- in a flat? _____ with other people? _____
- in a group home? _____
- with how many people? _____
- in a residential complex? _____
- in a boarding house/hostel? _____

Who do you like to spend time with?

Who do you like to talk to?

What makes you feel happy?

Are you a member of a Club? Which ones?

Medical History

Date _____

Respondent to questionnaire:

Relationship to person with DS:

All questions refer to the adult with Down syndrome

Name: _____

Date of birth ____/____/____ Male / Female

Medicare Number _____

Health care card number _____

Health Insurance Co. _____ Number _____

Medical Alert Information : (Contacts/Hospital)

Contact sensitivity:

Other health problems:

Family doctor (if applicable):

Family medical history

Please fill in the medical details of the immediate family - grandparents, parents, brothers and sisters.

Conditions in the family:

*Who has it?
- relationship to adult with DS*

Down syndrome _____

Other intellectual disability _____

Diabetes _____

High blood pressure _____

High cholesterol _____

Thyroid disease _____

Arthritis _____

Dementia or Alzheimer's disease _____

Heart disease _____

Seizures _____

Stroke _____

Cancer (state type of cancer) _____

Leukaemia _____

Depression (other mental illness) _____

Alcoholism _____

Obesity _____

Other _____

Family Deaths

To help understand possible grief that the person with Down syndrome may experience from the memory of family members or friends who have died could you please record deaths of immediate family or anyone especially close (with the family "pet" name if applicable). Please include the year in which they died.

Grandfathers: _____

Grandmothers: _____

Mother: _____

Father: _____

Brothers: _____

Sisters: _____

Others: _____

Skills Profile

A baseline of the abilities, skills and habits of the person with down syndrome is needed so that future carers, medical practitioners etc will have a yardstick for any changes in skills and attention to self care. Changes in functional abilities and behaviours can be indicative of many treatable conditions and this profile will provide a guideline for assessment of possible deterioration in skills. You may like to add specific skills or characteristic behaviours to the list to build up a more accurate picture of your son or daughter. Please date each version of this profile and leave all versions for the record.

Date Completed : _____

Self Care Skills : (Independently, with Help, N/A)

Toilets _____

Dresses _____

Chooses own clothes _____

Buys clothes _____

Launders clothes _____

Cooks/shops _____

Organises social life _____

Cleans room _____

Manages money _____

Any others? _____

Literacy level Reads for pleasure

Functional reading

Unable to read

Numeracy: Money skills
Functional maths
No skill

Personality: Outgoing Timid Overbearing
Cooperative Sunny Sullen
Determined Motivated Withdrawn
Friendly Caring Complacent
High self esteem Low self esteem

Communication Clear speech Unclear speech Stutter
Wide vocabulary Limited vocabulary
Single words Uses signs
Augmented communication only

Other Comments:

SECTION FOR DOCTORS

This Personal Health Record (PHR) has been developed to assist you in caring for this person with Down Syndrome who may not be known to you. This document can be easily photocopied for your records. By entering the outcome of your consultation in this PHR you contribute to long term continuity of care for this person. Please refer to the previous section for the patients medical history and other personal details.

Key Points about People with Down Syndrome

- Most adults with Down syndrome enjoy good health, but their quality of life can be dramatically affected by chronic treatable conditions.
- Adults with Down syndrome may experience high levels of pain with comparatively little complaint and may localise pain poorly. It is recommended that all reports of pain be thoroughly investigated.
- In some cases, a change in behaviour may indicate an underlying medical condition causing chronic discomfort or pain. Behavioural disturbances may also indicate anxiety states, sexual abuse, death in the family, reaction to change or side effects of medication.
- People with Down syndrome will often comprehend more than may be evident by their speech.
- Generally, adults with Down syndrome enjoy being addressed directly in an age appropriate manner. Active involvement in their own health care should be encouraged.

Useful references

Cohen, W. et al, *Healthcare Guidelines for Individuals with Down Syndrome, Revised 1999*, **Down Syndrome Quarterly**, Vol 4, No 3, September, 1999
Maintained and updated by the Down Syndrome Medical Interested Group, copies available from DSA NSW or from the World Wide Web:

<http://www.denison.edu/dsq/health99.shtml>

Management Guidelines: People with Developmental & Intellectual Disabilities

Lennox, N and Diggins, J (eds), *Therapeutic Guidelines (Australia), 1999*
Management guidelines for general health care, written and edited in Australia, for general practitioners. Includes syndrome-specific information, and chapters on communicating with people with disabilities, behavioural issues.

<http://www.tg.com.au/disabili.htm>

Medlen, J. *Weight Management in Down Syndrome*, **Disability Solutions**, Volume 2, Issue 5, January/February, 1998

Copies available from DSA NSW, or from the World Wide Web:

<http://www.disabilitysolutions.org/volume2-5.htm>

Conditions commonly associated with Down syndrome

(% of adult population with Down Syndrome)

Abuse

People with an intellectual disability are very vulnerable to sexual, physical and psychological abuse often as an ongoing constant in their life. Inability to communicate effectively, lack of specific vocabulary and fear often allow the abuse to continue. The end result may be the development of a psychiatric disorder or behaviour problem.

Ageing

Be aware that accelerated ageing may affect functional abilities of people with Down Syndrome more so than Alzheimer disease.

Atlanto-axial instability

14% (approximately 1% will have symptoms)

Symptoms of subluxation: Incontinence, spasticity of lower limbs, stiff neck, headache, difficulty in walking. May occur after viral infection or because of neck injury.

Alzheimer's disease

Reversible dementia must also be **8% in under 50, 75% in over 60, seizures occur in 85% of dementia population** excluded, eg: . hypothyroidism, depression, folate/ B12 deficiency, bereavement, drug induced dementia, and uncontrolled epilepsy.

Cardiac anomalies

40% congenital heart disease

This group may need ongoing monitoring in adult life.

50% mitral valve prolapse

May lead to complications such as infective endocarditis and cerebral emboli. When present the use of antibiotic prophylaxis is recommended prior to dental or medical surgery.

Coeliac disease

7 - 16%.

May not have been diagnosed in childhood.

Due to increased incidence of autoimmune disorders.

Constipation - increased

Poor diet, decreased exercise and low muscle tone contribute.

Deafness - hearing loss in up to 78 %

Poor hearing often exacerbated by compacted wax and skin.
Early onset presbycusis.
Regular hearing assessment recommended (3-5 yearly by audiologist). Hearing loss may begin during adolescence which if undetected may lead to behavioural symptoms.

Diabetes - increased incidence at all ages

Late onset often secondary to obesity.

Epilepsy - increased incidence - ten times more than general population

Careful drug monitoring is called for in these patients.
Tonic-clonic seizures most common - responds well to therapy.

Eye disorders

Keratoconus up to 15%; Cataracts 25% - 85%; refractive errors common

Regular visual assessment recommended (3-5 yearly by ophthalmologist)

Gingivitis

Common

Helicobacter pylori

Common in people who live in institutions.

Hepatitis B

Carrier status as high as 33% in institutionalised population due to the decreased immune response to viral infection.
Immunisation is recommended.

Immune function

Mildly reduced antibody and cell mediated immune function.

Low blood pressure

Very common

Causes dizziness and fainting especially on rising in the morning.

Mental health problems, especially depression

More common in people with Down Syndrome than in the general community.

- Depression can present with lethargy, loss of skills, confusion, and lack of interest in usual activities.
- It can mimic the onset of dementia or hypothyroidism.
- People with Down Syndrome may not always be able to express feelings of sadness, and it is important consider grief and loss issues.

Musculoskeletal Disorders

Instability of the hip joint, patellar instability, pes planus and metatarsus primus varus.

Obesity

Very common

Due to lowered metabolic rate, dietary habits and sedentary lifestyle.

Osteoarthritis

Occurs due to poor posture / low muscle tone throughout life.

Osteoporosis

More common in all people with Down Syndrome. Made worse after menopause. Bone mineral density studies worth doing in those at risk of further fractures.

Periodontal Disease

50%

Due to the lower immunity.

Skin Problems- very common

Dry skin, eczema, skin infections, acne, alopecia areata.

Sleep Apnoea

Obstructive airway disease has been recognised as a significant problem.

Thyroid Dysfunction

25-50% -predominantly hypothyroidism

Can present insidiously with lethargy, depression, slow functional deterioration and memory deficits, as well as the usual physical signs . Therefore, a high index of suspicion is necessary and an annual assessment of thyroid function recommended.

Screening Test Checklist

Tick box as test performed and note with an * any abnormal results. Note details of result with date and action taken in chart on page 18

	2005	2006	2007	2008	2009	2010	2011
BP							
Weight							
Hearing check							
Vision check							
Breast /testes check							
Prostate/PR check							
Menstrual cycle							
Diet review							
Smoking/alcohol							
Dental review							
Blood Tests							
Thyroid function tests							
Blood glucose level							
Fasting lipids							
PSA							
Hep B studies							
Other							
Immunisations							
Influenza							
Pneumococcal vaccine							
Hepatitis A							
Hepatitis B							
Diphtheria							
Tetanus							
Mammogram							
Pap Smear							

Medication Record

DOCTOR - PLEASE FILL IN A CURRENT MEDICATION BOX AND
CROSS OUT THE PREVIOUS BOX.

DATE REVIEWED: ____/____/____

Drug (1) _____
Drug (2) _____
Drug (3) _____
Drug (4) _____

DATE REVIEWED: ____/____/____

Drug (1) _____
Drug (2) _____
Drug (3) _____
Drug (4) _____

DATE REVIEWED: ____/____/____

Drug (1) _____
Drug (2) _____
Drug (3) _____
Drug (4) _____

DATE REVIEWED: ____/____/____

Drug (1) _____
Drug (2) _____
Drug (3) _____
Drug (4) _____

DATE REVIEWED: ____/____/____

Drug (1) _____
Drug (2) _____
Drug (3) _____
Drug (4) _____

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DOCTOR - PLEASE FILL IN A CURRENT MEDICATION BOX AND CROSS OUT THE PREVIOUS BOX.

DATE REVIEWED: ____/____/____

Drug (1) _____
Drug (2) _____
Drug (3) _____
Drug (4) _____

DATE REVIEWED: ____/____/____

Drug (1) _____
Drug (2) _____
Drug (3) _____
Drug (4) _____

DATE REVIEWED: ____/____/____

Drug (1) _____
Drug (2) _____
Drug (3) _____
Drug (4) _____

DATE REVIEWED: ____/____/____

Drug (1) _____
Drug (2) _____
Drug (3) _____
Drug (4) _____

DATE REVIEWED: ____/____/____

Drug (1) _____
Drug (2) _____
Drug (3) _____
Drug (4) _____

Weight Chart

Write down your weight (in kilograms) on the first day of each month

	2005	2006	2007	2008	2009	2010
Jan						
Feb						
Mar						
Apr						
May						
Jun						
Jul						
Aug						
Sep						
Oct						
Nov						
Dec						

Period Chart

Put a letter in the box each day that you have your period

- N - put N in the box if your period is normal
- P - put P in the box if you have pain
- C - put C in the box if you have clots
- F - put F in the box for flooding

Days	J	F	M	A	M	J	J	A	S	O	N	D
1.												
2.												
3.												
4.												
5.												
6.												
7.												
8.												
9.												
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