

Annual health checks - learning disability

For teenagers and adults who have Down's syndrome

January 2024

Checklist for GPs

Ideally the following things should be included as part of a comprehensive and thorough annual health check.

What to expect from an annual health check

All GP practices should send/give a pre-health check Questionnaire. This will help prepare the patient and carer for the health check appointment, reduce anxiety, and improve the effectiveness of the appointment.

How long will the health check take

The appointment should be carried across two separate 30 minute appointments. One with the practice nurse followed with an appointment with the patient's usual doctor.

Routine blood tests

Try and arrange any routine blood tests at least 1 week before the health check.

Some patients may find blood tests difficult and will require extra explanation and support. The blood should be screened for the following:

- Full blood count (FBC)
- Urea and electrolytes (kidney function)
- Liver function tests
- Thyroid function tests
- Random glucose and glycosylated haemoglobin (HbA1c)
- Lithium and anti-epilepsy drug (AED) levels if relevant - check level before morning dose ('trough level')
- Calcium and vitamin D levels
- Consider C-reactive protein, plasma viscosity or ESR
- FSH in women who have not had a period for 6 months
- Consider prostate specific antigen in men over 50 years

Annual health checks for anyone with a learning disability should follow national guidance. When carrying out an annual health check for a person who has Down's syndrome, particular attention should be paid to the following issues:

Monitor for any loss of independence in living skills, behavioural changes and/or mental health issues.

Audio visual - ears and eyes

Ophthalmic issues such as cataract, glaucoma, keratoconus and refractive errors need to be checked:

- Full assessment by optician/optometrist at least every 2 years
- If examination difficult, refer to specialist optician or ophthalmologist for assessment

Audiological issues - hearing impairment and deafness Otoscopy (gentle examination as short ext. auditory canals)

Refer for audiological assessment if any concerns regarding possible hearing loss. A audiology assessment should also be carried out at transition from child to adult services and every two years thereafter.

Well over 50% of people who have Down's syndrome have significant hearing impairment, which can range from mild to profound. Sensorineural and/ or conductive loss may be present at any age. If undetected it is likely to be a significant cause of preventable secondary disability. The main cause of conductive loss is persistent OME, glue ear.

Dental

- Annual Dental Review as periodontal disease is common
- Look for signs of oesophageal reflux
- Poor oral health is linked to an increased risk of aspiration pneumonia and should be actively managed

Cardiovascular examination for adult

- Auscultation – particularly if imminent dental procedure
- A single ECHO should be performed in adult life
- Adults with a pre-existing structural abnormality should be informed of current prophylactic antibiotic protocols
- Blood pressure and heart rate

Coeliac disease

Screen clinically by history and examination annually.

Testing (Coeliac antibody test) in those with suspicious symptoms or signs, including:

- Disordered bowel function tending to diarrhoea or to new onset constipation
- Abdominal distension
- General unhappiness and misery
- Arthritis
- Rash suggesting dermatitis herpetiformis
- Test all those with existing thyroid disease, diabetes or anaemia

Endocrine system

There is an increased prevalence of hypothyroidism at all ages, rising with age with a small increase in hyperthyroidism.

- Thyroid function blood tests (TFTs), including thyroid antibodies every year (or more often if clinically indicated).
- Perform TFTs more often if accelerated weight gain, generally unwell, possible diagnosis of depression or dementia
- Type I diabetes is also relatively more common (2%) and should be checked for

Immunisation

Due to congenital heart disease and reduced immunity most teenagers and adults are eligible for Influenza and Pneumococcal vaccination. All teenagers (12 plus years) and adults should be offered COVID vaccination.

Musculoskeletal

Atlanto Axial Instability (AAI) - More commonly diagnosed in childhood. The majority of cases remain stable radiologically and do not develop clinical complications.

Routine cervical -spine X-ray not recommended.

It can present as acute or chronic cord compression:

- Neck pain
- Reduced range of neck movement, torticollis
- Unsteadiness

Assessment for spinal stenosis associated with AAI, with neurological assessment.

Assess/review:

- Joints
- Mobility
- Physical activity
- Postural care (if immobile)
- Feet and need for orthotic support

Consider the possibility of arthritis, including Down syndrome arthropathy (more commonly found in children), and osteoporosis.

Psychiatric/psychological

- Alzheimer's type dementia (clinical onset uncommon before 40 years)
- Check that people with a diagnosis of Alzheimer's disease have had depression, hypothyroidism, visual impairment, deafness and social/environmental changes excluded in the first instance
- Symptoms of dementia: decline in function, memory loss, ataxia, seizures or urinary and/or faecal incontinence
- Psychological problems often present as deterioration in self-help skills or behaviour change. Need to exclude depression, thyroid disorder, and hearing impairment
- Depression is common in older adults, often as a result of bereavement and/or changes in living situation
- Behaviours of distress (previously called challenging behaviour, or behaviour that challenges) is often incorrectly treated with psychotropic medications, with resultant issues related to side effects including over-sedation, confusion and constipation. Consider behaviours of distress as a form of communication. Causes of distress need to be identified, including physical health causes, mental health causes and social or environmental causes. Medication should only be used when absolutely necessary

Respiratory

Examine nose, oral cavity, and lungs:

- Blocked nasal passages
- Lower airway disease

Ask about sleep apnoea which may be due to a hypoplastic pharynx or nasal congestion.

Women

Review:

- Menstrual periods
- Access to cervical and breast screening –where appropriate provide advice and education re breast examination.

Check for hot flushes and menopausal symptoms in women over 40 as they have an earlier onset of menopause compared to women in the general population at an average of 44 years of age. The symptoms of menopause may look similar to those of dementia. Women who have Down's syndrome reach the menopause approximately 6 years earlier than the general population and are more susceptible to osteoporosis particularly if they are inactive.

Sleep

Sleep disturbance is common in people who have Down's syndrome and may occur for multiple reasons including Obstructive Sleep Apnoea (OSA).

Diet and nutrition

The following should be considered and checked as appropriate:

- Weight, height
- Feeding (including physical difficulties, swallowing, aspiration risk)
- Diet and nutrition
- Fluid intake
- Smoking
- Alcohol
- Substance misuse

Sexual health

The following should be considered and checked as appropriate:

- Sexual health and infection risk
- Examination of testicles (testicular cancer is more common in people who have Down's syndrome)
- Education and advice re testicular self-examination
- Contraception
- Sexual abuse and/or exploitation

Continence

The following should be considered and checked as appropriate:

- Urinary continence

- Constipation and soiling - People who have Down's syndrome are at high risk of constipation, which can become very severe, leading to faecal impaction, perforation, sepsis and death
- Constipation must be actively managed and complications must be considered with changes in symptoms or behaviour

Skin

The following should be considered and checked as appropriate:

- Eczema
- Dry skin
- Fungal skin or nail infections
- Folliculitis

Additional considerations

- Review communication needs
- Review medication
- Review health and wellbeing of carer(s) if appropriate
- Review any areas of pain or discomfort
- Consider safeguarding issues if relevant
- Consider end of life care planning, where appropriate

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