



**Down's Syndrome
Association**

A Registered Charity No. 1061474

Health Series



Respiratory infections



The
Down Syndrome
Medical Interest
Group

A Down's Syndrome Association publication

Our resources and Information Team are here to help

Please see our website for up-to-date information: www.downs-syndrome.org.uk

If you would like to talk about any of the issues raised in this resource, then please get in touch with our helpline by calling 0333 1212 300 or by emailing us on

info@downs-syndrome.org.uk.

Helpline Monday - Friday 10am-4pm | Telephone: 0333 1212 300

The Down's Syndrome Medical Interest Group (DSMIG)

This resource has been produced in collaboration with the Down's Syndrome Medical Interest Group (DSMIG).

DSMIG was launched in 1996 and is a registered charity. It is a network of healthcare professionals – mainly doctors – from the UK and Republic of Ireland whose aim is to share and disseminate information about the medical aspects of Down syndrome and to promote interest in the specialist management of the syndrome.

Both adults and children with Down's syndrome are more likely than others to develop infections of the respiratory tract and to require admission to hospital as a result of these infections.

Among young children with Down's syndrome, respiratory tract infections are responsible for approximately one third of all hospitalisations and should always be taken seriously, as these are the second leading cause of death in the under 18s. There are several ways we can help prevent respiratory tract infections and there is ongoing research to improve management of these infections.

What are Respiratory Tract Infections (RTIs)?

The respiratory tract can be divided into two parts (see fig 1); upper and lower. The upper respiratory tract consists of the nasal cavity, pharynx (the part of the throat that is behind the mouth and nasal cavity) and larynx (the "voice-box"). The lower respiratory tract includes the trachea ("windpipe"), bronchi (branches off the windpipe) and alveoli (small air sacs) which allow air to reach the lungs.

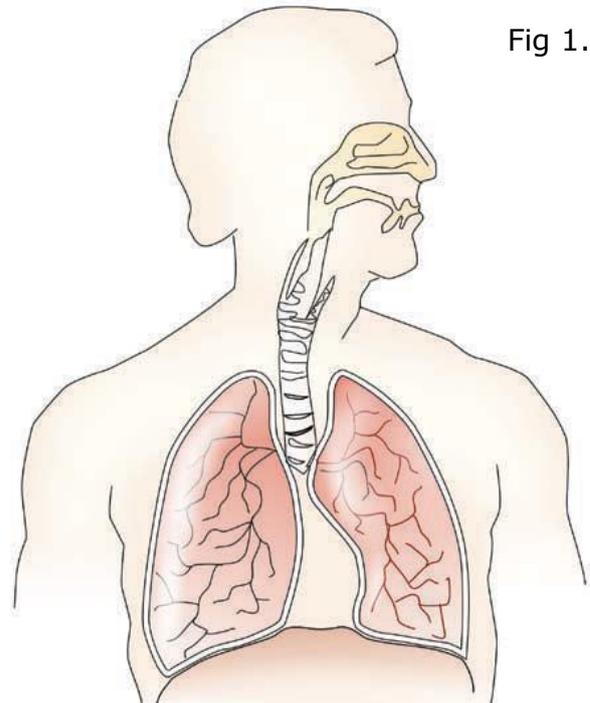
Infections of the respiratory tract can be caused by lots of different microbes. Most commonly these infections are caused by viruses (e.g. Respiratory syncytial virus) or bacteria (e.g. *Streptococcus pneumoniae*). Rarely, they can be caused by fungi (e.g. *Candida albicans*).

Infections of the upper respiratory tracts are very common. For example, most healthy children can be expected to have up to 6 episodes of infection per year. These may include ear infections, tonsillitis (infection of the tonsils), sinusitis (infection of the nasal cavities) or commonly a combination of all of these.

Infections of the lower respiratory tract are also common, but the seriousness of infection ranges from mild to severe. With mild respiratory tract infections individuals may have a cough or increased production of mucous (phlegm). In more severe cases, they can have difficulty breathing, wheezing ("tight chest") and low oxygen levels.

Often we can manage the symptoms of a respiratory tract infection at home with rest, pain relief and adequate fluid intake. Sometimes, additional support from the pharmacy or health professionals is required. This may include pain-relief, rehydration, decongestants, bronchodilators (e.g. inhalers and nebulisers) or antibiotics. Unfortunately, antibiotics only work on some bacteria and do not work on viruses at all. Antibiotics are very useful when they are indicated, but using antibiotics when they are not needed can cause side effects such as diarrhoea and thrush, as well as increase the risk of developing infections which are difficult to treat (e.g. MRSA, *Clostridium difficile*).

Unfortunately, adults and children with Down's syndrome are more likely to develop infections of the respiratory tract and to have symptoms which require treatment with antibiotics, admission to hospital and a longer stay in hospital.



Why are RTIs one of the common causes for hospital admission in individuals with Down's syndrome?

The upper airway in individuals with Down's syndrome is narrower and there are also some structural differences in the lower respiratory tract and within the lung tissues. These differences combined with low muscle tone and a higher prevalence of obesity may predispose them to developing infections.

The immune system in individuals with Down's syndrome is also thought to be slightly different. Research has demonstrated that there are lower levels of some lymphocytes (white blood cells) and antibodies (infection fighting molecules) in the blood of those with Down's syndrome. This may make it harder for them to both fight off and develop immunity to infection.

Compared to the general population, individuals with Down's syndrome are also more likely to have other health problems, such as congenital heart disease, sleep disordered breathing (sleep apnoea), gastro-oesophageal reflux and diabetes. These conditions can make them more likely to develop infections and make it more difficult to fight off infections.

Can you reduce the likelihood of RTIs developing?

At present it is not possible to prevent infections of the respiratory tract entirely but there are things we can do to reduce the likelihood and severity of infection.

Measures to reduce the likelihood and severity of respiratory tract infections:

- **Vaccinations**
- **Basic hygiene / infection control**
- **Healthy environments**
- **Maintaining good general health**
- **Avoiding unwell contacts**
- **Seeking help for unusual/persistent symptoms**

Vaccinations

Vaccines are one of the most effective ways we can prevent ourselves from developing serious infections.

Influenza Vaccine

The influenza vaccine aims to reduce the likelihood of developing flu. This vaccine is now routinely given to all children aged 2 to 6 years, however it should be considered in all individuals with Down's syndrome, young and old, after the age of 6 months. The vaccine has to be given every year, usually from October, as the influenza virus changes

over time. For children, the vaccine is usually given as a nasal spray and for adults an injection will be offered.

Pneumococcal (PCV) Vaccine

The pneumococcal vaccine aims to reduce infections caused by *Streptococcus Pneumonia*, a common bacteria that can cause infections of the respiratory tract. The pneumococcal vaccine is part of the normal vaccination schedule in the UK (2 months, 4 months and 1 year). However, an additional vaccine (Pneumovax II) should be considered for all individuals with Down's syndrome over the age of 2 years.

Respiratory Syncytial Virus (RSV)

RSV is a virus which commonly causes respiratory tract infections in the under 2s during the winter months. Unfortunately, there is no vaccine available to prevent RSV, but in high risk cases (e.g. congenital heart disease, the immunocompromised, neuromuscular and respiratory disorders) antibodies can be given to improve immunity (i.e. Palivizumab). Some research has shown that treatment with Palivizumab reduces the number of RSV related hospitalisations, but work is still being done in this area.

Basic hygiene / infection control

Microbes are all around us in our natural environment. There are many ways in which we might encounter microbes that cause infections; for example, coming into contact with others who are unwell, exposure to tiny droplets in the air, on surfaces or even in the food and drink we consume. While it would be impossible to avoid contact with any bacteria or viruses it is advisable to maintain basic hygiene and infection control to reduce the chances of infection. This may include hand washing after contact with others who are unwell or who show signs of respiratory tract infections, avoiding the sharing of personal items (used cutlery, cups, etc.) and avoiding putting hands or other unclean objects into the mouth.

Avoiding unwell contacts

It is not necessary for adults or children with Down's syndrome to actively avoid contact with others. Social contact is extremely important for our mental and social wellbeing, However, it would be sensible to avoid contact with those who are very unwell (e.g. patients in hospital) or who have infections which are known to be highly contagious.

Healthy environments

Damp, mouldy or cold housing is known to exacerbate existing respiratory conditions such as asthma. High levels of air pollution, for example in some cities or near busy roads, may also contribute to breathing problems. Maintaining a home environment which is warm (18-21C) and dry, and ideally avoiding areas of excessive air pollution, may help reduce the severity of respiratory symptoms.

Maintaining good general health

Maintaining good general health is vital to support our body in fighting infection. This includes regular exercise (recommended at least 1 hour of moderate or vigorous exercise per day for children and at least 20mins per day for adults), having a balanced and varied diet and avoiding behaviours which are known to be harmful (e.g. smoking, excessive alcohol). Smoking or passive exposure to smoke is known to predispose to respiratory infections and increase the severity of symptoms.

Seeking help for unusual / persistent symptoms

As individuals with Down's syndrome are at a higher risk of developing respiratory tract infections and of needing treatment and/or hospitalisation, it is recommended that they should have a lower threshold for seeking a medical opinion, so seek out medical advice at an early opportunity, even if this is for reassurance. You should always seek medical advice if your child (or adult) is experiencing symptoms which are unusual or persistent. For example, a fever lasting more than five days, cough lasting more than 6 weeks or night sweats and unexpected weight loss.

Annual health checks for people with Down's syndrome (aged 14 years plus)

In the past people with learning disabilities have not had equal access to healthcare compared to the general population. This, amongst other reasons, has given rise to poorer mental and physical health and a lower life expectancy for people with learning disabilities. Free annual health checks for adults with learning disabilities, with their GP, were introduced in 2008 as a way to improve people's quality of life.

The annual health check for people with learning disabilities is a Directed Enhanced Service (DES). This is a special service or activity provided by GP practices that has been negotiated nationally. Practices can choose whether or not to provide this service. The Learning Disability DES was introduced to improve healthcare and provide annual health checks for adults on the local authority learning disability register. To participate in this DES, staff from the GP practice need to attend a multi-professional education session run by their local Trust. The GP practice is then paid a sum of money for every annual health check undertaken.

Who can have one?

Annual health checks have been extended to include anyone with learning disabilities aged 14 years or above. So anyone with Down's syndrome aged 14 years or over can have an annual health check.

The benefits of annual health checks

- additional support to get the right healthcare
- increased chance of detecting unmet, unrecognised and potentially treatable health conditions

- action can be taken to address these health needs.

How to get an annual health check

- The GP may get in touch with the person with Down's syndrome to offer an annual health check but this doesn't always happen.
- A person with Down's syndrome and/or a supporter can ask their GP for an annual health check. You do not need to be known to social services to ask for an annual health check.

Not all GPs do annual health checks for people with learning disabilities but they should be able to provide details of other GPs in your area who offer this service.

What happens next?

- The GP practice may send out a pre-check questionnaire to be filled out before the annual health check takes place.
- The GP may arrange for the person with Down's syndrome to have a routine blood test a week or so before the annual health check.

Who attends the annual health check?

If the person with Down's syndrome (age 16 years or over) has capacity and gives their consent, a parent or supporter can attend the health check as well.

How long should an annual health check be?

Guidance from the Royal College of GPs suggests half an hour with your GP and half an hour with the Practice nurse.

What areas of health should be looked at as part of the annual health check?

We have produced a check list for GPs which contains information about what should be included as part of a comprehensive and thorough annual health check. This includes a list of checks that everyone with a learning disability should undergo as part of an annual health check and a list of checks specific to people with Down's syndrome. You can find the health check list at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

What happens after the annual health check?

Your GP should tell you what they and the nurse have found during the annual health check. You should have a chance to ask any questions you have. Your GP may refer you to specialist services for further tests as appropriate. Your GP should use what they have found during your annual health check to produce a health action plan. This should set out the key actions agreed with you and (where applicable) your parent or carer during the annual health check. Your GP has to do this as part of the annual health check service.

Information about health issues for GPs

There is information at our website for GPs about some of the more common health conditions seen in people with Down's syndrome. You will find this information at the 'annual health checks' section of our website under 'families and carers and 'health and wellbeing'.

GPs learning disability register

People with learning disabilities experience poorer health compared to the rest of the population, but some ill health is preventable. Over one million people in the UK have a learning disability but only 200,000 are on their GPs learning disability register.

We know that people with a learning disability often have difficulties accessing health services and face inequalities in the service they receive. The Government is asking parents and supporters to speak to their GP and ensure their sons/daughters or the people whom they support are registered. It is hoped that this drive will ensure better and more person centered health care for people with learning disabilities.

The Learning Disability Register is a record of people with a learning disability who are registered with each GP practice. The Register is sometimes referred to as the Quality Outcomes Framework (QOF) Register.

If you are not sure you are on the Register, you can ask the receptionist at your GP Practice to check for you.

The doctor may have made a note on the record that a person has Down's syndrome but this does not automatically mean they have been put on the Register. When you speak to the GP about being registered, the needs and support of the person in health settings can be discussed. This information can be entered on the person's Summary Care Record (SCR) so that all health professionals at the practice know about their needs and how best to support them.

If the person is over 16 years of age or older, they must give their consent (see section in this resource about the Mental Capacity Act 2005):

- for information about their support needs to be added to their SCR
- to which information can be shared and with whom

It's never too early (or late) to join your GP's Learning Disability Register; you can join at any age. It's a good idea for children with a learning disability to join the learning disability register at an early age. This means adjustments and support can be put in place before they reach adult services.

Reasonable adjustments in health care

You may have heard of the term 'reasonable adjustments' and wondered what it meant. Since the Disability Discrimination Act (1995) and the Equality Act (2010) (this does not apply to Northern Ireland) public services are required by law to make reasonable adjustments to help remove barriers faced by people with disabilities when trying to use a service. The duty under the Equality Act to make reasonable adjustments applies if you are placed at a substantial disadvantage because of your disability compared to people without a disability or who don't have the same disability as you.

So for people with physical disabilities reasonable adjustments may include changes to the environment like ramps for the ease of wheelchair users. For people with learning disabilities 'reasonable adjustments' may include easy read information, longer appointments, clearer signs at the practice, help to make decisions, changes to policies, procedures and staff training.

If a patient with Down's syndrome is NOT on their GP's Learning Disability Register then reasonable adjustments to care for that person cannot be anticipated and made.

Authors:

Dr Caoimhe McKenna, Dr Logan Manikam, Dr Elizabeth Marder, Prof Monica Lakhanpaul

The information in this resource is taken from an article published in DSA Journal 134 Autumn/Winter 2016

Publication date 2018

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

Contact us

Down's Syndrome Association

National Office

Langdon Down Centre,
2a Langdon Park, Teddington,
Middlesex, TW11 9PS

t. 0333 1212 300

f. 020 8614 5127

e. info@downs-syndrome.org.uk

w. www.downs-syndrome.org.uk

Wales

t. 0333 1212 300

e. wales@downs-syndrome.org.uk

Northern Ireland

Unit 2, Marlborough House,
348 Lisburn Road,
Belfast BT9 6GH

t. 02890 665260

f. 02890 667674

e. enquiriesni@downs-syndrome.org.uk



WorkFit® is a registered trade mark of the Down's Syndrome Association. Photographs courtesy of Cheshire Down's Syndrome Support Group.



www.dsactive.org



www.dsworkfit.org.uk



www.langdondownmuseum.org.uk



www.langdondowncentre.org.uk



© Down's Syndrome Association 2018