RSV - Why parents of all infants should be aware of Respiratory Syncytial Virus

EFCNI european foundation for the care of newborn infants

Dear Parents,

Congratulations on the birth of your child! Your baby's health is now one of your top priorities, and you have probably been confronted with a lot of information and advice regarding a child's health and well-being that parents are supposed to take into account. This can be overwhelming at times, especially since there is so much to consider.

Breastfeeding, for instance, is always – and very rightly so - mentioned as an important measure to support your baby's healthy development and immune system. Yet breastmilk alone cannot protect a baby's immune system from all sorts of diseases, and a baby's first infection and fever can cause a lot of concern. Therefore, it is vital for parents to be informed about potential risks and effective preventive measures. This is why we created a booklet that provides specific and understandable information on an important topic: Respiratory Syncytial Virus (otherwise known as RSV) is the most common cause of bronchiolitis and pneumonia in infants. In this booklet, you will find what you as parents should know about an RSV infection to help you take the right measures for your baby's health.

RSV is a contagious virus that is very common in infants. In the majority of cases, it will not cause severe disease. However, RSV is the leading cause of hospitalisation in infants, and although preterm and late preterm babies are among the high-risk populations, even in term newborns it is not possible to predict which babies will develop severe RSV disease with potentially long-term consequences such as recurrent wheezing in the first years of life. Many parents have actually never heard of RSV. Since almost every child will have RSV by the time they turn two, it is good to be aware of this common respiratory virus.

Another reason to stay alert are observations made during the COVID-19 pandemic. After a short decline in RSV circulation, likely due tothe COVID-19 safety and hygiene measures implemented in many places between 2020 and 2021, RSV is on the rise again worldwide. It has re-emerged in high numbers, and after some disruption following the COVID-19 pandemic, returned to the usual seasonality in most countries, which is typically the colder autumn and winter months in temperate climates.

Thus, this booklet shall serve as a source of information so you will understand RSV, learn which steps will be helpful to protect your baby (and yourself) from an RSV infection and what to do if your child may have caught the virus. You may want to share this booklet with your partner, family members, and close friends, so they are better aware of the potential risks posed by RSV and understand how important their help and support is to prevent the virus from spreading.

For a long time, there was no protection against RSV infection other than preventive hygiene measures and passive immunoprophylaxis for infants with certain underlying conditions such as prematurity, congenital heart and chronic lung disease. However, thanks to decades of research, new universal preventive solutions against RSV are gradually becoming available, which we will introduce in the course of this booklet.

We are particularly pleased that we have been able to work with renowned international experts in the field of neonatology and paediatrics, RSV and infectious diseases for this booklet to pass on valuable first-hand advice to you. In addition, you will also learn about the personal experiences of parents whose child was affected by RSV.

We would like to take this opportunity to thank our expert panel for their support and cooperation. Also, we would like to thank Sanofi for funding the production of this booklet.

We hope you will find a lot of valuable tips when reading this!

Silke Mader
Chairwoman of the Executive Board
and co-founder of EFCNI

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Have you heard of RSV?

Respiratory Syncytial Virus, in short RSV, is a common and very widespread virus that causes inflammation and diseases of the airways, such as rhinitis, bronchiolitis or pneumonia. Since it is so easy to catch, most children (about 90%) have contracted RSV by the time they turn two. Very often, an RSV infection will be similar to a cold with a runny nose or a mild fever. Yet, for babies younger than one year, RSV is of particular importance. If babies catch RSV in their first year of life, it can lead to problems in the bronchial tubes and lungs - the so-called lower airways – in about 10% of infants. The inflammation it creates in the bronchial tubes leads to swelling and narrowing of the inner lining of the tubes, which can make air flow in and out of the lungs difficult. As a result, RSV is the most frequent cause of pneumonia and bronchiolitis in infants.[1] In rare cases, these RSV infections can be severe, even life-threatening.

RSV infections are typically seasonal, occurring during the colder autumn and winter months. In temperate climates, the typical duration of RSV season is approximately five months, whereas in tropical climates, the season may last much longer. It should also be noted that the seasonality of RSV was erratic during COVID-19 and after the measures were lifted; however, the seasonality is expected to return to normal in the next seasons.

It is also important to note, that both adults and children can contract RSV more than once. Unlike measles or other childhood diseases, once you have had an RSV infection, you do not become immune to the disease. However, chances are low of getting a second severe RSV infection in the same season, and re-infections are in general milder in course.[2]

Facts about RSV

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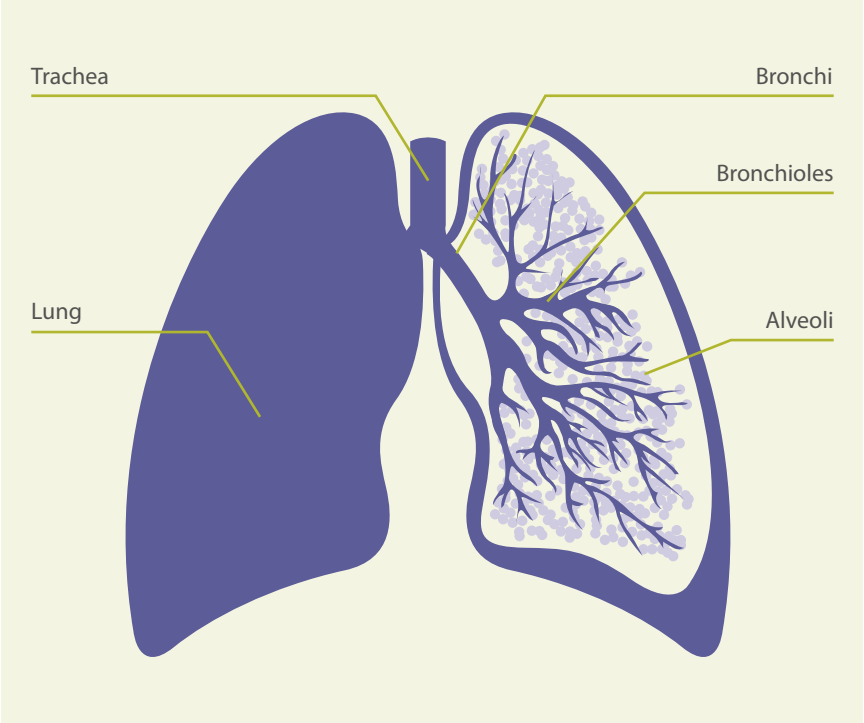
If RSV is so common in babies and toddlers and similar to a cold, why should parents be especially aware of this disease? The answer is that the potential complications of RSV infections can be very severe. In rare cases, RSV can be life-threatening for young babies and may even lead to admission to intensive care , and it is difficult to predict which infants will develop severe disease. Now, one could argue that this applies to the flu as well, and that is true. However, RSV causes emergency department visits and hospitalisations 16 times more often during infancy than influenza. This makes RSV one of the most common causes of infant mortality worldwide - especially in low- and middle-income countries.[3] Early life RSV infection has also been linked to subsequent childhood recurrent wheeze and asthma.[4] Even after the RSV infection has been resolved, some children continue to suffer long-term consequences to their respiratory system requiring subsequent doctor visits. Up to half of the children hospitalised for RSV infection may develop recurrent episodes of wheeze.[5]

2.1. How RSV affects the respiratory system

The respiratory system consists of the organs and other parts of our body involved in breathing. There is a distinction drawn between the upper and the lower airways, and the small and the large airways. The upper airways include the nose and the nasal passages. The lower airways contain the trachea, the bronchi and bronchioles, and the alveoli, which make up the lungs. The small airways can be described as the very delicate and fine extensions of the lower airways. The largest airway is the trachea – the windpipe.



Each time we breathe in, air moves through our airways and the route that air takes into the lungs can be pictured in a tree-like pattern: the large windpipe is the trunk, and the tubes through which the air flows are the branches. Just like the branches of a tree, they get smaller and thinner, until they are as thin as the veins in a leaf. If these tiny veins become blocked, the leaf can no longer be properly supplied with nutrients and the tree becomes ill. Now, if the smallest tubes in the airways leading to the alveoli are inflamed, they become blocked and are unable to transport enough air and consequently oxygen. This is the case when RSV causes bronchiolitis. Bronchiolitis is an inflammation of the small airways – not to be confused with bronchitis which affects the larger airways. The mucus gathers in these airways, which makes it difficult for air to flow freely in and out of the lungs. Breathing becomes harder and sometimes a whistling ("wheezing") sound can be heard. In cases where the lung tissue itself gets infected by RSV it is called a lung infection or pneumonia.

2.2. RSV and hospitalisation

RSV infection is a viral disease that has no specific medical treatment. The current disease management is to provide supportive care such as supplemental oxygen, intravenous fluids, and mechanical ventilation, if needed. In most cases, parents can care for their baby at home if they have contracted RSV and the symptoms are mild. However, if the infection is of a severe kind, hospitalisation may be necessary. This is the case in about 1 in 56 healthy and term born infants, especially in their first RSV season.[6] Hospitalisation rates are higher in younger babies, especially if infected in the first months of life. Preterm born babies, and those infants with underlying conditions like chronic lung disease of prematurity, congenital heart diseases, neuromuscular diseases, immune deficiencies or Down syndrome bear the highest risk of hospital admission; their risk of severe RSV infection is increased up to tenfold. Yet, looking at the absolute numbers of hospitalisation rates (at population level), preterm babies and infants with underlying conditions are a small patient group. Most infants (more than three quarters) admitted to hospital for RSV actually do have no underlying condition and are term-born, otherwise healthy babies.[7-11]
A small percentage of babies who are hospitalised with a severe RSV infection need to be admitted to an intensive care unit and some of those need mechanical (artificial) ventilation, if there is not enough oxygen transported through the lungs in the normal way.

In high-income countries, children with RSV infection rarely die from RSV infection. Yet, in low- and middle-income countries, RSV mortality is substantial because of the absence of intensive care units.

2.3. How is RSV transmitted?

RSV only replicates in the airways and is spread through direct contact, not by tiny particles called aerosols, unlike other viruses.[12] The virus then multiplies in the nasal and throat passages. RSV survives outside the body for up to 12 hours, suggesting that RSV sustains infectious hazard on contaminated surfaces for many hours. For example, hard surfaces such as countertops, tables, doorknobs, toys, or cot rails remain contaminated for six hours. The virus typically lives on soft surfaces such as towels, handkerchiefs, and hands for shorter amounts of time (around 45 min). That means one can get in contact with the virus by touching something (or someone) that is contaminated, and that is how one can also spread the virus. This is precisely why frequent and thorough hand washing is such an effective way to protect yourself, others and, of course, your baby from RSV.

A typical RSV infection lasts about a week, both in adults and children. A person infected with RSV is usually contagious for three to eight days. Even before first symptoms occur, the virus can be spread.

Some babies, as well as adults with a weakened immune system, can continue to spread the virus even after they stop showing symptoms, for as long as four weeks.[13] Infants are often exposed to and infected with RSV outside the home, in nurseries or generally in the company of other infants, or by family members and close contacts, especially older siblings.[14] If an infant catches the virus, they can transmit the virus to other family members.

good to know

RSV can spread:

- when an infected person coughs or sneezes without covering their nose and mouth and these droplets get into one's eyes, nose, or mouth
- by touching a surface that is contaminated with the virus, e.g. a doorknob, and then touching your face before washing your hands
- by getting into direct contact with the virus, e.g. through close body contact when cuddling or kissing an infected person

2.4. What are the signs and symptoms of RSV infections?

Unlike adults, who can sometimes get RSV infections and not have symptoms, infants almost always show symptoms. Some of the most common are:

- A runny nose
- Cough, which may progress to wheezing
- Irritability
- Decreased activity
- Decreased appetite
- Apnea (pauses while breathing)
- Fever (does not always occur with RSV infections)

How do I recognize severe RSV?

1. **Coughing** or **wheezing** that does not stop
2. A **bluish colour** around the **mouth** or **fingernails**
3. **Spread-out nostrils** and/or **caved-in chest** when trying to breathe
4. A **fever** (especially **greater than 38°C** in infants under 3 months of age)

If you see any of these symptoms listed above, call your paediatrician, midwife or general practitioner (GP) right away!

2.5. How is RSV diagnosed?

To diagnose RSV, your child's doctor will first ask you about your child's symptoms, listen to their lungs, look at their medical history and then perform a physical exam. A nasal swab test may be used to verify whether your child has RSV or another virus. This is similar to the swab used for a COVID-19 diagnosis.

Tests for suspected severe RSV infections include:

- measuring the oxygen saturation in the blood
- mucus tests of samples from your child's nose or mouth
- a blood and urine tests to look for a bacterial infection and make sure your child is not dehydrated
- if needed, chest x-ray to look for any signs of pneumonia

If your child is very sick, your doctor might do some additional tests, also to rule out other illnesses.

2.6. How is RSV infection treated?

At this stage, there is no specific medication that treats the virus itself. So, caring for a baby with RSV infection can only involve treating the symptoms and supporting the baby. Luckily, in most cases, a baby with an RSV infection can be cared for at home.[15]

Care for babies and young children with RSV at home by:

- removing sticky nasal fluids with a bulb syringe and saline drops
- using a cool-mist vaporiser to keep the air moist, help break up mucus and make breathing easier
- giving your baby fluids in small amounts, frequently throughout the day
- using non-aspirin fever-reducers such as acetaminophen/paracetamol or ibuprofen (if your baby is older than six months) ➔ **always seek the advice of your doctor before giving medication to your baby!**

Babies with more serious cases of RSV infection may need to go to a hospital. Their treatment may include:

- administering intravenous fluids (to stay hydrated for instance)
- administering medications to open their airways
- providing oxygen
- sometimes support of breathing with air or oxygen via mask, prongs or nasal cannula is needed
- mechanical ventilation if your baby is too weak to breath on their own

There is currently no effective curative treatment approved or recommended for RSV infection.

2.7. When should you see the doctor or take your baby to hospital?

Some RSV symptoms may indicate that your child has a severe form of the disease.

You should call your baby's doctor if you notice any of the following:

- Your baby makes a whistling or wheezing noise when breathing
- Your baby is unusually upset
- Your baby appears unusually quiet
- Your baby seems to have trouble breathing or you notice irregularities in your baby's breath
- Your baby refuses to breastfeed or bottle-feed
- Your baby shows signs of dehydration (e.g. a lack of tears when crying, little or no urine in their nappy for at least six hours, and cool, dry skin)

➔ If your baby is very tired, breathes rapidly, or has a blue tint to their lips or fingernails, call the emergency number or go to the emergency room immediately!

The younger the baby, the higher the risk for severe disease and the more difficult it may be to recognise the symptoms, especially during the first months of life. Therefore, in your baby's first year of life, ask advice from your doctor immediately if you observe any of the above-mentioned symptoms or behaviour resembling these symptoms. No one will think you are overreacting or asking unnecessary questions. When it comes to your baby's health, it is better to ask early rather than late.

Professor Luc Zimmermann,
Senior Medical Director at EFCNI, Professor of Paediatrics and Neonatology at Maastricht UMC+, the Netherlands

The controversy with RSV infection is that it is not very well known and parents usually haven't heard of this infection even though it is so widespread and can sometimes be very serious. An RSV infection usually starts with a runny nose and very often it stays at that. However, in more severe cases, after a few days, the baby gets short of breath, with wheezy respirations, and stops feeding well. My experience shows me that parents often have a very good sense that something is wrong with the baby and that they should contact a doctor. My advice to all parents is to please follow this instinct and don't hesitate to consult an expert before problems get worse.

How can you protect your baby from RSV

Since there is currently no treatment for RSV infection, preventative measures are even more important to protect your baby from a severe course of disease and potential long-term lung health issues.

3.1. Steps to reduce your child's risk of RSV infection

Simple and easy hygiene practices, included into your daily routine, can significantly reduce your baby's risk of catching RSV. In general, they are very similar to how we have learned to protect ourselves from COVID-19 and include, for example, frequent handwashing and covering your mouth and nose when we sneeze or cough.

7 steps to protect your baby from RSV disease

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1. **Wash your hands often**
   using soap and water or an alcohol-based hand sanitiser for at least 20 seconds before touching your baby. Remind others to do the same.
2. **Avoid crowds and close contact with sick people**
   and young children. This includes kissing, sharing cups or cutlery with people who have cold-like symptoms.
3. **Cover your coughs and sneezes**
   with a disposable tissue that you throw away after use, or cough and sneeze into your elbow.
4. **Clean and disinfect surfaces**
   regularly to remove droplets that may contain germs. RSV can live for up to 6 hours on doorknobs, toys or worktops.
5. **Maintain a smoke-free environment for your baby**
   by asking your friends and family to respect your non-smoking policy in your home and when they are around your baby.
6. **Try to breastfeed your baby**
   ideally for the first six months of life. However, breastfeeding beyond two months has been shown to protect against severe RSV infection.
7. **Ask your HCP about immunisation options**
   before RSV season (early autumn) and discuss with them the protective solutions available to safeguard your baby against RSV.

Reference:
http://www.webmd.com/lung/rsv-in-babies
[16] doi.org/10.1136/bmjgh-2022-009693

3.2. Preventive solutions on the horizon

For a long time, the only approved and recommended method of preventing severe RSV infection was only available to high-risk groups such as extremely preterm infants and those with certain underlying conditions like congenital heart disease or chronic lung disease. This preventive solution involves repeated monthly injections of monoclonal antibodies during the RSV season for these specific high-risk children. However, thanks to decades of research, there are new immunisation options that are gradually becoming available in various countries to protect all infants from RSV disease.

One preventive approach involves a new maternal RSV vaccine which has been approved in the US and Europe in 2023. Expectant mothers receive this vaccine to safeguard their baby. Following vaccination, mothers produce antibodies that pass to their unborn child through the placenta. This means the baby is born with an effective immune defence against RSV that lasts for the first few months of life.

Another recent development is a novel antibody called 'monoclonal antibody with an extended half-life' that has been approved by the authorities in Europe in 2022 and in the US in 2023. This monoclonal antibody is designed to provide prolonged protection against RSV for all infants, including those born full-term and healthy. It is given in a single injection at the start of your baby's first RSV season and provides passive immunisation throughout the RSV season.

Further options are under development, including a vaccine to protect toddlers in subsequent RSV seasons and another monoclonal antibody. In summary, there are promising preventive solutions on the horizon, either awaiting regulatory approval, implementation, or still in research and development. However, not all preventive solutions are available in all countries at the same time as national authorities and guidelines control their implementation and use.

Meanwhile, you can help reduce the risk of contracting the virus by practicing good hygiene, breastfeeding and avoiding passive smoking. It is advisable to ask a healthcare professional about the recommended and available protective measures for your child.

Quint and Elise Stolwijk,
parents of Mink, Utrecht,
the Netherlands

Earlier this year, our son Mink had to be treated for RSV in the Paediatric Intensive Care Unit (PICU). This time in the hospital was a period of uncertainty, anxiety and stress. However, we are glad we listened to our inner voice and had our baby examined by experts. We can only warmly recommend this to all parents: listen to your gut feeling and don't wait to take action! There are also a few things you can do in everyday life that can reduce the risk of infection for your baby. For example, it is okay to keep visits after the birth limited, both in frequency and time. You should also not be afraid to ask that other children with a cold not to visit your baby until they recovered. Everyone wants the best for your child and will eventually understand.

3.3. What to consider after an RSV infection

If your child went through an RSV infection, and maybe even had to be treated in hospital, the time was certainly worrisome, and the healing phase was probably accompanied by concerns of a potential re-infection with the virus. Do not worry too much, but remain attentive, and implement purposeful, reasonable steps into your everyday life. You may, for example, support your and your child's immune system with a balanced diet, fresh air and sufficient sleep, along with some basic hygiene and distancing measures that have already proven effective during the COVID-19 pandemic. This can help protect your child from re-infection and contain the spread of the virus.

RSV concerns all infants and it is important to remain vigilant, to recognise the signs and to take the necessary measures to prevent an infection.

If your baby had RSV, you may have gone through a very intense and worrisome time and are now concerned about your baby's health and further development.

Stay educated, discuss your RSV risks. If a re-infection occurs, it is often milder with less severe symptoms. Stay vigilant and do not hesitate to raise concern with your physician, neonatal staff or healthcare provider ahead of time.

Trust your instincts. If your intuition tells you that something is not right, follow it, seek help immediately and see your paediatrician for a proper diagnosis.

Keep your distance. Try to keep other adults and children with cold-like symptoms from touching and cuddling your child. Physical distance and the proven hygiene measures will continue to help prevent re-infection, especially during winter months.

You are not alone. Ask others in your family or circle of friends for support, and feel free to share your experience, maybe also on social media, to raise awareness of your emotional journey and the warning signs of RSV infection.

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5 Further information, helpful addresses and links*

*Without claim to completeness

General information

Le Haute Autorité de santé (HAS) *https://www.has-sante.fr*

National Health Service (NHS) *https://www.nhs.uk*

Nemours KidsHealth *https://kidshealth.org*

Robert-Koch-Institut (RKI) *https://www.rki.de*

Associations, networks, and societies for parents, patients, and healthcare professionals

National

France

Association de formation professionnelle en pédiatrie (AFPA)
Web: ***https://afpa.org***

Germany

Deutsche Gesellschaft für pädiatrische Infektiologie (DGPI)
Web: ***https://dgpi.de***

Arbeitsgemeinschaft Influenza (AGI): Informationen zur Aktivität akuter respiratorischer Erkrankungen (ARE) in Deutschland
Web: ***https://influenza.rki.de***

Italy

Società Italiana di Pediatria (SIP)
Web: ***https://sip.it***

Spain

En Familia AEP (Asociación Española de Pediatría)
Web: ***https://enfamilia.aeped.es***

Europe

European Lung Foundation -
Information available in several languages
Web: ***https://europeanlung.org***

RSV patient network
Web: ***http://www.resvinet.org***

Respiratory Syncytial Virus Consortium in Europe (RESCEU)
Web: ***https://resc-eu.org***

European Respiratory Society
Web: ***https://www.ersnet.org***

International

International Respiratory Syncytial Virus Society (IRSVS)
Web: ***https://isirv.org***

Forum of International Respiratory Societies
Web: ***https://www.firsnet.org***

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Despeena, born at 24 weeks, weighing 820 grams / 1.8 lbs

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RSV - Why parents of all infants should be aware of Respiratory Syncytial Virus

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