Living with CF

THE NORWEGIAN
CYSTIC FIBROSIS ASSOCIATION

People with CF and PCD should have the same opportunities as everyone else!

cfnorge.no

Contents

The Norwegian Cystic Fibrosis Association 4
Abstract 9

CYSTIC FIBROSIS 11
What is Cystic Fibrosis? 11
Genetics 12
Diagnostics 13
Treatments 14
- Daily treatments 14
- CFTR Modulator treatment 15
- Follow-up 17
- Lung transplantation 17
- Prognosis 17

Infection control 18
Vaccination 18

LIFE STAGES WITH CF 21
Cildren with CF 21
- Educating the child and those around them about CF 21
- Individual plan 22
- Kindergarten 23
- School 24

Youth with CF 26
- Puberty 27
- Sexuality 28
- Party habits with CF 29
- Education with CF 31

Adults with CF 32
- Work life 32
- Family planning 34

Growing older with CF 36

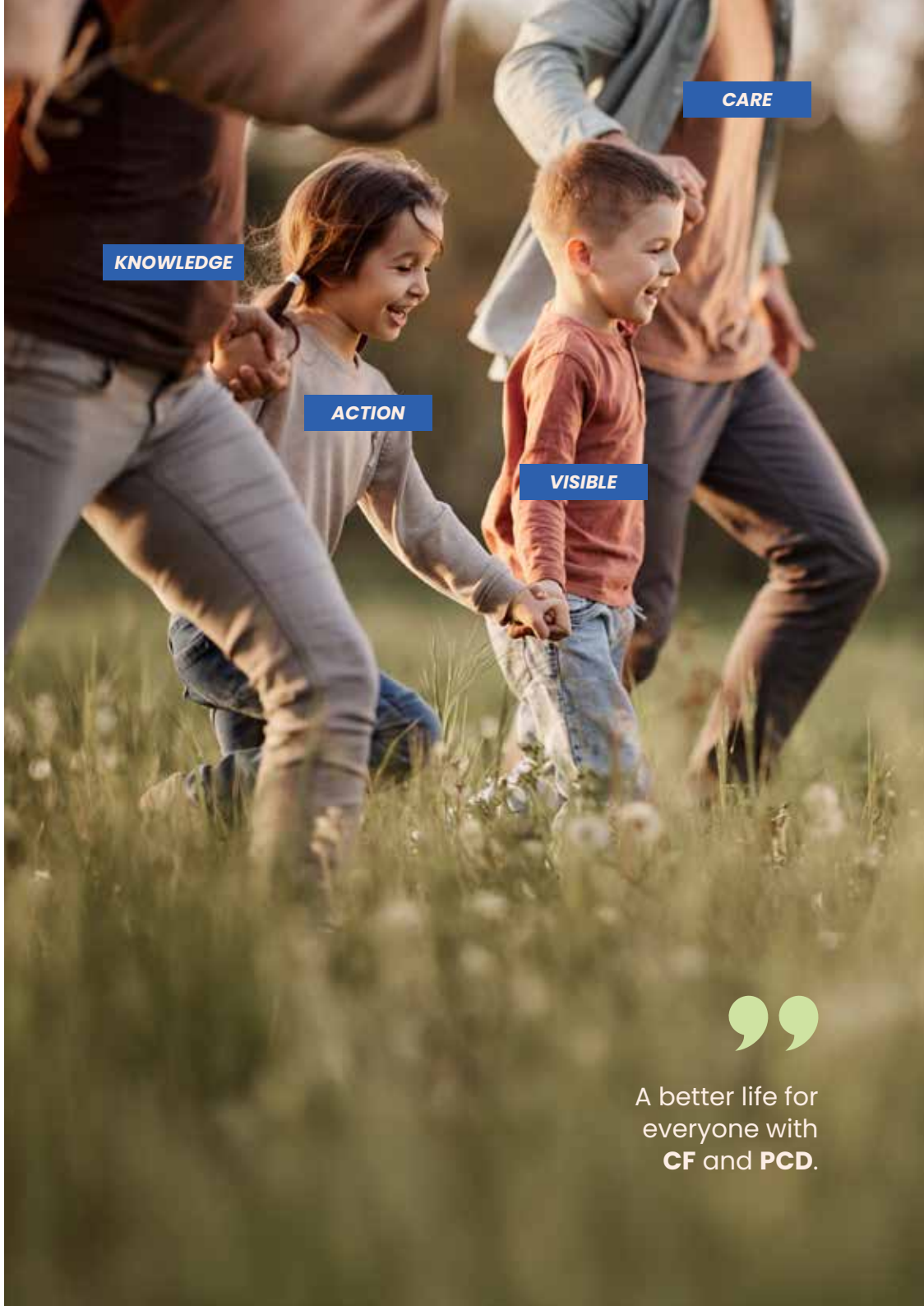
RELATIVES AND CLOSE ONES 39
Parent and CF 39
Siblings and CF 42
Grandparents and CF 45
Children of people with CF 49
Partners of people with CF 51

RESOURCES 54

The Norwegian Cystic Fibrosis Association

Established in 1976, the The Norwegian Cystic Fibrosis Association (NFCF) is a nationwide organisation for people with cystic fibrosis (CF), primary ciliary dyskinesia (PCD) and their relatives. We work to improve everyday life and quality of life through knowledge-sharing, support, community and advocacy.

We operate with a small administration in Oslo, a central board and four regional chapters. South-East, Mid, West and North, to ensure local presence. We collaborate closely with healthcare professionals and have a clinical advisory board that contributes to counselling and quality assurance of health information for our channels and events.



A better life for everyone with **CF** and **PCD**.

Our tasks:

1 **Information**
Provide up-to-date, reliable and accessible information about CF and PCD to patients, relatives, healthcare staff and wider society.

2 **Treatment & rights**
Raise awareness of available treatments, support schemes and entitlements, to ensure that CF and PCD patients receive the help they are entitled to.

3 **Meeting places & community**
Creating safe spaces for experience sharing, support, and social community for those living with or close to someone with CF and PCD.

4 **Research**
Support and promote research to improve understanding, treatment and quality of life for those affected by the diagnoses.

5 **Awareness in the Support System**
Contribute to increased awareness of CF and PCD in the healthcare system, schools, NAV, and other public services.

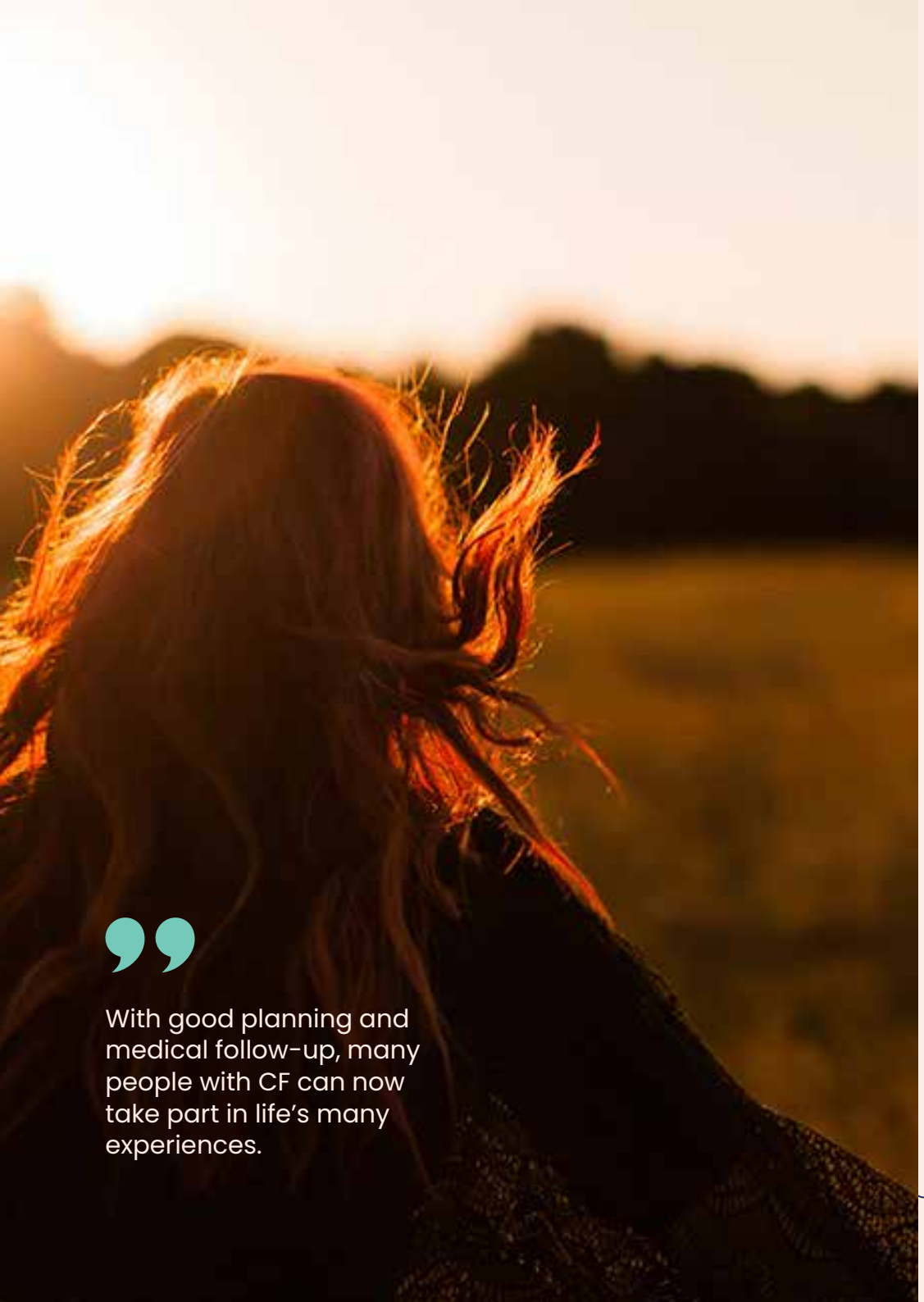
6 **Advocacy Work**
Fight for rights and equality, access to medications and treatment through dialogue and advocacy with authorities, politicians, and decision-makers to ensure equity and treatment options regardless of where one lives.

7 **Cooperation**
Strengthen collaboration with national and international expert communities, patient organizations, and other relevant stakeholders.

As a member of NFCF, you join a strong community and get reliable information, invitations to courses and gatherings, and access to peer support (Likepersoner) where you can share experiences and receive support from other members.

Your membership fee directly supports efforts for better treatment options, faster access to new medications, increased expertise in the support system, and funding for research. Together with others, you give NFCF a stronger voice in meetings with politicians, authorities, and other decision-makers.

WANT TO BECOME A MEMBER?
You can register yourself and your household as members at cfnorge.no by scanning the QR code.



With good planning and medical follow-up, many people with CF can now take part in life's many experiences.

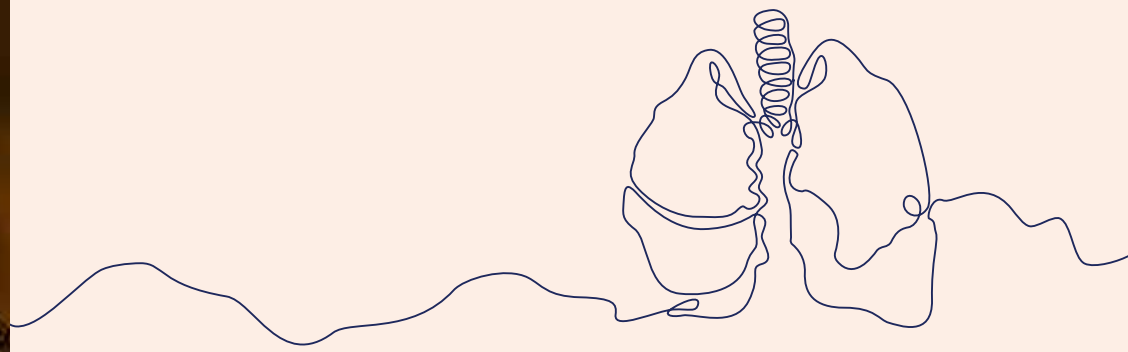
Abstract

Receiving a permanent, serious diagnosis affects not only the person diagnosed but also those around them. The time before, during and after the diagnosis can feel relieving, confusing and demanding, and it is normal to be left with many questions, thoughts and worries.

Living with cystic fibrosis (often abbreviated as CF) can feel heavy and present challenges at different stages of life. At the same time, medical treatment and life expectancy have improved significantly in recent years. What was once considered a childhood disease is now a diagnosis that many people live long and fulfilling lives with, and this progress will only continue to improve in the years to come.

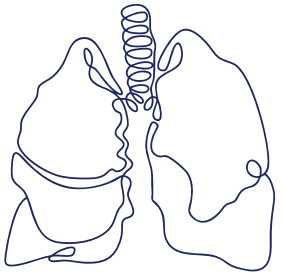
With proper planning and medical follow-up, many people with CF can now participate in life's many experiences, such as education, work, travel, and hobbies. More and more are also experiencing the opportunity to become parents and perhaps even grandparents. However, it's worth noting that CF is a condition with great variation, where some are heavily affected by the disease, while others experience symptoms to a lesser degree. Therefore, knowledge, experience sharing, and support are crucial for both those with diagnosis and their loved ones. This brochure provides a simple introduction to CF and valuable information for those newly diagnosed, their relatives, or anyone wishing to learn more about living with the condition. We hope it can serve as a source of knowledge, hope, and community.

The Norwegian Cystic Fibrosis Association



> As of 2024, around 400 people live with CF in Norway, and 65% of them are adults over 18 years old.

Cystic Fibrosis



WHAT IS CYSTIC FIBROSIS?

Cystic fibrosis (CF) is a congenital, hereditary and serious multi-organ disease that primarily affects the airways and digestive system. It is caused by a gene defect that changes the transport of salt and water in cells, making mucus thick and sticky and hindering the body's ability to remove bacteria and particles, especially in the lungs and airways.

The thick mucus accumulates in the bronchi, preventing the tiny cilia in the airways from transporting it out of the body. This creates a breeding ground for repeated and persistent infections, which over time can damage lung tissue and reduce lung function. Many people with CF experience symptoms such as prolonged coughing, shortness of breath, sinus problems, and pneumonia. Frequent infections can lead to scarring in the lungs, and in the most severe cases, a lung transplant may become necessary.

CF affects not only the lungs but also other parts of the body, such as the digestive system, liver, and pancreas. In the pancreas, thick mucus can block the release of digestive enzymes needed to break down and absorb nutrients from food. This can lead to challenges such as poor weight gain, abdominal pain, and deficiencies in essential nutrients. In some cases, the liver may also be affected.

Each year, approximately 8–10 children are born with cystic fibrosis in Norway. As of 2024, around 400 people are living with the diagnosis in the country, and about 65% of these are adults over 18 years old. There are significant individual differences in how CF manifests. Some lead active lives with mild symptoms and good quality of life, while others require extensive medical support. Although the disease often progresses negatively over time and requires lifelong treatment, todays treatment options offer strong hope for the future.

GENETICS
Cystic fibrosis is an inherited disease caused by mutations in the CF gene on chromosome 7. The disease is inherited in an autosomal recessive manner, meaning a child must inherit the mutated gene from both parents to develop CF. If both parents are healthy carriers of the gene mutation, there is a 25% chance in each pregnancy that the child will have cystic fibrosis.

There are many different mutations in the CF gene, and each mutation can affect the severity of the disease. Some mutations result in a more severe form of CF, while others lead to milder symptoms. In Norway, the most common mutation is known as Delta F508, but with over 2,000 known variants of the CF gene, symptoms and disease progression can vary significantly from person to person.

The newborn screening is conducted by taking a blood sample from the baby's heel.

DIAGNOSTICS
Since 2012 CF has been included in Norway's newborn screening programme, which now covers 30 congenital hereditary diseases. All newborn babies are offered testing for CF in hospitals, and nearly all parents consent to this. Early diagnosis enables prompt treatment, which can significantly slow disease progression and improve quality of life. If the newborn screening indicates a suspicion of CF, the child undergoes further evaluation with a sweat test and genetic blood tests to confirm or rule out the diagnosis. The sweat test is a key method, as high levels of salt (chloride) in sweat are a hallmark of CF.

Most people diagnosed today are identified in childhood through newborn screening. For those born before 2012, a diagnosis may still be made later in life based on symptoms that develop gradually. Thanks to screening, it is expected that fewer people will receive a late diagnosis in the future.

> CFTR modulator treatment strengthens the CFTR protein and improves chloride transport across the cell membrane.

TREATMENT

As CF is a complex multiorgan disease, it requires interdisciplinary collaboration within the healthcare system. Early diagnosis through newborn screening enables the rapid initiation of preventive treatment, which is crucial for slowing disease progression. The treatment approach is comprehensive and often includes nutritional support, physiotherapy, and medications, tailored to each individual patient based on their unique disease profile.

Daily treatments

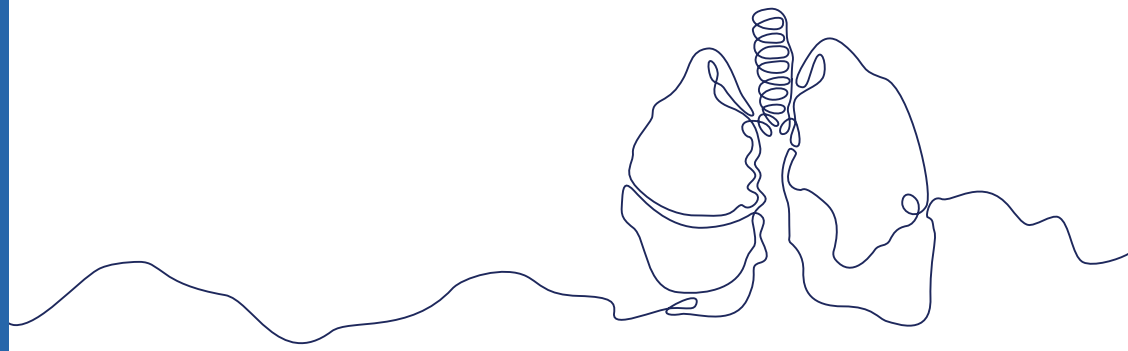
Respiratory physiotherapy is a cornerstone of CF care. Through inhalations and breathing techniques, mucus is loosened and removed to prevent infections and preserve lung function. Many people also receive antibiotics to treat or prevent respiratory infections. Physical activity, such as structured exercise or other movement, supports lung health, improves stamina and appetite, enhances nutritional status and reduces stress. A balanced diet with vitamin and enzyme supplements is important since CF can affect digestion and nutrient uptake.

CFTR modulator treatment

In recent years, new gene-modifying drugs, known as CFTR modulators, have revolutionized the treatment of cystic fibrosis. The first modulator was introduced in 2012, and in 2020, Kaftrio, a triple therapy with the active substances ivacaftor, tezacaftor, and elexacaftor, was approved in Europe. Kaftrio strengthens the CFTR protein and improves chloride transport across the cell membrane, directly addressing the cause of cystic fibrosis. In Norway, the fight to have Kaftrio approved was long and challenging. With the slogan “Everyone has the right to breathe,” the Norwegian Cystic Fibrosis Association raised national awareness and gained political support. In 2022, after 600 days of effort, Kaftrio was approved and is now covered by the public healthcare system. From July 1, 2024, the treatment became available for children as young as two years old with at least one F508del mutation, marking a significant breakthrough for cystic fibrosis treatment in Norway. From August 25, 2025, Kaftrio was also approved for use in patients with mutations beyond the F508del mutation. In July 2025, Alyftrek, the successor to Kaftrio, was also approved in Europe. The majority of individuals with cystic fibrosis in Norway can now benefit from CFTR modulators, while research continues to develop therapies for those with rare mutations or those who have experienced side effects and are therefore unable to use these medications.

I want to live a long life ...

#righttobreathe



Follow-up

Individuals with cystic fibrosis are offered regular check-ups with doctors and other healthcare professionals who have specialized expertise and experience with cystic fibrosis. Most CF patients have check-ups at hospitals every 6 weeks to every 3 months, depending on the severity of the disease and their individual symptoms. These check-ups may take place at local hospitals in collaboration with larger specialized centers. In Norway, there are two such centers: one at Haukeland University Hospital and one at Oslo University Hospital Ullevål. The latter is called the Norwegian Resource Centre for Cystic Fibrosis (NSCF) and has overarching responsibility for the entire Norwegian CF population. The NSCF is part of the National Center for Rare Diagnoses at Oslo University Hospital.

Lung transplantation

For individuals with severe and irreversible lung damage that does not respond to other treatments, lung transplantation may be necessary. With advancements in medical treatment, the need for lung transplantations is expected to be significantly reduced in the future. Read more about lung transplantation on The Norwegian Organ Donation Foundation's webiste: **organdonasjon.no**.

Prognosis

Thanks to modern treatments, the prognosis for individuals with cystic fibrosis has greatly improved. Regular follow-up by multidisciplinary CF teams, respiratory physiotherapy, antibiotics, and CFTR modulator therapies enable many to live longer with a higher quality of life. With future treatment advancements, there is hope that life expectancy for many with CF may approach that of the general population.

Regular handwashing is important for people with CF in order to protects themselves against infections.

INFECTION CONTROL

Individuals with cystic fibrosis have a weakened immune system in their airways and cannot protect themselves against disease-causing microbes as effectively as the general population. This increases the risk of severe and prolonged infections, particularly in the lungs, making preventive infection control measures crucial for protecting lung health. There is extensive international collaboration within the CF community to continuously assess and adapt recommendations for effective infection control, and these guidelines have been revised and updated over time. Research shows that individuals with CF can transmit and contract microbes that are particularly dangerous to others with the same diagnosis. These infections can worsen lung symptoms and reduce lung capacity. To reduce infection risk, people with cystic fibrosis should maintain at least a two-meter distance from others with CF and anyone who is sick, regardless of their condition. Close-contact group activities are discouraged for those who do not live together. However, this does not mean that individuals with CF must avoid gatherings or social events. It is entirely possible to meet safely. NFCF regularly organizes events, such as the annual learning weekend, where individuals with CF and their families can meet in a safe manner. It is important to follow current infection control guidelines to protect health. Good hygiene practices, such as regular handwashing and disinfection of equipment and surfaces, are strongly recommended. More information on infection control can be found on our website: **cfnorge.no**.

VACCINATION

It is recommended that all individuals with CF follow national guidelines for vaccination of children, adolescents, and adults, including recommended seasonal vaccines such as the influenza vaccine. See the Norwegian Institute of Public Health recommendations at **FHI.no**.

Life Stages with CF

Throughout the various stages of life from childhood to adulthood, people with CF face both challenges and opportunities. CF is a part of life from birth to the end, but there are many ways to live a rich and meaningful life. In this section, we explore how CF impacts daily life at different ages: from early diagnosis and childhood years, through the adolescent quest for independence, to the opportunities in adulthood for work, family, and personal growth.

CHILDREN WITH CF

Children are natural explorers, discovering the world around them through sensory experiences at different stages of development. For children born with cystic fibrosis, the disease changes as the child develops, leading to new experiences and challenges that may arise, requiring special adaptations and considerations.

Educating the child and those around them about CF

When a child begins participating in activities such as playgroups, kindergarten, or spending time with babysitters or extended family, it is important to inform those around the child about cystic fibrosis. This includes teaching other adults about the importance of good hygiene, how to administer any medications and other treatments, and how best to support the child in these situations. It is also crucial to ensure that the child's environment is clean and safe to prevent infections that could affect their health.

It is recommended to start explaining CF to the child as early as possible in a way that is tailored to the child's age, emotional needs, personality, and cognitive development. If you are unsure about how to communicate this information effectively, you can always ask the child's CF healthcare team for advice and support. As the child grows older and becomes more independent, they will, like taking on greater responsibility in other areas,

also need to take more responsibility for their own health. A natural relationship with their condition can be helpful in this process.

Individual Plan (IP)

For both kindergarten and school, it can be helpful to have an Individual Plan (IP) in place that outlines the child's specific needs and provides guidance on how these can best be met. An Individual Plan should be developed in collaboration with parents, kindergarten or school staff, local healthcare services, and CF healthcare professionals. This plan is a valuable tool for coordinating services and ensuring that the child receives appropriate support at home, in kindergarten, and at school. It can also help alleviate some of the responsibility for parents by providing a clear overview of goals, measures, and division of responsibilities.

Kindergarten

Kindergarten is a child's first encounter with other children, where they gain important experiences and develop social skills. Like other children, it is generally common for children with cystic fibrosis to attend kindergarten. However, there are some recommendations that can make the transition to kindergarten better tailored for children with CF. Many find it beneficial to carefully plan the start of kindergarten in collaboration with parents, kindergarten staff, and relevant healthcare professionals. The need for additional resources in the kindergarten to accommodate the child's specific requirements should be assessed. It is kindergarten that applies for such resource allocation. Depending on the child's health, it is generally recommended to delay the start of kindergarten until the child is at least two years old. This delay allows time to establish individualized treatment and gives the family time to adjust to the demands of a condition that requires planning and tailored accommodation.

To ensure this process goes smoothly, it can be helpful to begin planning a year in advance of the start, ensuring that both the child and those around them have the necessary conditions for a successful transition. Cystic fibrosis is a rare disease, and kindergarten staff need specific training to understand how the condition affects the child. It is important that kindergarten staff are aware of the child's individual needs regarding infection control, hygiene, and treatment in the daily kindergarten routine.

To ensure that all involved parties have sufficient knowledge, it is recommended that kindergarten staff complete the online course "Cystisk fibrose i barnehagen", available at www.sjelden.no. This course provides basic training about the condition and how best to support the child in the kindergarten setting. When it comes to informing other parents about the child's condition, there is no one-size-fits-all approach to sharing this information. However, most choose to be open about it, with some parents preferring to share the information themselves, while others involve kindergarten staff or healthcare professionals in the process. Written materials can also be helpful, and such materials can be found on the Norwegian Cystic Fibrosis Association's website, **cfnorge.no**.

Making the right adjustments can be essential for a good daily life.

School

Similar to kindergarten, the transition to school requires thorough planning, and it is recommended that this process begins the autumn before the school year starts. Experiences from kindergarten regarding accommodations are valuable information for the school when welcoming a student with cystic fibrosis. The need for additional resources is assessed by the school in collaboration with parents and healthcare professionals, and an application for resource allocation is required. The school day is more structured with a fixed timetable, making accommodations crucial to ensure a good daily routine. For example, many choose to schedule lung therapy with a physiotherapist during after-school programs to avoid missing instructional time, though there are significant individual differences in how this is managed. Planning for the start of school includes many of the same elements as for kindergarten. Important information about cystic fibrosis, the need for proper cleaning, hygiene, accessible toilets, exercise facilities, showers, and changing rooms must be addressed. An Individual Plan (IP) should also be developed to ensure tailored support. In school age, classmates and others around the child are often curious and want to learn more. The book ''Sånn er det'' by Widar Aspeli provides a good introduction to what life with CF can be like and what the condition entails. You can contact the Norwegian Cystic Fibrosis Center to order the book. Some children choose to inform their classmates about the condition themselves, while others prefer that parents, teachers, or healthcare professionals handle the information. There are also those who choose not to share anything at all, which is perfectly fine. There is no one-size-fits-all approach. Each family and person with CF finds a solution that works best for them.

On sjelden.no, you can find the e-learning course "Cystisk fibrose på skolen." This course provides an accessible and thorough introduction to how best to accommodate students with cystic fibrosis. It is recommended that school staff complete this course as part of the school start preparations.

YOUTH WITH CF

Being a teenager with cystic fibrosis means living with a chronic illness during a life phase marked by significant changes. Adolescence is the time when one transitions from childhood to adulthood, gaining more freedom but also more responsibility. For teens with CF, this often means gradually taking over tasks previously handled by parents, such as managing medications, physiotherapy, and nutrition. It's important to remember that your CF team is there to support you and help you become confident and independent during these transitions. Some may find the increased freedom and responsibility exciting, while others may feel frustration or anger about the demands of the condition and wish to live as normally as possible.

CF is a disease that is often not visible on the outside, which can make it hard for others to understand what it's like to live with it. It can be challenging to feel that others don't always believe you when you say you're tired, in pain, or need accommodations. Especially in adolescence, when the desire to fit in with peers is strong, this can understandably feel frustrating. It can therefore be helpful to find someone to talk to who truly understands. On cfnorge.no, you can find a list of peer supporters, such as other young people with CF, whom you can contact for support and to share experiences. Many teenagers with CF today benefit from effective treatments that reduce symptoms and improve health. This can make you feel healthier and function more like other teens at times. However, CF will always be a part of your life and will affect you to varying degrees through different life stages. Remember, though, that the disease is something you have, not something you are!

Puberty

Previously, it was common for puberty in young people with cystic fibrosis to be delayed. Today, this is not necessarily the case, and most individuals with CF enter puberty at the same time as their peers. However, depending on health and nutritional status, some may experience delays, such as delayed breast development and menstruation in girls, or delayed growth spurts, body hair development, and voice changes in boys. This is not abnormal, and remember that the timing of puberty vareis even among healthy individuals. If you have any questions, it can be helpful to discuss them with your doctor.

Sexuality

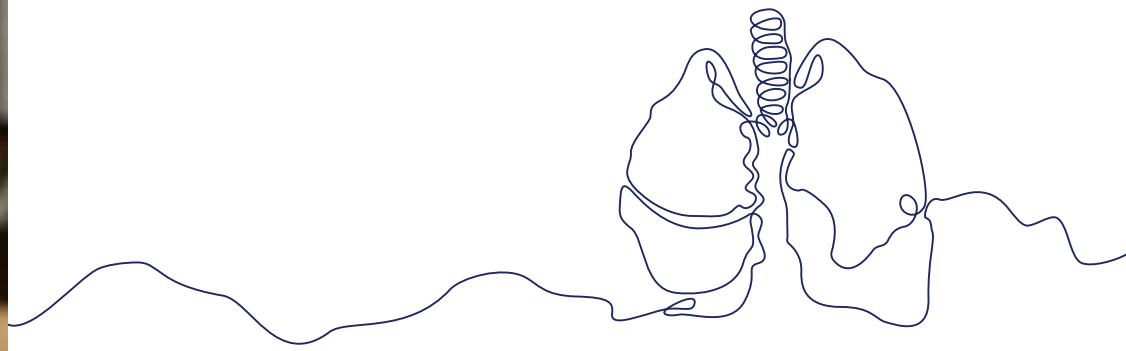
With cystic fibrois you can live a normal sexual life just like anyone else, and the condition itself does not affect yout ability to engage in sexual activity. However, physical symptoms such as fatigue, breathing difficulties, or stomach issues may impact desire and comfort in intimate situations. This is completely normal. Even during periods when you may not feel like or have the energy for sexual activity, the need for closeness, such as hugging, kissing, and feeling loved, can still be strong. Open communication with your partner and healthcare professionals can help ensure comfort and accommodations.

Remember that protection is important if you want to avoid unplanned pregnancy, especially since certain antibiotics can reduce the effectiveness of birth control pills. Women with CF who use hormonal contraception should inform their doctor to ensure the right method is chosen.

Party habits with CF

Drinking too much alcohol is not good for anyone, whether you have cystic fibrosis or not. That said, this doesn't mean you can't enjoy a glass of wine or beer with a meal or join friends at a party. The key is to be aware of how alcohol can affect your body, especially if you take medications that may strain the liver. For some, alcohol can worsen liver function or make medications less effective. Therefore, you should talk to your doctor about what is safe for you. Together, you can figure out what works best for your situation.

Adolescence is a time when many test boundaries, and there can be significant peer pressure around things like smoking and vaping. However, it is crucial for those with CF to avoid these activities. CF already affects the lungs, and smoking harms nearly every part of the body, especially the airways. Smoking when you have CF can be directly dangerous. Some teens with CF find it helpful to use their condition as a reason to say no if pressured to try smoking or vaping. It's also important to avoid second-hand smoke, such as being in smoky environments or around people who are smoking, as this can also harm your lungs. Taking care of your lungs is one of the most important things you can do for your health and quality of life. This involves making conscious choices, even in social situations where it might be tempting to "do what everyone else is doing."



Education with CF

Moving away from home and starting studies with a lifelong condition like cystic fibrosis requires some extra accommodations, but with good planning, support, and awareness of your own needs, it is entirely possible to thrive and succeed in this transition. Many find that taking more control over their own life and health brings a sense of mastery and increased freedom.

The transition to adult healthcare services often happens around the same time as starting studies. This means you will need to take a more active role in communicating directly with healthcare professionals and managing your treatment and appointments. If you move, it may be wise to switch to a general practitioner near your new place of residence and familiarize yourself with how your new hospital or CF team operates.

When you no longer have someone around to remind you about medications, treatments, or cleaning equipment, maintaining good routines can become challenging. In a busy and new daily life, it's therefore important to establish practical systems—such as phone reminders, a weekly plan, or visual aids. For many with CF, combining full-time studies with a part-time job or other commitments can be demanding. Fortunately, there are various support options available, including additional grants from the Norwegian State Educational Loan Fund (Lånekassen) for students with disabilities. You can find more information about your rights and the application process at **lånekassen.no**.

It's also important to remember that studying isn't for everyone. CF affects each person differently, and for some, prioritizing health will be the most important task in adulthood. Finding a path that brings you joy and meaning in life is a success in itself.

ADULT WITH CF

Adulthood with cystic fibrosis can be full of both joys and challenges. Some enjoy the freedom and greater scope for action, while others may find it complicated. While some balance treatment and daily life with work, others find meaning and strength through different pursuits. There is no standard template for what adulthood with CF looks like, just as there is no standard for what an "ordinary" adult life looks like. At the same time, there are certain topics that may particularly affect adults with CF, and in this chapter, we explore these.

Work life

For some adults with cystic fibrosis, managing their health with treatments and everything that comes with it can feel like a full-time job in itself. For others, it is entirely possible to have a meaningful and fulfilling professional life. However, the nature of the condition may require specific accommodations in the workplace. Treatment routines and medications need to be integrated into the workday, and absences may be necessary for medical appointments or illness. Flexibility in the work routine can therefore be key for some. This might include options for remote work, additional rest breaks, adjustments to job tasks, or transitioning to a different role. Some may need a reduced work percentage, while others can maintain full work capacity with the right accommodations.

> For my part, managing self-treatment and periods of illness, in addition to caring for children, has been enough. Therefore, working has not been an option for me.
>
> Woman, 55 years

When choosing a career, it's wise to consider what suits your health. Avoid environments with a lot of smoke, dust, or chemicals, as these can irritate the lungs. Workplaces with a high risk of infections, such as kindergartens or hospitals, can also be challenging, as infections can hit particularly hard when you have CF. A careful assessment of what works for you is therefore important—there are many opportunities for good education and a fulfilling job. If you face health challenges that make it difficult to enter or remain in the workforce, you are entitled to support and accommodations from NAV (the Norwegian Labour and Welfare Administration). NAV offers various measures and individualized follow-up to assist you in working life. Through contact with NAV, you will receive good guidance and information about the opportunities available to you.

Family planning

In adulthood, many people enter a phase where they settle down, and for many, it becomes natural to start thinking about starting a family. There are several options for family planning for individuals with cystic fibrosis, but it often requires extra time and thorough medical follow-up. Approximately 97% of men with CF are infertile, primarily because their vas deferens, the tubes connecting the testicles to the seminal vesicles, are absent or end blindly. As a result, their ejaculate does not contain sperm. Despite this, men with CF who wish to become fathers can do so through sperm retrieval and assisted reproductive techniques such as in vitro fertilization (IVF) or intracytoplasmic sperm injection (ICSI). Today, there are governmental schemes in place that provide state support for assisted reproduction.

Women with CF generally do not face the same level of fertility challenges as men, but about 20% may still experience reduced fertility. This can be due to thickened cervical mucus, which can make it harder for sperm to reach the egg, or malnutrition, which can negatively affect hormone balance and the menstrual cycle. Nevertheless, many women with CF conceive naturally. For women considering pregnancy, it is recommended to contact the CF team at least one year before planning to conceive, to optimize health and medical treatment in advance. During pregnancy, closer follow-up is important to ensure good health for both mother and baby.

In addition to the practical aspects of conception, another important factor to consider during the family planning process is genetics. It is recommended that both men and women discuss genetic risks with healthcare professionals: A person with CF has two copies of a defective CFTR gene and will always pass one copy to their child. If the partner is also a carrier of a CFTR mutation (without having the disease themselves), there is a 25% chance that the child will have CF. Genetic counseling and testing of the partner are therefore recommended to assess any potential risks.

GROWING OLDER WITH CF
Growing older is a natural part of life for most people, but for those born with cystic fibrosis who are now approaching old age, it is both unexpected and miraculous at the same time. When they were growing up, they faced very different life circumstances, and many did not plan for old age as a result.

With medical advancements, an increasing number of people with CF are now approaching an elderly life, but for many, this is an entirely new world to navigate when they suddenly need to start planning for a retirement they hadn't previously envisioned. This brings both challenges and many joys that previous CF generations did not experience.

"We are the first CF generation that has to think long-term. It's both a challenge and a victory."

– Man, 40 years old

Cystic fibrosis is a lifelong and progressive disease, meaning it can become more challenging over time. At the same time, growing older with CF is a relatively new phenomenon, even for the healthcare system. CF teams have high expertise, but because older adults with CF is a relatively new group, healthcare professionals are still learning how best to support you. In many ways, you are paving the way for the future.

When interacting with new healthcare providers, it's important to clearly communicate your medical history, medications, and needs. This represents a paradigm shift that raises new questions. A 58-year-old woman describes it this way:

"Every time I meet a new doctor, I have to explain my entire medical history, the medications I take, and what I can't tolerate. Who will do that if one day I can't remember it myself?"

As you age, new health challenges may arise, just as they do for everyone else. For those with CF, it's particularly important to monitor conditions such as osteoporosis, CF-related diabetes, sleep apnea, liver disease, cardiovascular issues, antibiotic resistance, or, in some cases, cancer in the digestive tract. Regular and tailored follow-up with healthcare professionals is key, and your needs will vary based on your genetic variant, disease progression, and unique situation.

A community:
Alongside the new opportunities and challenges that come with aging with CF, there may also be a stronger need for community and sharing experiences. The Norwegian Cystic Fibrosis Association offers support through its peer support service, including the private and confidential Facebook group "Adults with CF." Here, you can share questions, thoughts, experiences, frustrations, and find support, humor, and a sense of belonging among others in the same situation.

Wondering about group membership? Contact the editorial team at: **redaksjonen@nfcf.no** and we'll gladly assist you.

You can also reach out directly to one of our adult peer supporters if you want to talk to someone who understands what it's like to live with CF as an older adult. More information is available at **nfcf.no/likepersone**r.

«Being a mother to a child with cystic fibrosis is an emotional journey with highs and lows. Some days are filled with joy, where we cherish the small, everyday moments and laugh together. Other days, the weight of worry feels overwhelming. Yet, through it all, my child's incredible strength and courage shine through, inspiring me to find resilience and hope no matter what each day brings.»

– Mother of a child with CF

Relatives and close ones

Being close to someone with cystic fibrosis can bring both joys and challenges. Whether you are a parent, grandparent, sibling, partner, or child, thoughts about your relative or close one's health and future can feel heavy at times. At the same time, no experience as a relative or close one is the same. Everyone processes and handles their role in their own way. Norwegian Resource Centre for Cystic Fibrosis offers family courses for parents of children with CF, providing support and knowledge. Many also find comfort and inspiration in reading about others' experiences. Therefore, we share some stories about the different roles of being a relative or close one to someone with CF, hoping to offer you support and new perspectives.

PARENTS AND CF

It is completely normal to feel overwhelmed when you learn that your child has cystic fibrosis. The information you receive early on can feel daunting, and it's natural to worry about what this will mean for both your child and your family. You may have many questions, and your emotions may fluctuate. A good piece of advice for parents is: Take it one day at a time. There's a lot to process, but you don't need to understand everything right away.

Many parents find it tempting to search for answers online or on social media. Keep in mind that information there can often be misleading, outdated, or not relevant to your child's specific situation. Instead, rely on trustworthy sources such as the CF team caring for your child, public healthcare services, and the Norwegian Cystic Fibrosis Association, which also serves as a support network and meeting place for many families. There, you can connect with others in similar situations, ask questions, share experiences, and find community. Being a parent to a child with CF can, for some, involve extra caregiving responsibilities. You may need to spend more time on treatments and take certain precautions that others might not. This can require adjustments in the beginning. At the same time, many families find that the new routine eventually settles, and things that initially felt difficult or different soon become part of everyday life.

”

Being a parent to a child with CF means a lot of extra planning and care, but it also teaches you to appreciate the moments that are completely ordinary for others.”

– Father of a child with CF

Accept help when it’s offered

Many people around you want to help but may not know how. Be specific with friends and family about what you need and inform those around you about what they can do to make your daily life easier. For many parents, it’s a relief when those around them also gain enough knowledge about the diagnosis, so you don’t have to keep repeating yourself or deal with stereotypes or misconceptions.

The Norwegian Cystic Fibrosis Association has many members who are parents. Among us, you’ll find peer supporters who are happy to talk to you as a new parent. Don’t hesitate to reach out to one of them. Sharing experiences is often the most valuable support for parents.

SIBLINGS AND CF

When one child has cystic fibrosis, it affects the entire group of siblings. Siblings need time to get used to the fact that their brother or sister has medical needs and must undergo treatments, whether the siblings are older or younger. It's important that they have the opportunity to ask questions and share their thoughts and feelings. Many siblings respond positively with care and love, but some may struggle to adjust to the situation. Children with CF often receive a lot of extra attention due to treatments and hospital stays, which can make siblings feel overlooked or left out.

Teaching siblings about CF can help them understand why their brother or sister receives more attention. Books about CF, designed specifically for children and young people, can be useful for explaining the condition in an accessible way. You can ask Norwegian Resource Centre for Cystic Fibrosis about the book Sånn er det, a book about CF tailored for children.

> In our family, our younger daughter gained a new understanding when she herself became ill and had to be admitted to the hospital. She was thrilled to finally have her own hospital experience. Previously, it was mostly her older brother who went off with mom or dad, often staying overnight, while she stayed home without understanding what was happening. Although she had joined some visits, being a patient herself was a completely different experience. It was only when she was admitted that she gained a concrete understanding of what a hospital stay entailed, and perhaps also a sense of being just as important as her brother.
>
> – Mother of a child with CF

To help siblings feel important and included, efforts should be made to spend time with each child individually as much as possible. You can also involve siblings in hospital visits or let them participate in simple parts of the treatment, which can give them a sense of involvement and responsibility. Some siblings may need extra support, and it can be helpful to talk to the CF healthcare team, which has resources and experience in supporting the entire family. Many share positive experiences from participating in family gatherings from a young age, such as regional events or the learning weekend organized by the Norwegian Cystic Fibrosis Association. At these events, siblings are also included in fun activities, and older siblings can receive information and meet other relatives and close ones.

Growing up with a brother with CF gave me a different perspective on certain things in everyday life. Over time, I realized that play wasn't just play for him—it served as exercise and could therefore be extra exhausting. It was also strange to realize that he couldn't do all the same things I could, and I remember that sometimes made me sad. It's still hard to fully understand what it's like to live with a chronic illness. But it has made me realize that being healthy is not a freedom he has, and as his sister, I want to contribute to helping him live as well as possible.

– Sister of a brother with CF

GRANDPARENTS AND CF

When a child is diagnosed with cystic fibrosis, it affects the entire family, including grandparents. Often, they are among the first to be informed about their grandchild's condition, and many grandparents feel both care and concern, not only for their grandchild but also for their own child, who now faces a demanding parenting role. There are hundreds of grandparents in Norway with grandchildren who have CF. For many, this is a new and unfamiliar situation that raises both questions and emotions. How can you support both your child and grandchild without taking over or interfering too much? How can you be present, offer help and comfort, without crossing the parents' boundaries?

Supporting both parents and child

It's important to recognize that the role of grandparents often involves balancing different needs. They must support their own child, who is now a parent to a child with a chronic illness, while also being there for their grandchild. Many children turn to their grandparents for comfort and open up to them in a different way than they do with their parents, giving grandparents a unique and valuable position in the child's life. A CF grandfather expresses it this way:

> We were initially frustrated as parents because we couldn't help our son help his own child. We've learned that it's not always best to give advice based on our own experiences. Instead, we do what we can to support the family and let the parents figure out what's right for their child.
>
> – Grandfather of a child with CF

Finding the right balance

Grandparents face many questions: How can you be close without being overbearing? How can you help without taking over? What is my role in relation to the child's parents? It's largely about finding the right balance—being available but not dominant. Above all, it involves listening to the parents' wishes and needs and respecting the boundaries they set. Showing that you are reliable and provide reassurance when looking after the grandchildren is crucial, especially since CF requires ongoing attention to treatments and strict hygiene routines.

Knowledge brings confidence

The most important thing grandparents can do is to educate themselves about the condition. Understanding CF, its treatments, infection control guidelines, and how to adapt daily life provides both confidence and the ability to offer meaningful help. You can show interest by reading up, for example, through informational materials like the A5 booklet Grandparents and CF, and by asking the parents if you can join them for medical appointments—if they feel comfortable with that.

> Being a grandmother is a gift. My grandchild is cheerful and full of life, despite cystic fibrosis affecting his lungs and stomach. We rejoice in his smile but worry about treatments and infections. We adapt our lives to protect him, washing hands and being cautious. All for our grandchild.
>
> – Grandmother of a child with CF

> With new treatments, the future looks brighter for my mom than when I was growing up. Back then, the prognosis was completely different from today. Now I can look forward to her getting the chance to become a grandmother. Although I'm more optimistic now, I grew up marked by grief and a constant fear of losing her. I probably kept her at a distance to protect myself, but now I'm working on letting her back in and looking forward to our future together.
>
> – Grown woman, daughter of mother with CF

CHILDREN OF PARENTS WITH CF

Growing up with a parent who has cystic fibrosis can be confusing for children. Many parents with CF are unsure about how much they should tell their children about the condition, and young children often receive information only through everyday conversations without a structured explanation. Research from Norwegian children of CF patients shows that children and teenagers often have limited knowledge about CF, even though they live closely with the condition in daily life. Children may have existential questions that parents can feel unprepared to answer. The specialist healthcare system has a responsibility to ensure that children of parents with CF receive tailored and age-appropriate information, but this requires that parents themselves receive support and knowledge to feel confident in their role as communicators.

Some children growing up with a parent who has a lifelong illness may experience increased stress and emotional challenges. Some report living with greater fear, while others say they think less about it. Children's emotional responses also depend on external factors, so there is no one-size-fits-all answer to how a child will feel. Nevertheless, it's important to be attentive to children's needs and reactions. Therefore, it's recommended that parents set aside time for honest, age-appropriate conversations, ideally in collaboration with healthcare professionals.

Children should have the opportunity to ask questions, express their feelings, and know that it's okay to feel scared, angry, or confused. Parents should help their child not to worry alone. Explain that CF is part of the family's everyday life, but also that there is support and hope. It can be helpful to talk about changes in the parent's health when the child notices them—this can be a natural entry point for conversation. Children often understand more than we think, and openness creates a sense of security.

To you as a child

If you have a mom or dad with CF, it's completely normal to have lots of thoughts and feelings. You might wonder what CF really is, or you might worry about how your parent is doing. It's okay to feel confused, scared, nothing at all, or everything at once. Talk to your parents about what's on your mind—they want to help you understand. You can also talk to another adult you trust, like a teacher or another family member. Remember that you're not alone, and there are many other children like you across the country. If you want to talk to someone who understands you, you can ask your parents to contact The Norwegian Cystic Fibrosis Association, who can help you connect with others in similar situations.

> I think it's important that children get enough information about their parent's diagnosis and that opportunities are created for fact-based conversations. Preferably together with healthcare professionals.
>
> – Son of a mother with CF

PARTNERS OF PEOPLE WITH CF

Being a partner to someone with cystic fibrosis can involve a wide range of experiences, depending on your partner's individual health condition. It's completely normal to feel overwhelmed at the start. The medical terminology, treatment routines, and the emotional responsibility many partners take on can feel intense. As a partner, you are often the closest person, sharing a home and gaining a unique insight into what it's really like to live with a chronic, serious illness.

While family and friends may see your partner during healthier periods, you also witness the tougher days, which can feel isolating for some. This is especially true if you feel that others don't fully understand your shared daily life. But you are not alone, and there are many ways to make life fulfilling for both you and your partner. CF is part of everyday life, but it does not define your partner. There is still room for laughter, joy, and shared dreams. However, a common cold or flu can become serious for someone with CF, and as a partner, it can be hard to watch them struggle without being able to take away their pain. As a partner, you can provide valuable support through small, practical actions.

Assisting with daily routines—whether related to treatment, household chores, or emotional support, can be important. At the same time, it's equally important to take care of yourself. Set aside time for activities that give you energy, and remember that it's always good to have someone to talk to, whether it's a friend, family member, or others. In periods when things feel overwhelming, family therapy or conversations with healthcare professionals can help you find balance. Open communication is key. Ask your partner what they need, and share your own thoughts and concerns. Be generous with both your partner and yourself.

It can also be helpful to attend doctor's appointments or check-ups with the CF team to learn more about the condition. If you feel that others don't fully understand the challenges you face, connecting with a community can make a difference. The Norwegian Cystic Fibrosis Association offers support for partners through its peer support service, where you can talk to others who understand your daily life.

> It can be tough to see my partner sick, and at times I've been both scared and sad. My wife and I have been good at talking about it, and we've also gone to family therapy to help us be the best we can together during times when she's sicker.
>
> – Husband of a wife with CF

Resources

Whether you live with cystic fibrosis, are a relative or close one, or simply want to learn more, there are many forms of support, resources, and communities that can help you in everyday life. Here is an overview of key professional organizations, associations, and services that provide knowledge, support, and opportunities to connect with others who understand your situation.

PROFESSIONAL ORGANIZATIONS AND ASSOCIATIONS

Norwegian Resource Centre for Cystic Fibrosis (NSCF)
The NSCF is Norway's national competence center for CF. Here, you can find specialized knowledge, treatment guidance, and support for those with CF and their relatives and close ones.

- Visit: www.oslo-universitetssykehus.no/fag-og-forskning/nasjonale-og-regionale-tjenester/norsk-senter-for-cystisk-fibrose

The Norwegian Cystic Fibrosis Association (NFCF)
The NFCF is a patient organization that works for individuals with CF and their families. We offer support, information, and community through events and services. Become a member through our website and join the community.

- Visit: www.cfnorge.no

Sjelden.no
Sjelden.no gathers knowledge about rare diagnoses and offers digital courses and learning resources for patients, families, and professionals. Here, you can find e-learning courses to help you better understand CF.

- Visit: www.sjelden.no

National Center for Rare Diagnoses (NSSD)
The NSSD is a nationwide competence center that provides guidance and support for rare diagnoses, including CF. They offer courses, counseling, and information for both you and your relatives and close ones.

- Visit: www.sjeldnediagnoser.no

CONNECTING WITH A COMMUNITY

Peer Support Service
The NFCF offers peer support conversations for its members, where you can talk to someone who has CF or is a relative or close one. This is a valuable opportunity to share experiences, ask questions, and receive support from someone who understands your daily life.

- Find out more: www.cfnorge.no/likepersoner

Private Facebook Groups
The NFCF manages private Facebook groups for youth, adults with CF, and relatives and close ones. These groups are safe spaces where you can share thoughts, ask questions, and find community with others in similar situations. For access, contact: redaksjonen@nfcf.no

This brochure was created by the Norwegian Cystic Fibrosis Association with financial support from Vertex Pharmaceuticals.

Publisher:
Norwegian Cystic Fibrosis Association

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www.cfnorge.no

Design and printing:
Flisa Trykkeri AS

Thanks to our Professional Advisory Board for their medical contributions.

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