

# Staying on Track

Tips to help promote cystic fibrosis (CF) treatment adherence

This tool was created based on the research conducted by Professor Alexandra Quittner (PhD) on treatment adherence in cystic fibrosis.

Additional insights on the topics of adolescents and transitioning were provided by Ms Charlotte Dawson.

Additional insights on the topic of physical health were provided by Dr Evanirso Silva Aquino.

This document is intended for healthcare professionals to support their discussions with CF patients.

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# What is adherence and why does it matter?

‘Adherence’ is the extent to which you are able to stick to the treatments that your healthcare provider has prescribed.<sup>1</sup>

While you might see your treatment regimen as complex and time-consuming, it’s important that you take your prescribed treatments as directed by your healthcare provider, even if you are feeling well. Adherence keeps you healthy and is the best way to help you continue doing all the activities you enjoy.

Adhering to your prescribed treatment plan can help to:<sup>2</sup>

- Keep your lung function steady
- Avoid going into hospital
- Keep you healthy
- Continue your pleasant activities. Adherence means pursuing all of your enjoyable activities – not just CF treatments

In this document, we discuss some useful tips that can help you overcome the most common barriers to adherence that you might face.

Use the tabs to flip straight to the sections that are most relevant to your life right now.

## Common barriers to adherence:



Building confidence and knowledge in your treatments



Time-management and unexpected interruptions to your routine



Balancing treatments with other activities



Feeling comfortable telling people about your CF



Big life changes



Paying attention to how you feel – physically and emotionally

# CONFIDENCE & KNOWLEDGE

## Building confidence in and knowledge about your treatments

Knowing what each of your treatments do to keep you healthy, and having the confidence to do each of them correctly can help you stick to your prescribed treatment plan.



### Talk to your care team

- Make sure that you discuss each of your treatments in depth with your care team so you are clear what each of them does to keep you healthy
- Speak to your care team so that you know that you're taking each of your treatments correctly
- Ask the team if you are unsure about any of your treatments
- Talk to your care team if you are struggling to do any of your treatments as prescribed



Work with your CF team to create **a clear treatment plan**



Your prescribed treatment plan can be composed of a variety of treatment options



For further reading, please see the online resources below:

[COUNTRIES TO INSERT LOCAL WEBSITE AND TRUSTED WEB SOURCES]

# EXAMPLE OF A PRESCRIBED TREATMENT PLAN

To be completed by a healthcare professional

## Example treatment plan template

Treatment	Sequence of treatments	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday	Do I need to renew my prescription this week?
		Planned time for treatment							

Your prescribed treatment plan can be composed of a variety of treatment options. Each patient's treatment plan will vary.

# TIME & ROUTINE MANAGEMENT

## Managing your time and treatment routine

Work out a system that 'fits' your treatments into your daily routine, making it flexible enough to adapt to unexpected changes in your schedule.

Following are some suggestions:



Create a schedule that makes doing a **habit**

- Multitask your treatments with other activities that you enjoy, for example:
  - While watching a movie
  - When texting or emailing friends
- Move dinner to a later time to fit in with your treatments



Use your **day planner**

- Establish a routine for your treatments based on your schedule during the week and the one on weekends
- Highlight free time for treatment throughout each day



**Customise** your treatment

- If possible, ask your pharmacist if they can create customised blister packs to help you take your medicine



**Prepare for unexpected changes** in your routine

- Pack extra medication in your bag or backpack so that you are always prepared to do your treatments
- If possible, you may wish to keep a spare supply of medications in a place you visit often (i.e. grandparents' house, school/workplace locker)  
**Remember: Don't keep enzymes in a hot car!**<sup>3</sup>



Eat whenever it is **convenient** for you

- Change your mealtimes to accommodate your treatments



Keep an **emergency food stash** handy

- Keep this ready for any medications that need to be taken with food

# TIPS FOR BALANCING TREATMENT AND OTHER ACTIVITIES

## Balancing treatment and other activities

Combining your treatments with other activities you like can make it easier to stick to your treatment plan every day.



**Use the time you spend on treatments** to do other things:

- Study and read your notes
- Chill out and watch TV
- Read a book



**Create a reward system**

- Go for a walk with friends after you finish your treatments
- Spend time in nature to de-stress
- Try exercising
- Put yourself first by saying “No” when you need to
- Identify a rewarding self-care activity (such as getting your hair done, getting a massage, watching a film or favourite TV programme, or listening to music)
- Have a long walk at the park, on the beach or around your neighbourhood



**Have fun** with multitasking and your reward system:

- Watch a film with friends (virtually as needed)
- Have lunch or dinner with friends (virtually as needed)
- Play computer games
- Listen to your music

## TIPS FOR DISCLOSING YOUR CF

### **Telling people around you about your CF**

Telling your friends, peers, and partners that you are living with CF can be challenging. In this section, you will find some helpful language to get the conversation started. Remember that it is your choice to disclose what information you want, when you want to, and to whom.

# TIPS FOR DISCLOSING YOUR CF

Here is some helpful language to get the conversation started when disclosing to people around you:

## Ways of talking about your CF:

“Are you ready to go out for dinner?”

“I would love to go out, but I need to do a treatment before I go. If you don't mind, you could hang out with me while I do it.”

“What are you doing that takes so long in the mornings?”

“I have cystic fibrosis. I have to spend some time doing treatments every day. You are welcome to sit with me while I do them.”

## Additional tips:

- If you feel comfortable, try disclosing more details about your CF
- Let people see what your daily routine is like
- Share your feelings about CF and how it affects you day to day, both physically and emotionally
- Let your loved ones know what to expect when you have to go into the hospital for days or weeks at a time
- If you are in the hospital, contact others for support; let them know what works best for you
- If you need extra time to complete school or work assignments, ask for what you need
- **It's also OK not to disclose your CF; it's your choice!**



# TIPS FOR DISCLOSING YOUR CF

Here is some helpful language to get the conversation started when **talking to a peer or acquaintance**:

## Ways of talking about your CF:

“What are those pills for?”

“I have cystic fibrosis, so these pills are part of my treatment regimen.”

OR

“These pills help me with my cystic fibrosis symptoms.”

“You’ve had a cold for a while. Is everything OK?”

“I have cystic fibrosis, which causes me to cough, but it is not contagious.”

## Additional tips:

- Feel free to change the topic you are discussing following your response
- Disclose as much or as little information as you feel comfortable with
- **It’s also OK not to disclose your CF; it’s your choice!**

A PEER OR ACQUAINTANCE  
SUCH AS A TEACHER, COLLEAGUE OR FELLOW STUDENT

# TIPS FOR DISCLOSING YOUR CF

## Telling people around you about your CF

Telling your friends, peers, and partners that you are living with CF can be challenging. Remember that it is **your choice to disclose** what information you want, when you want to, and to whom.

### Take the next step: find a **treatment buddy**

This should be someone who cares about you and will encourage you to do your treatments regularly – even when you do not feel like doing them. Examples of a treatment buddy can include:<sup>2</sup>

- A friend
- A room-mate
- A family member
- A partner
- Someone who is also working to achieve a goal – you can encourage each other!

# BIG LIFE CHANGES

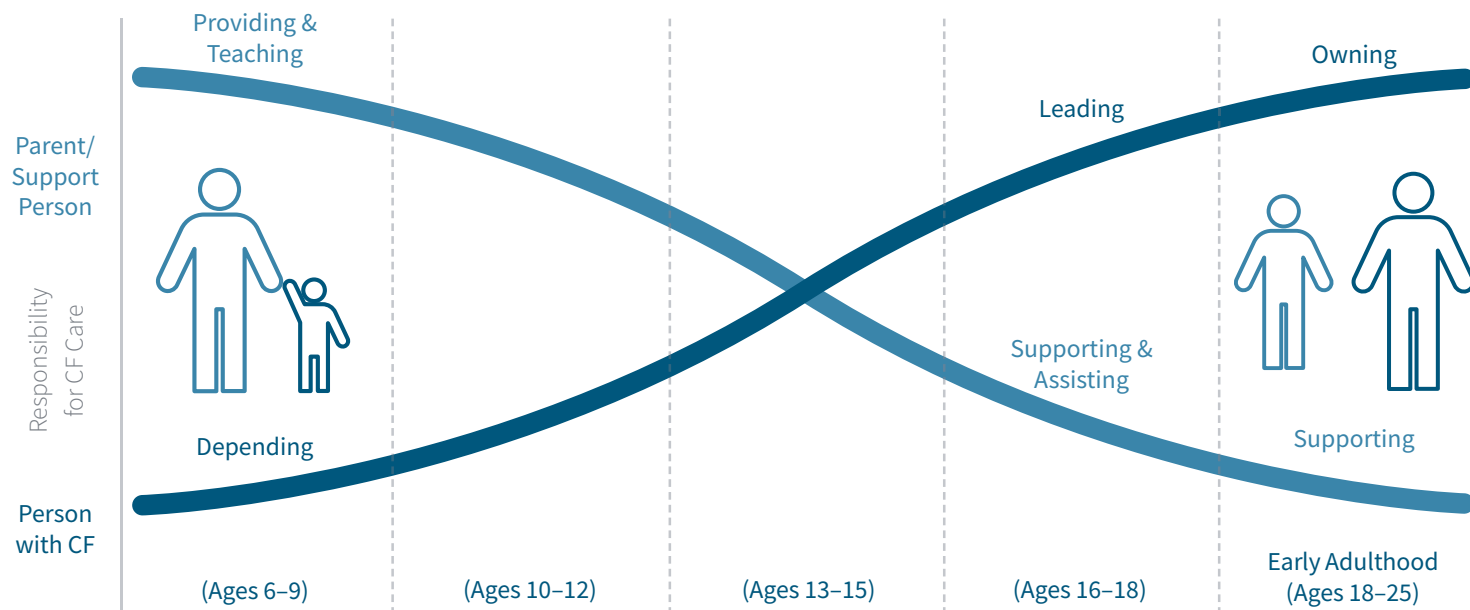
## Transitioning from the paediatric to adult clinic

The process of gradually preparing you for the change from paediatric to adult care is referred to as a 'transition'.

It is a process that happens over time, and is designed to help you:<sup>4-6</sup>

- Prepare to transfer from the paediatric clinic to the adult clinic
- Prepare for the transfer of responsibility from your parent/caregiver to yourself as an adult patient
- Take ownership of your treatment, as you become more independent

Take a look at the figure below to see how and when the transfer of responsibility can happen gradually as you grow into adulthood:<sup>4</sup>



Adapted from: <https://www.cfrise.com/cystic-fibrosis-transition>. Accessed June 2022.

# ADOLESCENCE

## Transitioning from the paediatric to adult clinic

Tips to help you begin to take responsibility for your own care:

### Ask questions and practise managing CF on your own

As an adolescent, you can participate in clinic visits while your parents stay outside the room.

- Ask to have part of the clinic visit on your own; then the CF team can bring your parents in to review

Think of questions that you would like to ask your CF Team. Don't worry if it feels unusual at first – this is your chance to practice!

- Before your next visit, prepare a question or two that you would like to ask your CF team

### Take responsibility for your own treatment adherence

Remember to apply the adherence tips discussed earlier in this flipchart:

- Make your treatment a part of your daily routine
- Be prepared for unexpected changes to your schedule

### Meet your new care team

Before transferring to an adult clinic, your paediatric CF team can schedule a meeting to introduce you to your new adult CF team.

Consider sharing your contact details with your CF care team – this is a great way to build a relationship with your healthcare providers from the get go!

**COUNTRIES TO ADAPT ACCORDING TO LOCAL REGULATIONS ON PERSONAL DATA SHARING BETWEEN PATIENTS AND HCPs**

# ADOLESCENCE

## Transitioning from the paediatric to adult clinic

### A MESSAGE TO CAREGIVERS:

Children with CF often rely on their caregivers for help in managing their medications and organising their treatment schedule. Parental support often has positive effects on treatment adherence.<sup>2</sup>

**However, as your child approaches adolescence, it is important to:**<sup>2,6</sup>

- Gradually introduce tasks that they can do on their own
- Educate them about their medications and treatments
- Help them learn to identify and track their symptoms
- Encourage them to become more independent and start transitioning some of the responsibility to them

This helps to prepare a child for the transfer to their adult clinic. **Remember – the goal is to empower the child or adolescent to maintain treatment adherence into adulthood.**

Empower your adolescent to take ownership early on to help normalise the CF transition process and align it with adolescent development.<sup>4</sup>

This helps make the transfer to an adult centre an expected and planned event.<sup>5</sup>

With the help of your child's healthcare team, you can play a critical role in preparing your child/adolescent for life as an adult with CF.<sup>6</sup>

# EARLY ADULTHOOD

## Embracing independence during early adulthood

Moving out of the house to attend school or start a new job is an exciting step that is full of opportunities for adventure and self-growth.

During this time, it is important that you find ways to take care of yourself physically and emotionally – including staying on top of your daily treatments.

Here are some suggestions to help you to take responsibility for your treatments:<sup>2</sup>



### Continue to involve your CF team

- As your schedule changes, your CF team can work around it



Remember the suggestions earlier in this guide around **managing your time and preparing for unexpected changes to your routine**



### Establish a social and emotional support system:

- Friends can keep you company while you do your treatments
- Friends can provide support and encouragement to get treatments done
- Remember the suggestions that you just learned on disclosing your CF
- Remember that your emotional well-being is important too. Asking for help and support is key!

# PARENTHOOD

## Parenthood and CF

Becoming a new parent is a stressful time for any adult, but the added burden of doing your CF treatments and staying healthy can be more difficult.

For some parents, having a child can be a powerful source of motivation to stay healthy, while sometimes, personal health needs become less of a priority than the needs of your child.<sup>7</sup>

**Here are some suggestions to help you prioritise your health as a new parent, and help you stay on track with your treatments:**



### **Look to your CF team for support with:**

- Planning outpatient appointments, providing homecare, and keeping in touch through phone or video calls
- A referral to a midwife or health visitor to help relieve stress for both you and your partner



### **Remember that your partner is part of your support system too**

Appointments, providing homecare, and keeping in touch through phone or video calls

- Your partner should be involved in all aspects of daily life, including helping you find time for yourself and for your treatments, caring for your child, and helping with household tasks



### **Naptime is YOUR time**

Your child's naptime is a great opportunity to dedicate some of this time to doing your treatments



### **Call on your family and friends**

Ask family or friends to watch your child so that you can focus on doing your treatments and getting some time to rest



### **Reach out to the CF community**

New parents with CF are a great resource to provide you with adherence tips and emotional support

# PHYSICAL, MENTAL & EMOTIONAL HEALTH

## Taking care of your physical health

Understanding that your physical and emotional functioning are tied together is an important factor in staying adherent and keeping yourself healthy. Exercise can help your mood!

### Talk to your CF care team before starting any new exercise regime

- Exercise does not replace your regular airway clearance (chest physiotherapy)
- Incorporate huff coughing during your exercise – it will help to remove lung secretions<sup>8</sup>

### Patients with bone mineral deficiency

- Avoid contact sports unless approved by a physiotherapist
- Weight training is encouraged

### Exercise can help<sup>9</sup>

- Increases endurance and improves circulation
- Releases endorphins, which positively affect emotional function



# PHYSICAL HEALTH

Exercise can be beneficial for all people living with CF, regardless of their lung function. Check out these age-based recommendations for **1–6 year olds** to get some inspiration for their exercise routine:<sup>10,11</sup>

**60 minutes/day** of developmentally appropriate activity that engages the whole body, increases breathing and heart rate, and increases muscle strength, such as:

- **Jumping**
- **Walking**
- **Cycling**
- **Sports**
- **Climbing**
- **Running**
- **Swimming**
- **Playground activities**



**TIPS:** Play and have fun, involve the whole family and try lots of different activities. Be a role model. Children who regularly see their parents enjoying sports and physical activity are more likely to do so themselves.<sup>12</sup> When possible, exercise should be seen an essential daily routine, like brushing your teeth.

# PHYSICAL HEALTH

Exercise can be beneficial for all people living with CF, regardless of their lung function. Check out these age-based recommendations for **7–12 year olds** to get some inspiration for their exercise routine:<sup>10,11</sup>

**60 minutes/day** in a variety of enjoyable activities, in particular with family or friends

## **AEROBIC EXERCISES** (30–60 minutes at least 3x/week)

- Walking, running, swimming, biking, dancing, team sports, outdoor adventure activities, active video games
- Take classes, join a team, or club

*The intensity of the exercise should be where breathing is somewhat hard, but you are still able to have a conversation*

## **RESISTANCE TRAINING**

- Body-weight-engaging activities can be done to strengthen muscles and bones:
  - Running, jumping and ball games



**TIP:** Activities should promote normal motor development, such as agility and balance/coordination skills

# PHYSICAL HEALTH

Exercise can be beneficial for all people living with CF, regardless of their lung function. Check out these age-based recommendations for **13–18 year olds** to get some inspiration for their exercise routine:<sup>10,11</sup>

**60 minutes/day** in a variety of enjoyable activities, in particular with family or friends

## AEROBIC EXERCISES (30–60 minutes at least 3x/week)

- Walking, running, swimming, biking, dancing, team sports, outdoor adventure activities, active video games
- Take classes, join a team, league, or club

*The intensity of the exercise should be where breathing is somewhat hard, but you are still able to have a conversation*

## RESISTANCE TRAINING

- Formal resistance training 2–3 times per week per muscle group
  - Upper limbs, lower limbs, and trunk muscles
- Should complete 1–3 sets of 8–12 reps (weight training must be supervised)

*Ask your CF care team to evaluate your exercise capacity and set your training intensity according to your fitness level*



**TIP:** Choose activities that fit your interests and abilities.

Talk to your doctor or other member of your healthcare team for advice on how to adapt physical activity for CF-related complications (for example, CF-related diabetes)

# PHYSICAL HEALTH

Exercise can be beneficial for all people living with CF, regardless of their lung function. Check out these age-based recommendations for **19+ year olds** to get some inspiration for their exercise routine:<sup>10,11</sup>

**150 minutes/week or more** (preferably 300 minutes/week)  
in a variety of activities of choice

## AEROBIC EXERCISES (30–60 minutes at least 3x/week)

- Walking, running, swimming, biking, dancing, team sports, outdoor adventure activities, active video games
- Take classes, join a team, league, or club

*The intensity of the exercise should be where breathing is somewhat hard, but you are still able to have a conversation*

## RESISTANCE TRAINING

- Formal resistance training 2–3 times per week per muscle group
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*Ask your CF care team to evaluate your exercise capacity and set your training intensity according to your fitness level.*



**TIP:** Talk to your doctor or other member of your healthcare team for advice on how to adapt physical activity for CF-related complications (for example, CF-related diabetes)

# MENTAL HEALTH

## Paying attention to your mental health

People with CF often report high rates of anxiety and depression, which can be a barrier to getting your treatments done.<sup>13-16</sup>

These feelings may also increase as you get older or if you experience worsening health. It is helpful to acknowledge these feelings when they happen and have activities to help you relax your mind and de-stress.

### Activities to reduce stress and calm your mind



Pause and take a few deep breaths



Talk to someone in your support system<sup>2</sup>



Develop a guided imagery practice and add music if you like<sup>17</sup>



Write down 'moments of joy' (moments when you felt good or something went well). Try to notice and record **one to three of these moments each day**<sup>16</sup>



Do progressive muscle relaxation



Challenge negative thoughts and replace them with positive ones



Learn how to access your 'relaxation response'. Download a meditation or mental health app on your smartphone



Being in nature has been shown to have many benefits. Feel yourself be more present and aware of the beauty around you

# EMOTIONAL HEALTH

## Paying attention to your well-being

Consider learning some cognitive behavioural therapy (CBT) skills. Use the following points to cope with stress and anxiety in your daily life:

### Identify a key stressor in your life<sup>17</sup>



- How does it affect your emotions, thoughts, and behaviours?
- How are you currently coping with this stressor?
- Use alternative coping strategies:
  - Deep breathing
  - Progressive muscle relaxation
  - Problem-solving
  - Listening to music
  - Identify a place in nature you find relaxing
  - Relaxing guided imagery exercises can be done with music

### Identify moments when you are present<sup>16</sup>



#### Experience moments of joy:

- Write down one to three (but at least one) of these moments each day
- This exercise helps you notice the smaller moments that we often overlook, when something joyful happens
- It's especially hard to notice these moments when you are busy and feeling stressed

### Use behavioural activation<sup>18</sup>



#### When you feel sad, pick an activity that distracts you from these negative feelings and re-engages you with positive thoughts.

- Yoga
- Visit a close friend
- Take a bike ride
- Listen to a podcast
- Cook
- Bake some of your favourite foods
- Call someone for support

### Use problem-solving<sup>19</sup>



#### Identify your own barriers to adherence – think about what is preventing you from staying on track.

- Identify the barrier
- Brainstorm possible solutions (with or without the help of others)
- Rate each solution with a '+' or '-' and consider only the solutions that get a positive rating
- Think about how you will execute the plan: who, what, where, and how

# BEFORE YOU LEAVE YOUR APPOINTMENT

**Take 2 minutes!**

**With your CF team member, write down your answers to the following questions on a piece of paper:**

1. What is one thing that you learned today?
2. What is one thing that you will start doing to improve your adherence to your daily treatments?
3. Who is one person you can call if you need motivation or encouragement to do your treatments?

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