

Welcome to the CF CARE Adherence Management Flowchart

Dear colleagues,

The factors that influence treatment non-adherence in CF are wide ranging and can vary vastly from patient to patient. To help you better understand these factors, we have developed this comprehensive flowchart on the drivers of non-adherence and strategies to address them.

Based on the latest CF adherence research, this interactive flowchart is intended to support you in creating personalised care plans to address non-adherence with the aim of improving outcomes in CF.

We hope you find it useful.

The CF Collaborative Adherence Resources & Education (CARE) Steering Committee

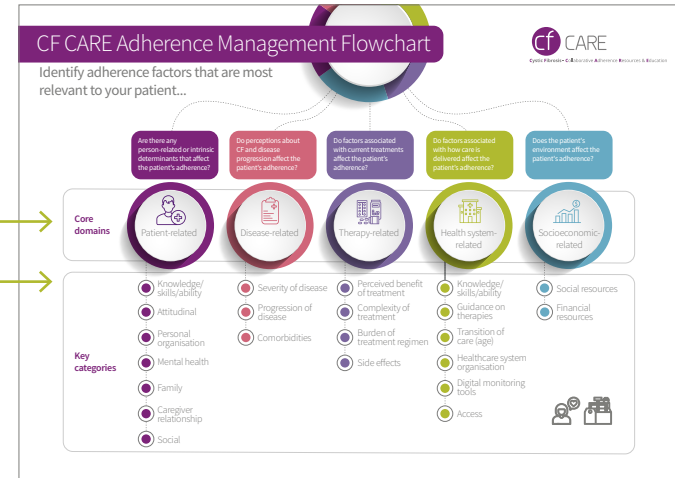


How to use guide

The material is fully interactive and a series of icons can help you navigate to areas of interest and factors that you have identified in your patient with CF.

The flowchart is organised in a hierarchical manner in which there are five **core domains** which cover broad areas of adherence. Each core domain is broken down into a series of **key categories**. By selecting a key category you will deep-dive into the material and explore critical factors that you see in your patients in clinic as well as **possible interventions** that could support and promote optimal adherence.

Home page



Core domains

Key categories

Deep dive



Key categories

Possible interventions

Critical factors

Home button

Reference bank



CF CARE Adherence Management Flowchart

Identify adherence factors that are most relevant to your patient...

Are there any person-related or intrinsic determinants that affect the patient's adherence?

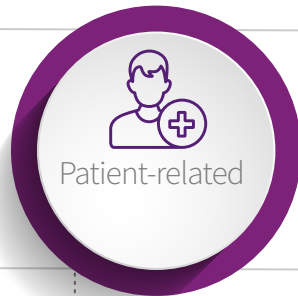
Do perceptions about CF and disease progression affect the patient's adherence?

Do factors associated with current treatments affect the patient's adherence?

Do factors associated with how care is delivered affect the patient's adherence?

Does the patient's environment affect the patient's adherence?

Core domains



Key categories

Knowledge/skills/ability

Attitudinal

Personal organisation

Mental health

Family

Caregiver relationship

Social

Severity of disease

Progression of disease

Comorbidities

Perceived benefit of treatment

Complexity of treatment

Burden of treatment regimen

Side effects

Knowledge/skills/ability

Guidance on therapies

Transition of care (age)

Healthcare system organisation

Digital monitoring tools

Access








Social resources

Financial resources





Patient-related

-  Knowledge/skills/ability
-  Attitudinal
-  Personal organisation
-  Mental health
-  Family
-  Caregiver relationship
-  Social

Knowledge/skills/ability

Critical factors affecting adherence


Treatment knowledge¹⁻¹⁰ e.g. lack of understanding of efficacy, safety and mode of action of medication, treatment- and care-taking procedures, lack of clarity on treatment recommendations, lack of confidence to discuss treatment management

Disease knowledge^{5,7,11-16} e.g. limited understanding can lead to incorrect perception and behaviours, lack of confidence to discuss disease can lead to disengagement with HCPs/family/friends/peers, full disease understanding is not always necessary

Capability of administering therapy^{2,10,12,15,17} e.g. experience complications and discomfort, incorrect technique, misunderstanding instructions

Academic education¹⁸⁻²⁰ e.g. lower level of education can result in less adherence

 Click for possible interventions

 Click for list of references





Patient-related

- Knowledge/skills/ability
- Attitudinal
- Personal organisation
- Mental health
- Family
- Caregiver relationship
- Social

Possible interventions to support optimal adherence

Provision of treatment and disease information^{1,3,4,9,12}

Availability of patient-centred, age-appropriate, information to encourage treatment involvement and informed decision-making, and may provide additional motivation

- **Varied content** such as disease background information and description of potential benefits and side effects of treatment
- **Multi-format** can increase reach of education such as leaflets, videos, demonstrations and webcasts/podcasts
 - National CF foundations have multi-format content for patients and parents/caregivers. Examples of CF organisations include: www.cff.org (US), www.cfcc.org.au (Australia) and www.cysticfibrosis.org.uk (UK). Further information on national organisations can be found at: www.ecfs.eu/ctn/national-cf-associations

Clear patient communication and assessment regarding knowledge^{4,11,12,14,15}

- Assessment of knowledge by CF care teams is vital and can determine if re-education is required
 - Consider utilising the 'teach-back' method – a method used to confirm whether a patient understands what is being explained to them – if they understand, they are able to 'teach-back' the information accurately
- Actively listen to patients in an open and honest manner so their knowledge and misconceptions are open for discussion
 - See [Motivational Interviewing resources](#)²¹ (Motivational Interviewing Module 3, 'Listening and building a relationship' educational video)

Facilitating administration of treatment¹⁶

- Educational programmes to reinforce and educate patients on treatment and provide practical guidance on administration techniques, e.g. the US ReEducation of Airway Clearance Technique (REACT) programme
- Early development of self-care skills through repeated practice and encouragement



Patient-related

Knowledge/
skills/ability

Attitudinal

Personal
organisation

Mental health

Family

Caregiver
relationship








Social

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Patient-related

-  Knowledge/skills/ability
-  **Attitudinal**
-  Personal organisation
-  Mental health
-  Family
-  Caregiver relationship
-  Social

Attitudinal

Critical factors affecting adherence

Desire for normality¹⁻⁹ e.g. treatments can interfere with leading a ‘normal life’

Feeling well enough that treatment isn’t needed^{1,10} e.g. not taking treatment when the patient “feels ok” or has no physical symptoms

Believing that 100% adherence is unachievable¹ e.g. “it’s never going to be absolutely one hundred percent”

Believing in treatment success^{3,9,11-15} e.g. the perception of how important or necessary certain treatments are and their benefit










 Click for possible interventions

 Click for list of references





Patient-related

-  Knowledge/skills/ability
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Attitudinal

Critical factors affecting adherence


Coping strategies¹⁶ e.g. positive reframing, acceptance, and humour (positive coping strategies)

Cognitive dissonance^{17,18} e.g. incompatible beliefs such as “I’m sensible and want to be well” and “I don’t do my treatment”

Religious/spiritual beliefs (literature/research from the US)¹⁷⁻²⁴ e.g. parents who give responsibility to God to care for their child after they have done what is within their own power










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Attitudinal

Critical factors affecting adherence

Denial of diagnosis²⁵ e.g. denial and avoidance as psychological resistance strategies

Intentionally forgetting²⁶ e.g. utilising forgetfulness to normalise more consistent non-adherence to treatment

Refusing to take medication^{1,27} e.g. ignoring reminders to take treatment or unwillingness to take medication in public



 Click for possible interventions

 Click for list of references





Patient-related

Knowledge/
skills/ability

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Personal
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Family

Caregiver
relationship

Social

Possible interventions to support optimal adherence



Engage patients in their care¹¹

To allow them to develop an understanding of the disease and its treatment, their skills, and confidence to effectively manage their regimen

- See the **Individual Treatment Plan (ITP) tool**²⁸ (denotes purpose of treatment to reinforce importance of adherence and set individualised goals)
- See the **Visual Analogue Scale for Adherence and Non-Adherence (VASANA) tool**²⁹ (identifies patient's confidence with current treatment/therapy)
- See the **Motivational Interviewing resources**³⁰ (Motivational Interviewing Modules 3–5, 'Evoke reasons to change' and 'Starting to think about a plan and the importance of increasing confidence' educational videos, adherence booklet and adherence toolkit)

Behavioural change¹⁷

Patient-centred counselling style to help patients change behaviour

- See the **Visual Analogue Scale for Adherence and Non-Adherence (VASANA) tool**²⁹ (measures current adherence)
- See the **Motivational Interviewing resources**³⁰ (all Motivational Interviewing modules, all educational videos, adherence booklet and adherence toolkit)





Patient-related

Knowledge/
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Possible interventions to support optimal adherence

Positive feedback/affirmations and reinforcement¹⁷

Provide systematic encouragement and rewards to patients for reaching goals while avoiding blame and criticism
– See the [Motivational Interviewing resources](#)³⁰ (Motivational Interviewing Module 5, adherence booklet, adherence toolkit)

Develop communication skills in health carers¹⁷

To enable constructive conversations with patients and avoid unhelpful exchanges that increase resistance to change in poorly adherent patients
– See the [Motivational Interviewing resources](#)³⁰ (Motivational Interviewing Modules 3 and 4, 'Focusing on change and handling resistance' and 'Listening and building a relationship' educational videos, adherence booklet and adherence toolkit)





Patient-related

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References

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Patient-related

Knowledge/
skills/ability

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Personal
organisation

Mental health

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Caregiver
relationship

Social

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Personal organisation

- Knowledge/skills/ability
- Attitudinal
- Personal organisation
- Mental health
- Family
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- Social

Critical factors affecting adherence


Time management¹⁻¹⁹ e.g. lack of time or time pressures, reduced adherence during weekends/holidays/summer, highlighting the need for a structured daily routine with potential for flexibility to reflect need for independence (especially for adolescents)

Unintentionally forgetting treatment^{2,4,6,7,9,20} e.g. forgetfulness

Prioritisation of care^{5,7,13,16,17,21} e.g. intentionally deprioritising treatments due to competing priorities such as being busy with other activities, competing social and work demands



 Click for possible interventions

 Click for list of references





-  Knowledge/skills/ability
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-  Personal organisation
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-  Family
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-  Social


Personal organisation

Critical factors affecting adherence

Adapting to change in environment^{2,9,11,13,15,22-24} e.g. long-distance travel, social events, new workplace/school, unexpected errands, change in circumstances, logistical barriers when travelling with CF equipment and medications



 Click for possible interventions

 Click for list of references





- Knowledge/skills/ability
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Possible interventions to support optimal adherence

Treatment reminders^{5,7,16}

To provide structure and remind patients to take their medication or complete their therapy

- See the **Individual Treatment Plan (ITP) tool**²⁵ (denotes day and time for treatments)
- See the **Motivational Interviewing resources**²⁶ (Motivational Interviewing Module 5, 'Starting to think about a plan and the importance of increasing confidence' educational video)
 - E.g. mobile phone alarms, digital apps, stickers, placing medications in accessible locations, and incorporating treatment into an existing routine or behavioural sequence (i.e., teeth brushing)

Tailor/simplify patients' treatment regimen^{1,3}

To reduce complexity, meet the patient's individual needs, ensure compatibility with the patient's daily routine, and make the treatment plan easier to follow

Establish structured daily routines^{5,13,14,18}

With consultation between the healthcare professional and patient/family to ensure time for treatment and other activities, as well as integrate treatment plans within the family's and/or the patient's daily activities

- See the **Individual Treatment Plan (ITP) tool**²⁵ - develop the treatment plan in collaboration with the patient and family/caregiver
- See the **Motivational Interviewing resources**²⁶ (adherence booklet and toolkit [weekly diary, change plan])
- While developing daily routines is key, flexibility to adjust schedules is an equally important skill for patients/caregivers to learn

Uncover real reasons for non-adherence and devise potential solutions²⁶

- See the **Motivational Interviewing resources**²⁶ (Motivational Interviewing Module 5, 'Starting to think about a plan and the importance of increasing confidence' educational video, adherence toolkit - e.g., problem-solving worksheet)



Patient-related

Knowledge/
skills/ability

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Patient-related

- Knowledge/skills/ability
- Attitudinal
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Mental health

-  Knowledge/skills/ability
-  Attitudinal
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-  Caregiver relationship
-  Social


Critical factors affecting adherence

Depression¹⁻¹⁶ e.g. denial of CF diagnosis, symptoms and comorbidities, low perception of parental relationship, reduced motivation, negative perception of medication, avoidance behaviours

Anxiety^{1,3,4,6,8,14,16-18} e.g. fear, irritability, anger, worries about the future, feelings of loss of control, acute and excessive fear of a medical or surgical procedure leading to avoidance, fear of cross infection, avoidance behaviours

Poor caregiver mental health^{1,12,19-21} e.g. feeling isolated, unresolved grief around CF diagnosis

 Click for possible interventions

 Click for list of references





Possible interventions to support optimal adherence

Routine patient care to prevent poor mental health^{1,3,4,6,20-25}

- Patients with CF and caregivers should be offered education and preventative, supportive interventions to promote coping skills and disease management, e.g. cognitive behaviour therapy and problem-solving techniques
- Multidisciplinary care teams should provide support in a sensitive and empathetic manner
- Social workers or mental health specialists can provide family-based assessment and intervention
- Self-care and emotional wellness should be encouraged for patients with CF and caregivers
 - National CF foundations have supportive materials on emotional wellness. Examples of CF organisations include: www.cff.org (US), www.cfcc.org.au (Australia) and www.cysticfibrosis.org.uk (UK). Further information on national organisations can be found at: www.ecfs.eu/ctn/national-cf-associations

Ensure screening for mental health^{1,2,5,6}

- Per the International Committee on Mental Health in CF (ICMH) guidelines, annual screening for both caregivers and patients should be conducted. If elevated levels of depression and anxiety are noted, clinical diagnostic procedures should be implemented, followed by evidence-based psychological and/or pharmacological interventions¹
- **CF Foundation and European CF Society consensus statements**¹
 - **European CF Society Mental Health Working Group website** (contains information on mental health, screening and treatment tools, and online webinars/courses)²⁶



Patient-related

Knowledge/
skills/ability

Attitudinal

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organisation

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References

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Patient-related

- Knowledge/skills/ability
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






Patient-related

Family

Critical factors affecting adherence

Family support and organisation¹⁻²⁰ e.g. parents' intentions to support adherence, family dynamics and function, communication within the family, routine family behaviours, importance of routine and consistency

Differences in treatment beliefs between the patient and family² e.g. beliefs regarding perceived treatment benefit

-  Knowledge/skills/ability
-  Attitudinal
-  Personal organisation
-  Mental health
-  Family
-  Caregiver relationship
-  Social



Click for possible interventions










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Patient-related

-  Knowledge/skills/ability
-  Attitudinal
-  Personal organisation
-  Mental health
-  **Family**
-  Caregiver relationship
-  Social

Family

Critical factors affecting adherence

Family involvement^{2,8,10,14-17,20-22} e.g. resentment from young patients, tensions as responsibility for care changes with age, parents letting go too soon, adult patients with children having less time for treatment, partner involvement with care, adult patients as carers, adults patients may have a reliance on social support


Parent/caregiver mental health^{4,10,12,15,23-26} e.g. suffering anxiety and depressive symptoms, feeling isolated

Responsibility for treatment management^{1-3,27} e.g. relying on caregivers, distrust between the patient and HCPs/family when expectations are not met*

*adult patient



 Click for possible interventions

 Click for list of references





Patient-related

Knowledge/
skills/ability

Attitudinal

Personal
organisation

Mental health

Family

Caregiver
relationship

Social



Possible interventions to support optimal adherence

Motivational interviewing including family members and the patient together²⁸

To elicit behaviour change to resolve ambivalence

– See the **Motivational interviewing resources**²⁸ (adherence booklet)

Provision of treatment information and family support^{6,10-12}

Can be used to support/initiate conversations regarding adherence and gain confidence in providing treatment as well as identifying the key necessary aspects of care

– National CF foundations have supportive materials on emotional wellness. Examples of CF organisations include: **www.cff.org (US)**, **www.cfcc.org.au (Australia)** and **www.cysticfibrosis.org.uk (UK)**. Further information on national organisations can be found at: **www.ecfs.eu/ctn/national-cf-associations**

Suggest connecting with patient organisations^{29,30}

Open forum for patients as well as parents/caregiver to share concerns and discuss experiences with their peers, i.e. balance of CF care with other family members

– National CF foundations have supportive materials on emotional wellness. Examples of CF organisations include: **www.cff.org (US)**, **www.cfcc.org.au (Australia)** and **www.cysticfibrosis.org.uk (UK)**. Further information on national organisations can be found at: **www.ecfs.eu/ctn/national-cf-associations**





- Knowledge/skills/ability
- Attitudinal
- Personal organisation
- Mental health
- Family
- Caregiver relationship
- Social



Possible interventions to support optimal adherence

Ensure appropriate access to mental-health services^{23,24,31}

Annual screening of parent/caregiver/adult patient mental health and awareness of support programmes

– **CF Foundation and European CF Society consensus statements²³**

– If moderate-to-severe clinical severity has been diagnosed, awareness of evidence-based psychological interventions (including CBT, IPT and ACT) and treatments should be considered^{24,31}

Determine responsibilities in disease management^{2,27}

Identify family member who is primarily responsible for each component of disease management and transition of parent-guided to self-guided care





Patient-related

- Knowledge/skills/ability
- Attitudinal
- Personal organisation
- Mental health
- Family
- Caregiver relationship
- Social



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Patient-related

- Knowledge/skills/ability
- Attitudinal
- Personal organisation
- Mental health
- Family
- Caregiver relationship
- Social










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Caregiver relationship

-  Knowledge/skills/ability
-  Attitudinal
-  Personal organisation
-  Mental health
-  Family
-  Caregiver relationship
-  Social

Critical factors affecting adherence

Child engagement in care routine¹⁻³ e.g. taking on greater responsibility for their care

Transitioning of caregiver support^{1,4,5} e.g. relying less on caregivers, parents unwilling to 'let go', caregivers letting go too soon, increased need for caregiver support when health status deteriorates

 Click for possible interventions

 Click for list of references





Patient-related

Knowledge/
skills/ability

Attitudinal

Personal
organisation

Mental health

Family

Caregiver
relationship

Social



Possible interventions to support optimal adherence

Gradual immersion into independent self-management⁴

To encourage progression into adulthood and enhance understanding of the disease and its treatment, their skills, and provide support to effectively manage their regimen⁴

- See the **Individual Treatment Plan (ITP) tool**⁶ (denotes purpose of treatment to reinforce importance of adherence and set individualised goals)
- See the **Visual Analogue Scale for Adherence and Non-Adherence (VASANA) tool**⁷ (identifies patient's confidence with current treatment/therapy)
- See the **Motivational Interviewing resources**⁸ (Motivational Interviewing Modules 3–5, 'Evoke reasons to change' and 'Starting to think about a plan and the importance of increasing confidence' educational videos, adherence booklet and adherence toolkit)

Access to wider CF care team^{1,4}

Provide outpatient care to support self-management responsibilities and assist patients with medication access¹

Encourage help-seeking behaviour

To accept support from partner/family/friends as they are unable to be solely responsible



Patient-related

Knowledge/
skills/ability

Attitudinal

Personal
organisation

Mental health

Family

Caregiver
relationship

Social










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Patient-related

-  Knowledge/skills/ability
-  Attitudinal
-  Personal organisation
-  Mental health
-  Family
-  Caregiver relationship
-  Social

Social

Critical factors affecting adherence


Social life¹⁻⁵ e.g. interferes with social activities, want to lead a 'normal' life with school, work or family goals

Social pressures^{2,5-11} e.g. social embarrassment, desire for social acceptance, recursive perception*

Non-familial support system^{2,12,13} e.g. restricted peer support due to infection avoidance

*how an individual perceives how others view them

 Click for possible interventions

 Click for list of references





- Knowledge/skills/ability
- Attitudinal
- Personal organisation
- Mental health
- Family
- Caregiver relationship
- Social



Possible interventions to support optimal adherence

Engaging young patients with other patients who have CF^{5,7}

Involve them in ways to improve communication of their experiences so peers understand them and they feel understood

- Older adults with CF share their stories of navigating social implications of their disease via forums and blogs
- Electronic interactions with other patients with CF through social media and web-based social support

Wider support network^{1,5}

- One-on-one appointments with social workers, therapists, and other healthcare professionals
- Encourage support from friends without CF and inclusion in their CF story

Tailor/simplify patients' treatment regimen¹⁴

To reduce complexity and strike a balance between burden and feeling 'normal', meet the patient's individual needs and make the treatment plan easier to follow

- See the **Individual Treatment Plan (ITP) tool¹⁵** (denotes day and time for treatments)

Career advice/counselling^{16,17}

Discuss career goals and potential limitations, workplace risk for patients with CF, disclosure of diagnosis and work adjustment (i.e. flexible hours)



Patient-related

- Knowledge/skills/ability
- Attitudinal
- Personal organisation
- Mental health
- Family
- Caregiver relationship
- Social






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Disease-related

Severity of disease

-  Severity of disease
-  Progression of disease
-  Comorbidities

Critical factors affecting adherence

Deteriorating health¹⁻³ e.g. lung function, gastrointestinal symptoms

Recent pulmonary exacerbations and/or hospitalisations^{2,4,5}

Perception of disease severity^{6,7} e.g. perceive their health issues as less/more severe than that reported by healthcare professional, or necessity for medication may be influenced by the severity of their illness



Click for possible interventions



Click for list of references





Disease-related

Severity of disease

Progression of disease

Comorbidities

Possible interventions to support optimal adherence

Assess medication belief system and effective communication⁶

Explore patients' and families' belief systems and communicate in an open and honest manner the reality of the disease condition, its progression and consequences for everyday activities into adulthood

- Over-adherent patients/caregivers need to be reminded although treatment is important, so are other aspects of their lives such as school/work and social interaction

Regularly monitor patient's health status¹

- Regularly monitor pulmonary function and provide patients with function test results to help increase adherence
- Establish individual health reference points with patients to help estimate their disease severity and physical condition, such as changes in their fitness during the same activity (e.g. everyday walk), to realign their therapy as needed

Skills training for patients/caregivers⁸⁻¹⁰

E.g. how to use a nebuliser or a positive expiratory pressure mask for airway clearance, as inhalers and therefore technique changes with age

- Educational programmes to reinforce and educate patients/caregivers on treatment as well as periodically assess and provide practical guidance on administration techniques, e.g. US ReEducation of Airway Clearance Technique (REACT) programme
- Increase familiarity with the medication, e.g. providing patient-friendly instructions, encouraging parental involvement via direct and non-direct instructions



Disease-related



Severity of disease



Progression of disease



Comorbidities






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Disease-related

Progression of disease

-  Severity of disease
-  Progression of disease
-  Comorbidities

Critical factors affecting adherence

Accelerated disease progression in adolescents¹ e.g. developmental challenges intersect with disease progression

Anxiety due to disease progression² e.g. increased anxiety when considering disease progression

Patient perception as disease progresses³ e.g. patients perceive themselves to be less healthy



Click for possible interventions



Click for list of references





Disease-related

- Severity of disease
- Progression of disease
- Comorbidities

Possible interventions to support optimal adherence

Strike a balance between psychological wellbeing and disease progression²

- Skilled CF care team can delicately communicate the realistic potential of disease progression without causing increased anxiety
- Referral to appropriate care providers or counselling should be made available to patients/caregivers to assist with appropriate coping skills

Highlight importance of preventative treatment^{2,3}

- As CF disease progresses, adolescent patients who perceive themselves to be healthy may be particularly non-adherent during times of decreased symptoms and sense less empathy from their physicians
- To overcome this, patients/caregivers need to be educated about the importance of preventative and suppressive treatment, instead of treating the symptoms

Optimise communication skills⁴

- Clinicians should receive training to support conversations with patients/caregivers to subsequently develop stronger relationships and establish trust, improve goal setting and/or elicit behavioural change
- See the [Motivational Interviewing resources](#)⁵ (all Motivational Interviewing modules, all educational videos, adherence booklet and adherence toolkit)

Home monitoring and digital technologies⁶

- Adherence monitoring can support treatment guidance and allow clinicians to better differentiate if clinical changes are related to disease progression, poor adherence or a combination
- Self-monitoring can also help patients better understand and self-manage their condition



Disease-related



Severity of
disease



Progression of
disease



Comorbidities



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Disease-related

Comorbidities



Severity of disease



Progression of disease



Comorbidities

Critical factors affecting adherence

Physical comorbidities¹⁻³ e.g. CF-related diabetes, liver disease, pain

Mental health comorbidities^{4,5} e.g. clinical depression, clinical anxiety, attention deficit hyperactivity disorder, conduct disorder, obsessive compulsive disorder

For supplementary factors and interventions please refer to the mental health category under the patient-related core domain please [click here](#)



Click for possible interventions



Click for list of references





Disease-related

- Severity of disease
- Progression of disease
- Comorbidities

Possible interventions to support optimal adherence

Effective screening and support^{5,6}

- Integrated screening tools and practices during routine CF clinical appointments can enable diagnosis and earlier intervention
- Encourage extended care beyond the hospital and the importance of communication with school, appropriate organisations and or other community providers for patients with these additional problems (e.g., home support services, psychiatrists and social workers)



Disease-related



Severity of
disease



Progression of
disease



Comorbidities



References

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Therapy-related

Perceived benefit of treatment

- Perceived benefit of treatment
- Complexity of treatment
- Burden of treatment regimen
- Side effects

Critical factors affecting adherence

Immediate benefit¹⁻⁵ e.g. when an effect is not seen immediately, lack of perceived consequences, "honeymoon" period that temporarily increases adherence after the introduction of a new therapy

Perception of treatment success⁵⁻⁸ e.g. increase in life expectancy, altered disease trajectory, avoidance of becoming ill and need for hospital stays, improved quality of life

Perception of the need for treatment⁸⁻¹⁴ e.g. value of daily treatment if feeling 'fine' or not experiencing symptoms, some medication not as important as others, doubts about necessity of treatments



Click for possible interventions



Click for list of references





Therapy-related

- Perceived benefit of treatment
- Complexity of treatment
- Burden of treatment regimen
- Side effects



Possible interventions to support optimal adherence

Managing treatment expectations and instilling belief in treatment benefits^{1,8-10,12,14,15}

By understanding medication beliefs, clinicians may be able to identify potential barriers/risk factors for non-adherence as well as provide education on outcome expectancies, support to enhance self-efficacy, or refer patients for behavioural counselling

Set attainable treatment goals with patients and caregivers¹³

Necessity beliefs for treatment may differ with children having inconsistent treatment goals compared with those of parents and physicians

– See the **Individual Treatment Plan (ITP) tool**¹⁶ (denotes purpose of treatment to reinforce importance of adherence and set individualised goals)

- Develop the treatment plan in collaboration with the patient and family/caregiver



Therapy-related

- Perceived benefit of treatment
- Complexity of treatment
- Burden of treatment regimen
- Side effects







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Therapy-related

Complexity of treatment

-  Perceived benefit of treatment
-  Complexity of treatment
-  Burden of treatment regimen
-  Side effects

Critical factors affecting adherence

Difficulty administering treatment¹⁻⁶ e.g. complexity using nebuliser, difficulty opening medication, management and complexity of administering CF treatment in combination with treatments for comorbidities

Treatment familiarity⁷ e.g. starting a new treatment

Tailoring therapy^{8,9} e.g. dislike of using therapy, time the treatments take



Click for possible interventions



Click for list of references





Therapy-related

Perceived benefit of treatment

Complexity of treatment

Burden of treatment regimen

Side effects



Possible interventions to support optimal adherence

Skills training for patients/caregivers^{1,8,10}

E.g. how to use a nebuliser or a positive expiratory pressure mask for airway clearance

- Educational programmes to reinforce and educate patients/caregivers on treatment as well as periodically assess and provide practical guidance on administration techniques, e.g. US ReEducation of Airway Clearance Technique (REACT) programme^{1,10}
- Increase familiarity with the medication, e.g. providing patient-friendly instructions, encouraging parental involvement via direct and non-direct instructions⁸

Tailor/simplify patients' treatment regimen^{2,8}

To reduce complexity, meet the patient's individual needs and make the treatment plan easier to follow

- See the **Individual Treatment Plan (ITP) tool**¹¹ (denotes day and time for treatments)
 - Develop the treatment plan in collaboration with the patient and family/caregiver

Utilising pharmacist-provided outpatient care^{6,12}

Freely accessible healthcare professionals that can provide patient-centred education and support for challenges in medication use



Therapy-related

- Perceived benefit of treatment
- Complexity of treatment
- Burden of treatment regimen
- Side effects







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Therapy-related

Burden of treatment regimen

-  Perceived benefit of treatment
-  Complexity of treatment
-  Burden of treatment regimen
-  Side effects

Critical factors affecting adherence

Treatment duration¹⁻¹⁵ e.g. complex and time-consuming daily treatment regimens

Treatment frequency^{2,5,6,16,17} e.g. number of times treatment is administered per day

Patient perception^{5,18} e.g. treatments may be too complicated to understand or too time consuming from the patient's perspective resulting in stress and inconvenience on daily life, variability in patient and family/caregiver perception

Tiredness, fatigue or burnout¹⁹ e.g. impact of doing treatments every day



Click for possible interventions



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Therapy-related

- Perceived benefit of treatment
- Complexity of treatment
- Burden of treatment regimen
- Side effects



Possible interventions to support optimal adherence

Assess treatment burden²⁰

To understand what is practical and achievable for the individual patient and family

Tailor/simplify patients' treatment regimen^{20,21}

To reduce complexity, meet the patient's individual needs and make the treatment plan easier to follow

– See the **Individual Treatment Plan (ITP) tool**²² (denotes day and time for treatments)

- Develop the treatment plan in collaboration with the patient and family/caregiver

Provide a variety of treatment recommendations¹²

E.g. present different options for physical therapy techniques so that the patient can choose which suits them best

Pharmacist involvement in the multidisciplinary team^{20,21}

To assist in optimal medication management, patient education and maintenance of health-related quality of life

Improved drug delivery systems^{6,14,16}

E.g. ultra-fast nebulisers to reduce treatment duration



Therapy-related

- Perceived benefit of treatment
- Complexity of treatment
- Burden of treatment regimen
- Side effects



References

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Therapy-related



Perceived benefit of treatment



Complexity of treatment



Burden of treatment regimen



Side effects



References





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Therapy-related

Side effects

-  Perceived benefit of treatment
-  Complexity of treatment
-  Burden of treatment regimen
-  Side effects

Critical factors affecting adherence

Patient experience of adverse events and side effects¹⁻⁴ e.g. difficulty swallowing, dislike of taste, disruptive to life

Polypharmacy² e.g. concurrent use of multiple medications



Click for possible interventions



Click for list of references





Therapy-related

- Perceived benefit of treatment
- Complexity of treatment
- Burden of treatment regimen
- Side effects



Possible interventions to support optimal adherence

Organisational^{1,2}

- Personalise disease management plans with a goal of lowering treatment burden and alleviate patients' symptoms, keeping an awareness of potential adverse events of the medication
- CF nurses and physical therapists can serve as the primary contact to help address treatment

Integrating pharmacists within the multidisciplinary team and utilising pharmacist-provided outpatient care^{5,6}

Pharmacists can provide patient-centred education and support for challenges in medication use, such as adverse effects, drug-drug interactions and appropriate medication dosing

Psycho-educational¹

Provide description of side effects



Therapy-related

- Perceived benefit of treatment
- Complexity of treatment
- Burden of treatment regimen
- Side effects

References

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6. Zobell JT, et al. *Pediatr Pulmonol*. 2017;52:1006–12.











Health system-
related

Knowledge/skills/ability

Critical factors affecting adherence

CF team knowledge¹⁻³ e.g. unaware of current information

CF team communication skills⁴⁻⁹ e.g. ability to connect and support patients and/or families living with CF, input from healthcare professionals can influence patients'/ caregivers' beliefs about disease and treatment, miscommunication or misinterpretation when discussing barriers, awareness of cultural factors and family beliefs

-  Knowledge/skills/ability
-  Guidance on therapies
-  Transition of care (age)
-  Healthcare system organisation
-  Digital monitoring tools
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Possible interventions to support optimal adherence

Continually update knowledge¹⁻³

To stay up to date regarding adherence, CF treatment landscape and patient/caregiver communication skills to ensure informed clinical decision-making and comprehensive patient support takes place

Optimise communication skills^{4,9}

- Clinicians should receive training to support conversations with patients/caregivers to subsequently develop stronger relationships and establish trust, improve goal setting and/or elicit behavioural change
- Hands-on demonstrations to enact care can improve learning for patients
- See the **Motivational Interviewing resources**¹⁰ (all Motivational Interviewing modules, all educational videos, adherence booklet and adherence toolkit)
- See the **e-learning modules**¹¹ (denote adherence challenges faced by patients/caregivers at different developmental stage and possible interventions)



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Guidance on therapies

Critical factors affecting adherence

Assistance with therapy^{1,2} e.g. when starting a new therapy, with airway clearance therapy



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Possible interventions to support optimal adherence

Providing assistance when starting therapy^{1,2}

- Encourage parental/guardian/caregiver assistance when starting therapy, such as airway clearance therapy
- Consider utilising the “teach-back” method – a method used to confirm whether a patient understands what is being explained to them – if they understand, they are able to “teach-back” the information accurately

Providing support³

Patients with CF and caregivers should be offered ongoing education and preventative, supportive interventions to promote coping skills and disease management, e.g. cognitive behaviour therapy and problem-solving techniques

Behavioural change⁴

Patient-centred counselling style to help patients change behaviour

- See the [Visual Analogue Scale for Adherence and Non-Adherence \(VASANA\) tool](#)⁵ (measures current adherence)
- See the [Motivational Interviewing resources](#)⁶ (all Motivational Interviewing modules, all educational videos, adherence booklet and adherence toolkit)



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Transition of care (age)

Critical factors affecting adherence

Patient age¹⁻¹⁶ e.g. transition from adolescent to adult, moving to college/university can impact routine, competing priorities, insufficient preparation for adulthood

Point of access to care¹⁶⁻¹⁹ e.g. adult care services



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Possible interventions to support optimal adherence

Structured transition programmes^{1,17,19,21}

Transition of young adults with CF from paediatric to adult medical care should be structured and incorporate a developmental approach and individualised information on CF, self-advocacy and self-management skills, future healthcare needs, lifestyle implications and how to navigate the healthcare system

Education and training appropriate for life and disease stage of each patient^{16,17}

To reduce the likelihood of declining lung function and CF-related complications during the transition period

- Enhance self-efficacy and improve monitoring skills
- Personalise information to address knowledge gaps
- Educational roadmap: annual, structured assessments of strengths and weaknesses in knowledge, and plan for the following year
- See the **e-learning modules**²² (denote adherence challenges faced by patients/ caregivers at each key developmental stage)





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Possible interventions to support optimal adherence

Empowering patients to encourage self-care^{1,16,18}

Develop strong relationships with CF care team and involve patients in treatment decisions

- See the **Individual Treatment Plan (ITP) tool**²³ (denotes purpose of treatment to reinforce importance of adherence and set individualised goals)
 - Develop the treatment plan more closely with the patient as they mature
- See the **Motivational Interviewing resources**²⁴ (Motivational Interviewing Module 5, 'Starting to think about a plan and the importance of increasing confidence' educational video)

Encourage caregivers to prepare patients for adult life, promoting confidence and ownership of their condition





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

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Healthcare system organisation

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Critical factors affecting adherence

Multidisciplinary team support¹⁻⁶ e.g. collaborative, patient-centred approaches to consultations and management of patients with CF, helping patients adjust to changing needs

Standard practice to discuss adherence^{7,8} e.g. whether a CF care centre has standard practices in place for discussing adherence or intervening when a patient is non-adherent

Data collection^{7,9-13} e.g. variable and unreliable techniques, data recordings from electronic devices and questionnaires that provide non-adherence information to healthcare professionals

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Possible interventions to support optimal adherence

Implementation of evidence-based adherence promotion at CF clinics⁷

To ensure that adherence is assessed and addressed at each visit

Providing child/family-friendly settings³

Clinic settings with access to play facilities; appointments with the same healthcare professional at each visit

Utilising pharmacist-provided outpatient care^{1,14}

Freely accessible healthcare professionals that can provide patient-centred education and support for challenges in medication use

Train staff in (intercultural) communication¹⁵

To offer empathetic and culturally appropriate care





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Possible interventions to support optimal adherence

MDT approach to care¹⁶

To enhance individualised care, increase efficiency and ensure engagement between patient and staff

- Increase patient contact time during clinic visits with members of multidisciplinary teams and decrease waiting time between consultations
- Wherever possible, keep those involved in the adherence clinics consistent
- Establish a key worker to employ patient activation or Motivational Interviewing skills
- As a team, be clear about treatment aims for the patient

Utilise reliable adherence measures and leverage digital technologies and home monitoring^{3,13}

- Self-monitoring helps patients to better understand and self-manage their condition. Digital approaches individualised to the needs of the patient could be explored, such as CF-specific apps
- Ensure validation of adherence rates through multiple measuring techniques and include more reliable approaches such as electronic monitoring (i.e. electronic nebulisers can monitor adherence via breath-inhalation ([Adaptive Aerosol Technology™])





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




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Digital monitoring tools

Critical factors affecting adherence

Usage¹ e.g. lack of experience with digital monitoring tools, poor digital literacy, lack of awareness of all features

Patient preference² e.g. patients preferring a different type of technology compared with their CF team

Additional burden³ e.g. home monitoring creating an additional task for a patient to do

Loss of novelty/interest^{1,3} e.g. decreased motivation over time, feelings of monotony similar to treatment regimens



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Possible interventions to support optimal adherence

Patient selection^{1,3}

Identify patients/caregivers who are most likely to benefit from using digital monitoring tools
– Careful selection can help mitigate time investment in training and deployment of digital tools

Selective use¹

Encourage use of digital monitoring tools at specific times if adherence is a problem, for example, using a tracking app a few days before a consultation or in connection with annual check ups
– Frequency and type of follow-up should be agreed with patients/caregivers in advance

Personalise introduction of technology¹

Use of digital monitoring should be tailored to patients' skills and ability e.g. gradually introducing an app's features, providing advice on app exploration, or explaining relevant aspects and/or rationale for use



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Access

Critical factors affecting adherence

Distance from outpatient care¹ e.g. travelling a long distance for routine outpatient care

Frequency of interaction with multidisciplinary team² e.g. patients living a long distance from a CF centre may be unable to visit their CF care team regularly

CF clinic attendance³ e.g. visiting a CF clinic can have a positive impact on adherence

Obtaining medicine⁴ e.g. limited access to medicine due to factors such as cost and the need to obtain nebulised medicine from the pharmacy



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Possible interventions to support optimal adherence

Implementing the use of telemedicine/regular phone communication²

Especially for patients living a long distance from a CF centre

Develop a support network for patients without home support⁴

To facilitate disease management

Explore the possibility of delivering and implementing care at outreach clinics⁵

To improve accessibility to healthcare

Integrating pharmacists within the MDT and utilising pharmacist-provided outpatient care⁶

Pharmacists can help navigate insurance coverage challenges and facilitate access to prescribed regimens and medications in a timely manner

MDT, multidisciplinary team.



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● Social resources

● Financial resources

Social resources

Critical factors affecting adherence

Academic education¹⁻³ e.g. lower level of caregiver education can result in less adherence

Family environment⁴⁻²⁰ e.g. parents' intentions to support adherence, family dynamics and function, communication within the family, routine family behaviours

For supplementary factors and interventions please refer to the family category under the patient-related core domain please [click here](#).

 Click for possible interventions

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Possible interventions to support optimal adherence

Provision of treatment information to family^{9,13-15}

Can be used to support/initiate conversations regarding adherence and gain confidence in providing treatment as well as identifying the key necessary aspects of care

- National CF foundations have multi-format content for patients and parents/caregivers. Examples of CF organisations include: www.cff.org (US), www.cfcc.org.au (Australia) and www.cysticfibrosis.org.uk (UK). Further information on national organisations can be found at: www.ecfs.eu/ctn/national-cf-associations

Motivational interviewing including family members and the patient together²⁰

To elicit behaviour change to resolve ambivalence

- See the [Motivational interviewing resources](#)²¹ (adherence booklet)

Social support within the CF team and wider networks^{4,17}

- One-on-one appointments with social workers, therapists and other healthcare professionals
- Encourage support from friends without CF and inclusion in their CF story



Socioeconomic-related

● Social resources

● Financial resources



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Socioeconomic-
related

● Social resources

● Financial
resources



 Social resources

 Financial resources

Financial resources

Critical factors affecting adherence

Household income¹ e.g. higher annual household income can result in better adherence

Insurance²⁻⁴ e.g. insurance coverage of prescribed medication, lack of insurance

 Click for possible interventions

 Click for list of references





Socioeconomic-
related

● Social resources

● Financial
resources

Possible interventions to support optimal adherence

Anticipate/identify obstacles and devise potential solutions⁵

See the [Motivational Interviewing resources⁵](#) (Motivational Interviewing Module 5, 'Starting to think about a plan and the importance of increasing confidence' educational video, adherence toolkit – e.g. problem-solving worksheet)

Integrating pharmacists within the MDT and utilising pharmacist-provided outpatient care⁴

Pharmacists can help navigate insurance coverage challenges to ensure patients have access to medications and receive these in a timely manner



Socioeconomic-
related

● Social resources

● Financial
resources

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