

<b>Title</b>	Psychology & Social Support
<b>Version</b>	2.0

<b>1</b>	<b>Psychology</b>
<b>2</b>	<b>Social Support</b>
<b>3</b>	<b>Consent and Confidentiality</b>

## 1. Psychology

### 1.1. Introduction

Living with CF can present stressful situations for the individual and their families leaving them vulnerable to a range of psychological and social difficulties. The nature of the illness impacts on their abilities to respond to ordinary daily tasks and extraordinary life events. Patients and families should be supported practically and emotionally by planned, positive, early interventions.

### 1.2. Staffing

There are Paediatric Clinical Psychologists working within the Paediatric CF Services in Stoke-on Trent and Shrewsbury and Telford. There is also a Clinical Psychologist available to adults accessing the Adult CF Services within Stoke-on-Trent, Shrewsbury and Wolverhampton.

The Clinical Psychologists are registered with the Health and Care Professions Council and are members of the UK Psychosocial Professions in CF Group (UKPPCF).

### 1.3. Service & Referral Indications

Patients and/or their families are seen within a range of settings – during clinic appointments; in-patient admissions; at home; or within school. Virtual consultations are also available.

Referrals to the Clinical Psychologist are accepted at any point within a patient's life. Teams can discuss referrals with the Team's Clinical Psychologist who will establish whether they are the most appropriate professional, or whether there is an external agency that can address the difficulties. The urgency of any intervention will be established during this discussion.

Common reasons for referral across the life span include:

- adjusting to the new diagnosis
- behavioural difficulties relating to treatment
- feeding difficulties
- procedural distress
- difficulties adhering to recommended treatment regimens
- emotional and psychological difficulties
- 'living well' with CF alongside ordinary life, including school and work
- deterioration in quality of life (QOL)
- increased isolation due to risk of cross-infection
- transition to adult CF Services
- transplantation
- fertility difficulties
- palliative care and bereavement

### 1.4. Roles

- To provide support for newly diagnosed patients and/or their families – in the case of late diagnosis, access to support for adults receiving a new diagnosis is essential
- To undertake psychological review as part of annual review including an assessment of behaviour, emotions and family functioning
- To provide psychological therapies including cognitive, behavioural, trauma and systemic therapies

- To aim to respond to referral of inpatient for specialist psychological input within 1 week where there is a specific psychological need relating to Cystic Fibrosis. Access to hospital based Mental Health Liaison Teams may be more appropriate in some instances.
- To aim to provide a Psychology service in parallel with CF clinics by responding to referrals within 2 weeks. Response time may vary within each geographical area.
- ‘Gatekeeping’ for the onward referral of patients to mental health services and/or other relevant agencies (e.g. liaison psychiatry, community psychology services)
- Liaise with Network Clinics, social services and other community agencies for psychosocial input
- Coordinate rapid access to on-call child and adult psychiatry services in cases of urgent psychiatric assessment for mental health concerns or risk of self-harm
- To provide consultation, support, training and supervision to other CF team professionals providing psychosocial interventions
- To be aware of and to follow safeguarding children/adults procedure where necessary
- To contribute to research in all areas of CF either through developing individual projects or participating in research carried out by the multidisciplinary team
- To keep up to date with advances in Clinical Psychology, psychological therapies, and evidence-based practice
- To participate in clinical audit activities on behalf of the CF service, contributing to ongoing service evaluation and development
- **Annual Review:**  
The patients/families should aim to see a Clinical Psychologist who will screen for potential difficulties and use validated screening tools when necessary. Where it is not possible for the Clinical Psychologist to attend then screening tools will be distributed and collected by the Clinical Nurse Specialist.
- **Transition Pathway for adolescents/young people:**  
To ensure that adolescents/young people are increasing their autonomy and confidence when accessing health services, the CF Team will support the individual to access services independent of their parents, whilst ensuring parents are supported throughout this process. Consideration of lifestyle, sexual health and psychological issues should be made, as well as transition to higher education or employment.

### 1.5. Impact of CFTR Modulator Therapy on Psychological Wellbeing

CFTR modulators have significantly improved physical health outcomes for PwCF, but Medicines and Healthcare products Regulatory Agency (MHRA) published an update on Kaftrio in May 2025 highlighting a small increase in the risk of psychological side effects such as anxiety, low mood, sleep disturbance, poor concentration, and forgetfulness. It has also been noted that in some children, these side effects may show in changes to behaviour, such as being more disruptive.

Changes typically occurred within the first 3 months of starting Kaftrio, but it is difficult to know whether this was a direct result of Kaftrio, or an adjustment to the improvements on physical health and quality of life. For many, the symptoms do not last long, but others will continue to experience these effects whilst taking Kaftrio.

Routine Outcome Measures (ROMs) will be implemented to support the early identification of emotional and behavioural difficulties. Their use is recommended at the initiation of CFTR modulator therapies and should also be considered during periods of behavioural or psychosocial change. See Table 1 for further information.

Age range	Routine Outcome Measures to be used	When to Screen
0-7	SDQ parent	- Initiating/changing modulators (screen at 3/6/12mthly for first year)
8-10	SDQ Parent RCADS Parent	

	RCADS self	<ul style="list-style-type: none"> <li>- Annual Review</li> <li>- When parents/carers/patients report behavioural changes/psychological impact</li> <li>- When trialling period of time off modulators or adjusting dosage due to behavioural changes/psychological impact</li> </ul>
11-17	SDQ Parent RCADS Parent SDQ Self RCADS Self	
18+	PHQ9 GAD7	

**Table 1. Routine Outcome Measures by age, and indications for use**

## 2. Social Support – The Welfare Advisor Role

### 2.1. Introduction

The NWMCFCC has a Welfare Advisor, who works across both paediatric and adult services. The Welfare Advisor is there to support the patients and their families or carers. Patients and/or carers can access the Welfare Advisor at any time. At times of crisis or deterioration of a patient’s condition, the Welfare Advisor can facilitate changes in their working/employment/financial life allowing them to maximise treatment and optimise health. The Welfare Advisor is aware of what support may be needed to support a pwCF and/or their family.

Support is offered in outpatient clinics, on the wards, in patient/carers homes, schools or a place suggested by the patient/carer. The Welfare Advisor maintains up-to-date knowledge regarding CF through continued membership of the UK Psychosocial Professionals in CF (UKPPCF).

### 2.2. Roles

- To support with nursery placements and education including university
- To support with difficulties with housing
- To support patients with access to work and maintaining employment
- To support with the completion of forms including, but not limited to child benefit claims, Universal Credit, Employment Support Allowance forms to Disability Living Allowance and Personal Independent Payment forms.
- To support patients to manage finances
- To attend meetings with patients where required, including appeal tribunals
- To signpost to appropriate organisations
- To be aware of and to follow safeguarding children/adults procedure where necessary. They are available to liaise with external agencies, and can offer support to families
- Patients should have access to the Welfare Advisor who can liaise with employers to minimise stress caused by time off work or with tutors at school/college/universities to minimise disruption to studies

## 3. Consent and Confidentiality

Both the Clinical Psychologist and Welfare Advisor will make sure that the patient has consented to their input. They are keen to maintain confidentiality but also sit within the Multi-Disciplinary Team. Therefore, they will ensure that they seek the patient’s permission to share information that has a direct bearing upon the management of Cystic Fibrosis. Occasionally, information will need to be shared without consent, for example where there is risk to themselves or to others.