

Title	Psychology & Social Support
Version	1.0

1	Psychology
2	Social Support

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 and early intervention

1.2. Staffing

There are two Paediatric Clinical Psychologists working within the Paediatric CF Services in Stoke-on-Trent and Burton; 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.

Referrals to the Clinical Psychologist are accepted at any point within a patient's life.

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
- balancing 'normal' life with management of a chronic condition
- deterioration in quality of life (QOL)
- increased isolation due to risk of cross-infection
- transplantation
- fertility difficulties
- palliative care and bereavement

1.4. Roles

- To provide support for newly diagnosed patients and/or their families – 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 and family therapies
- To respond to referral of inpatient for specialist psychological input within 1 week
- To provide a Psychology service in parallel with CF clinics by responding to referrals within 2 weeks
- '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 take part in audit on behalf of the CF service
- **Annual Review:** The patients/families should see a Clinical Psychologist who will screen for potential difficulties and use validated screening tools when necessary
There should be access to the Welfare Advisor during time of clinical deterioration as adjustments may need to be made to school/college/university or work patterns and types of employment.
- **Inpatients:** Patients should have access to a Clinical Psychologist within the CF Team when on the ward. 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
- **Services 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.

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 with many issues, and patients and/or carers can access the Welfare Advisor at any time. At times of crisis or deterioration on 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 has knowledge of Cystic Fibrosis and is aware of what support may be needed to support that individual and/or 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. Reasons for involvement include

- support with nursery placements, education including university, all
- housing situations, managing finances,
- supporting access to leisure and fitness centres/activities and gaining and maintaining employment
- completion of forms including child benefit claims, to Job Seekers Allowance, Employment Support Allowance forms to Disability Living Allowance and Personal Individual Payment forms.
- Attending meetings, including appeal tribunals.
- Signposting to appropriate organisations.
- The Welfare Advisor has Safeguarding Training, and can offer support to any families if they find themselves in a difficult situation, and provides liaison with external agencies.