Humber Teaching
NHS Foundation Trust

STANDARD OPERATING PROCEDURE CHILDREN'S AND YOUNG PEOPLE'S LONG TERM HEALTH CONDITIONS TEAM (HULL AND EAST RIDING)

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VALIDITY – All local SOPS should be accessed via the Trust intranet

CHANGE RECORD

Version	Date	Change details
1.0	*June 2023*	*New SOP. Approved at Divisional Governance Meeting (22 June 2023).*

Contents

1. Introduction

Humber Teaching NHS Foundation Trust provides a service to young people who are having difficulty psychologically adjusting to or managing their long-term health condition (LTHC). The service provides consultation or therapy to young people dependent on their presenting need. The service uses a range of therapeutic modalities including but not limited to CBT, ACT and CFT.

The LTHC team aims to provide support to families and young people who are adapting to a long-term health condition. It does not provide a mental health service and does not overlap with the service provided by the Core CAMHS team.

The LTHC team offers a service in different Trust buildings in Hull and the East Riding, within the working hours of Monday-Friday 9-5. There are also many opportunities for work to take place virtually which will continue to be offered in the long term.

There are different service specifications for Hull and East Riding see below:

Hull Service Offer

Diabetes:

- Information and emotional support for newly diagnosed patients
- Assessment of suitability for moving to insulin pump therapy
- Assessment and intervention for needs related to living with diabetes
- Consultation can be provided with patient consent, to other professionals involved in a person's care such as CAMHS, Specialist Nurses, Paediatricians, School.

Epilepsy:

- Assessment and intervention for needs related to living with epilepsy
- Consultation can be provided with patient consent, to other professionals involved in a person's care such as CAMHS, Specialist Nurses, Paediatricians, School.

Other Long Term Health Conditions can also access assessment, intervention or consultation such as:

- Headache
- Cystic Fibrosis
- Gastroenterology such as inflammatory bowel conditions, Crohns
- Cardiac
- Cerebral Palsy
- Pain
- Blood related conditions
- Rare/ chromosomal conditions which impact on health
- Rheumatology
- Asthma
- Other long term health conditions not listed if primary need is related to coping with/ emotional wellbeing related to the health issue.

East Riding Service Offer

Diabetes:

- Information and emotional support for newly diagnosed patients
- Assessment of suitability for moving to insulin pump therapy
- Assessment and intervention for needs related to living with diabetes
- Consultation can be provided with patient consent, to other professionals involved in a person's care such as CAMHS, Specialist Nurses, Paediatricians, School.

Epilepsy:

- Assessment and intervention for needs related to living with epilepsy
- Consultation can be provided with patient consent, to other professionals involved in a person's care such as CAMHS, Specialist Nurses, Paediatricians, School.

Other Long Term Health Conditions can also access consultation only such as:

- Headache
- Cystic Fibrosis
- Gastroenterology such as inflammatory bowel conditions, Crohns
- Cardiac
- Cerebral Palsy
- Pain
- Blood related conditions
- Rare/ chromosomal conditions which impact on health
- Rheumatology
- Asthma
- Other long term health conditions not listed if primary need is related to coping with/ emotional wellbeing related to the health issue.

Exclusion criteria

The following are excluded from the service offer at present.

- Tics or Tourette Syndrome
- Chronic Fatigue as the primary need
- Chronic Pain if a Specialist Pain service is required such as Leeds
- Acquired Brain injury/ Traumatic Brain injury rehab
- Cancer
- Life limiting conditions
- End of life care
- Non-epileptic seizure (consider if underlying trauma) unless in presence of epilepsy
- Chromosomal conditions causing neurodevelopmental needs.
- Physical disability (rather than health issue)
- Neuropsychological assessment
- ARFID/ Feeding difficulties

2. Scope

This standard operating procedure (SOP) applies to those referred to the long-term health conditions team from parents, professionals or self-referrals for those over the age 16 for young people in Hull or East Riding where the young person has a Hull or East Riding GP.

Application of the Trusts Waiting Lists and Waiting Times Policy principles will ensure that each client's journey is managed fairly and consistently in accordance with an agreed structured methodology. Treatment decisions will be fair and transparent. Families will be offered a service based on their chronological order on the waiting list. There may be some occasions where it is felt most appropriate to allow a short wait for an appropriate group to be available for the family or young person (for example the group may only have two members and would have greater benefit if a short wait allowed for 3 more to attend). If this was the case, this would be discussed with the family referred.

There are a number of core principles upon which the LTHC team will base their approach to waiting list management. The right to start treatment may not be appropriate if:

- The client and family choose to wait longer when an opportunity becomes available (this may be because they wish to be seen in a different location to the one being offered).
- Delay in the start of treatment is in the best clinical interest of the client and/or family, for example if other treatment approaches are ongoing and there is a risk that commencement of therapy in this team, in addition to these may overwhelm the family.

Service Configuration

The team is comprised of 0.6 8a Clinical Psychologist and 1.0 b7 WTE Clinical Psychologist. Support from a Consultant Clinical Psychologist is available in relation to service development and the service has support from the Lead Psychologist in Child services. There is a Clinical Team Lead who supports this team alongside others and an Operational Lead for the Neurodevelopmental Team.

3. Definitions

HUTH (Hull University Teaching Hospitals). This references the Trust who run the Paediatric department

LTHC (Long Term Health Conditions Team- Humber)

4. Duties and Responsibilities

Operational Manager and Clinical Team Lead

Responsible for the implementation of policy and procedures and training for relevant staff groups in their areas of responsibility. To support research, audit and evaluation within the team.

Clinical Team Lead
To screen referrals, facilitate the process of allocation of cases, to manage the waiting list and liaise with clinicians in relation to any challenges with managing capacity and demand.

Consultant Clinical Psychologist
To support the service development within LTHC, pathway development and evaluation, to support research, audit and evaluation within the team. To supervise clinicians or arrange this within the Psychology provision and support clinical governance of the service offer. To work in conjunction with the clinical team lead, clinicians and operational lead to achieve this.

Clinicians
To participate in the MDT, provide clinical work (including but not limited to consultation, assessment and intervention) to support research, audit and evaluation within the team.

Administration staff
To support the allocation of people to groups by sending appropriate communication and contacting families via telephone if considered clinically appropriate.

5. Process

Referrals are received via contact point and screened by the Clinical Team Lead for risk. Triage takes place within contact point if risk or uncertainty about co-morbid mental health difficulties. If accepted as the referral fits the above criteria for LTHC, they are discussed in the MDT and appropriateness for pathway considered. The pathways of care in LTHC are as follows:

Hull Pathways

- Diabetes
    - Newly Diagnosed with Diabetes
        - Group offer – see additional SOP (newly diagnosed with diabetes)
    - Pump Assessment- see below process

- Other Long-Term Conditions
    - Assessment/Consultation with the young person and/or family
    - Intervention

East Riding Pathways

- Diabetes
    - Newly Diagnosed with Diabetes
        - Group offer – see additional SOP (newly diagnosed with diabetes)
    - Pump Assessment- see below process

- Epilepsy
    - Assessment/Consultation with the family
    - Intervention

- Other Long-Term Conditions
    - Consultation with the young person and/or family

Consultation
Consultation in this instance references a one session appointment with a young person or family. It can be offered in all areas of service, either where service specification dictates this response, or where it is deemed the most appropriate initial offer based on the referral information available to the team.

Consultation includes the following elements:

- Gathering information on the history of the presenting difficulties, long term health condition details and general history of social, emotional and physical functioning and adjustment to diagnosis.
- Social, educational, family history and circumstances
- Relationships with family, friends and peers (including any bullying and history of abuse).
- Past or current mental health difficulties for carer(s)/parent(s), e.g. mood disorders or eating disorders.
- Risk behaviours, including self-harm, substance use or misuse of medication and suicidal ideas. The young person should be given the opportunity for a discussion separate from their parent/carers during the assessment process if required.
- Psychoeducation, strategies or coping mechanisms offered or taught during the session to help support psychological functioning or adjustment to diagnosis.

Assessment
Assessment in this instance references a one or two session appointment with a young person or family. It can be offered in the diabetes pathway (Hull and East Riding) where the outcome will influence the decision around whether they will be offered an insulin pump to manage their diabetes; in the Epilepsy pathway (East Riding) and in the Other Long Term Conditions pathway (Hull) where the outcome will influence the plan for intervention work offered in service or signposting to another appropriate service. Most children and young people referred to the long-term health conditions team will be seen in conjunction with their parents or carers as there is an acknowledgement that a long-term health condition impacts on the whole family. As is always the case, it may be appropriate to offer an individual appointment at the request of the child or young person, in which case assessment and consideration of capacity and risk should be made by the assessing clinician. Parental involvement should be discussed with the young person and planned for as soon as possible.

Assessment includes the following elements:

- Gathering information on the history of the presenting difficulties, long term health condition details and general history of social, emotional and physical functioning and adjustment to diagnosis.
- Social, educational, family history and circumstances
- Relationships with family, friends and peers (including any bullying and history of abuse).

- Past or current mental health difficulties for carer(s)/parent(s), e.g. mood disorders or eating disorders.
- Risk behaviours, including self-harm, substance use or misuse of medication and suicidal ideas. The young person should be given the opportunity for a discussion separate from their parent/carers during the assessment process if required.
- Information gathered in the assessment will be used to help inform a psychological formulation which is developed collaboratively with the young person and their family. This will provide a framework for making sense of the current difficulties and help to inform the interventions offered within the package of care. The formulation and subsequent care plan will be recorded in the electronic patient record and reviewed with the young person and family on an ongoing basis.
- In the case of diabetes pump assessments, the purpose of assessment is to ascertain the psychological appropriateness of this type of therapy. The information gathered informs a formulation developed in-vivo with the client and will inform clinical opinion on whether the pump would be manageable and beneficial to the client.

Interventions
Interventions in this instance reference a bespoke package of individual or family work. It can be offered in the diabetes pathway (Hull and East Riding); The Epilepsy pathway (East Riding) and in the Other Long Term Conditions pathway (Hull). Therapeutic modalities utilised include, but are not limited to CBT, CFT and ACT.

Discharge
All young people or families will be discharged from the service once intervention as detailed above has ended. A discharge letter or report will be completed, with GP and Paediatrics copied if the family and young person has consented to this.

Outcome measures
Outcome measures are used where clinically appropriate and recorded on patient notes.

6. Consultation

This SOP will be put forward for consideration with the clinical network and has been shared within service.

7. Implementation and Monitoring

The Operational Manager and Clinical Team lead will support the implementation of this SOP and the clinicians and administration staff will work to follow this process. The Consultant Clinical Psychologist will work in conjunction with the Operations Manager and Clinical Team to support the monitoring of this process and any clinical need to consider alternatives in the future.

8. Training and Support

All staff access line management from the Clinical Team Lead and clinical supervision from an appropriate Clinical Psychologist within the Neurodevelopmental Team. PADRs are completed in line with Trust Policy and individual training needs identified as part of this process.