

Complex Cancer Late Effects Rehabilitation Service (CCLERS)

Residential Programme

*A Centre of Excellence
Commissioned by NHS England*



This booklet provides important information about the two-week Complex Cancer Late Effects Rehabilitation Service (CCLERS) residential programme. Participation in this programme requires a significant commitment, so it is necessary to have an understanding of what it involves.

Aims of the programme

We aim to help you develop a tailored rehabilitation programme based on your personal needs and goals. To facilitate this, our specialist team will work with you to establish effective self-management tools. This could lead to an improvement in quality of life, ability to engage in valued activities, and confidence to navigate the condition in the long term.

Where is it based?

The programme takes place in the RNHRD and Brownsword Therapies Centre, which is situated at the Royal United Hospital (RUH) in Combe Park, Bath. Accommodation is provided in the purpose-built Bernard Ireland House, which is located in another part of the hospital site.

What to expect

The programme is intensive and runs from Monday to Friday for two weeks. It is non-medical and is delivered by our therapy team, which is comprised of specialist physiotherapists, occupational therapists (OTs), clinical nurse specialist, and a clinical psychologist, with input from other health professionals. There is a balance of one-to-one and group sessions. Although the groups are scheduled for everyone's participation, the one-to-one appointments may vary in duration and frequency according to your specific needs. We encourage you to attend all sessions to gain maximum benefit.

Programme schedule

The day usually runs from 09.00 until 16.00, with scheduled breaks. Transport is provided to ferry you between the accommodation and the Therapies Centre at the beginning and end of day and at lunchtime. Please note that you may be sharing transport with participants from another residential programme.

The first therapy day usually involves one-to-one assessments by the physiotherapists and occupational therapists. This helps us to get to know you better and to find out what your needs and goals are at that time. Please be patient if we ask you similar questions to those that you have already been asked in our initial outpatient clinics or by other health professionals – we can help you best if we have the most up-to-date information about you and your life situation.

There is also a welcome group on the first day, which will give you the opportunity to familiarise yourself with the programme and the new setting. There is a maximum of six participants per programme. Sessions are scheduled on a daily timetable, which is drafted at the end of each working day.

Groups

Groups are a fundamental part of the programme, and cover a range of topics relevant to living with complex cancer late effects (CCLEs). These include interactive workshops, relaxation, mindfulness, communication, useful exercises, and many more. Our pain consultant may also discuss pain-related topics with the group. Although we encourage active participation, there is no pressure to be a public speaker or to share personal information about yourself unless you are genuinely happy to.

One-to-one therapy

Since people with CCLEs often feel disconnected from the affected areas of their body, our therapy tends to focus on the altered awareness and thought processes that arise from this disconnection. This could be concerned with sensations in the body or our interaction with our environment, whether it is awareness of where a body part is or what it is in contact with, or how the rest of the body is compensating.

Sessions with the physios are primarily aimed at optimising function. Our approach is holistic and can seem very different and bizarre compared with most traditional forms of physio. Bear with us though, as things should start to make sense over the course of the programme.

Our OTs play a key role in this process, but their focus is more geared towards enabling you to live well and participate in valued activities in your life. These could be daily tasks at home, work life, travel, hobbies, leisure activities, rest, or sleep. They can help you problem solve and develop ways forward to improve your quality of life. Some of their suggestions may involve making changes in your home or working environment, or ways to manage your energy more effectively.

There is also the opportunity for daily hydrotherapy during the programme. This involves therapy in a warm water pool, which is situated in another part of the therapy building. Water can be a valuable tool in the rehabilitation process, as it provides buoyancy (so the body feels lighter) and can be very relaxing due to the natural properties of warm water. Despite the potential benefits, there is no pressure to engage in hydrotherapy. We appreciate that some people have problems with water and would not benefit from forcing themselves to join in. However, your ability to engage with water

may change over the course of the two weeks as you work with our therapists.

During the programme, there may be the opportunity to work one-to-one with our clinical psychologist. The purpose of such sessions would be to help you to navigate issues that are barriers to you getting the most out of rehab or are making you feel stuck, with the aim of helping you move forward. Please remember - speaking to a clinical psychologist should not be considered a negative thing; it is normal for us to need to speak to someone, especially when one has a persistent pain condition.

In summary, although there is a range of input from different members of the team, we are working towards the same end and communicate with each other throughout the day to help you meet your needs. Indeed, sometimes we will schedule joint sessions with you (eg. physio and OT) to help you with a specific task or activity.

Making it count

It is very common to experience fatigue when engaging with therapy, especially when it is as intensive as our programme is. We encourage you to be honest about this, not only to us but also to yourself! Similarly, your pain levels may increase, and we encourage you to be aware of this and not to push yourself needlessly. Quality is more important than quantity as far as our therapy is concerned.

As our programme is geared towards enabling self-management, it is essential that you continue to practise techniques and exercises that you have learned during the two weeks. Practice makes perfect, so doing it means that you are more likely to meet your rehabilitation goals. The two

weeks are not meant to be a quick fix, but instead can help you gain the tools to move forward.

Facilities

There is a dedicated rest room next to the therapy rooms, with tea, coffee, and water provided. You will have the chance to relax in here between sessions. We do provide some pens and paper, board games, and a stereo, but you may find it helpful to bring other forms of entertainment, such as a tablet. However, please remember to bring headphones if you do so to avoid disturbing the other group members who are sharing the room with you. We are also collecting books for a mini library in the rest room, so donations are welcome.

Accommodation

You should arrive at Bernard Ireland House the day before the first therapy day (usually a Sunday). You will be shown to your room by staff and orientated to the building. Your room is located upstairs, and is accessible by lift or stairs. All meals are provided in the day room and we will do our utmost to cater for dietary needs, so please let us know about these. There is also a secluded garden area that you will be able to relax in. Please be aware there is a curfew at midnight, after which doors are locked.

Please note that there are no medical staff situated in Bernard Ireland House, so you would need to treat any out-of-hours health issues as you would normally if you were staying away from home. More details about the site and facilities are available in the admission letter that is sent to you when your place on the programme is confirmed.

Weekends

There is no therapy input at the weekend, so you are free to stay in the accommodation or go home. However, if going home involves a long journey or a significant amount of stress, then we would recommend staying at the hospital. Wherever you are, we encourage practising what you have learned on the programme so far.

Friends and family

You have the opportunity to invite any friends or family members to attend a group, which usually occurs on the last day. They will have the chance to find out more about the condition or how they might best support you.

Follow Up

You will be offered a review appointment that happens three months after finishing the programme. After this, our nurse specialist will be in touch to check on how you are doing, usually at six and twelve months.

Research

As a national service that is involved in a range of research projects, we may ask you for permission to be involved in any such work. This is strictly voluntary, so please don't feel pressured to participate, although doing so could help us develop even better treatments in the future. During the programme, our research team will usually come and talk to the group about current developments.

There are also some questionnaires that we ask you to complete before the programme and after commencing it. We really appreciate you completing these, as they help us to measure the effectiveness of the therapy and the programme itself.

Thank you for taking the time to read this booklet.

Further information can be obtained from:

Tim Lane

Pain Specialty Administration Manager

Royal United Hospitals NHS Foundation Trust

Combe Park

BATH

BA1 3NG

Tel: 01225 473462

Email: ruh-tr.RNHRDCRPSteam@nhs.net

Website: <https://www.crpsandcancerlateeffects-bath.org.uk>

Please contact the Patient Advice and Liaison Service (PALS) if you require this leaflet in a different format, or would like to feedback your experience of the hospital. Email ruh-tr.pals@nhs.net or telephone 01225 825656.