

Pain-related Complex Cancer Late Effects Rehabilitation Service **CCLERS**

Rehabilitation Programme



In partnership with

MACMILLAN
CANCER SUPPORT



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

If you have any questions regarding this information, please contact your service administration team.



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.

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 and occupational therapists (OTs), a psychologist, a clinical nurse specialist, and a therapy assistant.

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 strongly encourage you to attend all sessions to gain maximum benefit.

There is a maximum of six participants per programme.

Patient Transport

A car is provided to shuttle you between the accommodation and the Therapies Centre. Assistance to access the car is available if required.

Please refer to the **BIH Patient Accommodation Guide** for further information.

Programme schedule

The day usually runs from **08.30 until 16.30, with scheduled breaks**.

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.

Sessions are scheduled on a daily timetable, which is displayed 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 pain-related complex cancer late effects (CCLEs). These include interactive workshops, relaxation, mindfulness, communication, pain medication, useful exercises, and many more.

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 do so.

One-to-one therapy

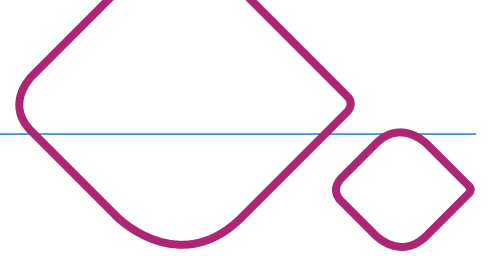
Since people with pain-related CCLEs often feel disconnected from the affected areas of their body, our therapy tends to focus on the altered awareness and thought processes that arise from this disconnection. This could be concerned with sensations in the body or our interaction with our environment, 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 to 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 **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 **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 (e.g. 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 practice 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.

Between sessions

You will have the opportunity to relax between sessions in our dedicated rest room which is located next to the therapy rooms.

The rest room is equipped with the following:

- tea and coffee making facilities
- water
- microwave for warming heat packs
- mini fridge
- stereo
- a small selection of pens, paper, board games and books

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.

After the programme

Letter of attendance

A letter confirming your admission dates will be sent to your GP and/or referrer on the last day of programme. If you require a copy of this letter to take home, please request this from a member of the therapy team prior to your last day.

Sick note

Should you require a sick note (for example for your employer) you will need to contact your GP to provide this.

Follow-up

You will be offered up to 3 routine follow-up appointments after completing the programme to review your progress.*

You can request additional follow-up with the Clinical Nurse Specialist outside of these routine appointments if required.

***Please note that participants whose treatment is NOT funded by NHS England will not be eligible for follow-up appointments without prior approval of funding.**



What to bring

- All your **regular medication to cover the duration of the programme.**
We cannot provide you with any medications that you have forgotten.
- All mobility aids as discussed at assessment
- Enough clothing for your stay, including sensible footwear and comfortable clothes suitable for activities such as exercise.
- Swimming costume (please note hydrotherapy is not compulsory but recommended).
- Pool towel as only basic towels are provided in hydrotherapy.
- Drinking water bottle (recommended)
- Notebook and a pen
- Glasses, hearing aids, or any other equipment you would normally need
- A small bag or holdall to carry essential items to and from the therapy centre
- Toiletries

Please do not bring hot water bottles.

There is a dedicated microwave for warming heat bags if you choose to bring this as an alternative - please ask one of the health care assistants or therapy team.

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.

Please advise the administrative team prior to admission if your intention is to return home at the weekend as staffing levels need to be planned well in advance.

Inhealthcare

The Inhealthcare platform is part of your routine care within our service.

The information that you provide helps us to understand more about pain-related CCLEs which can help to improve care.

What is the Inhealthcare Platform?

The Inhealthcare platform is a digital tool that you can access online. The platform will allow you to:

- Easily complete forms to monitor your progress
- Access information about our Bath National Pain Service
- Access information on topics that may be of interest

Any information that you provide will only be accessed by your clinical care team.

To find out more about the platform, please visit this website: <https://www.ruh.nhs.uk/ihc>

When will I be asked to complete forms/questionnaires?

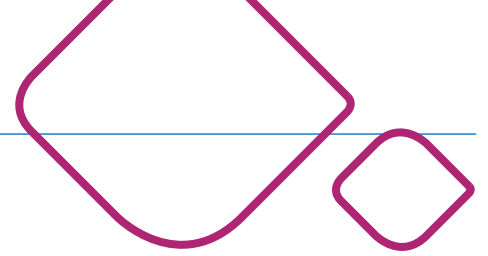
You will be prompted to complete a range of questionnaires at certain points during your treatment:

- Initial assessment (telephone triage appointment)
- MDT clinic
- Post-programme
- Prior to routine follow-up at 3, 6 and 12 months post-programme

The information collected at these timepoints will provide valuable insights for your clinical team and will help them to monitor your progress.

What happens if I don't register to use the platform?

If you would like to opt out of using the Inhealthcare Platform for any reason, this will not affect the quality of your care. Just let us know and we will make a note on the system accordingly, so that someone from your clinical team will be able to enter your data onto the platform on your behalf. You will then not receive any text/emails from the platform asking you to complete forms.



Research

We are a research active service and undertake a wide range of studies to give us a better understanding of pain-related late effects. It is through clinical research that we provide evidence upon which we base our care, improve our treatments or find new ones.

Our specialist areas of interest are the mechanisms behind pain-related late effects, building a picture of your experience of living with the condition, and exploring potential treatment options. People who are living with pain-related cancer late effects can make valuable contributions to our studies, either as research participants or through patient and public involvement.

What does taking part or participation in research mean?

If you are a participant, then you are actively taking part in a research study. For example, you may be asked questions about your health condition or asked to test a new treatment.

It is your right to be able to participate in research, as long as you have consented to do so and meet the requirements for the study. It is important to remember that this is completely voluntary, so you should only give your consent if you wish to do so. You will receive very clear information about each study to allow you to consider any issues before consenting to take part.

What is patient and public involvement in research?

Involvement is where research is undertaken with you, instead of about you. Examples include being a member of a research advisory group, project steering committee, or being asked to identify future research topic areas that are important to you. It is not about taking part in research as a study participant.

How can I find out more about participating or becoming involved in research?

If you would like to know about any future research studies that we are running, then you will need to give us your written consent. This only allows us to contact you with information about research and does not mean that you have committed to take part in any studies.

Please email ruh-tr.RNHRDcclersinfo@nhs.net if you would like to receive a copy of the consent form, or if you have any questions about our research.

If you would like to find out about what that is happening in your local area or would like to access further information about healthcare research, then you may find the following websites helpful:

NIHR Be Part of Research <https://bepartofresearch.nihr.ac.uk>

NIHR Evidence <https://evidence.nihr.ac.uk>

Thank you for taking the time to read this booklet

Further information can be obtained from:

Pain-related CCLERS Administration Team

Bath National Pain Centre

Dept F19

RNHRD & Brownsword Therapies Centre

Royal United Hospitals NHS Foundation Trust

Combe Park

BATH

BA1 3NG

Tel: 01225 821126 (Mon – Fri 08.30 – 17.00)

Tel: 01225 821031 (Mon – Fri after 17.00 & weekends)

Email: ruh-tr.RNHRDCCLERSinfo@nhs.net

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

Royal United Hospitals Bath NHS Foundation Trust
Combe Park, Bath, BA1 3NG

01225 428331 | www.ruh.nhs.uk

If you would like this leaflet in email form, large print, braille or another language, please contact the Patient Support and Complaints team on 01225 825656.

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