Introduction

You have been invited to attend the inpatient programme for patients with Complex Regional Pain Syndrome (CRPS). This leaflet explains the aims of the programme and the type of treatment you will be expected to participate in. Deciding to commit to participating in a rehabilitation programme is an important decision and this leaflet provides information and addresses common questions. Quotes from previous participants are highlighted in the speech bubbles.

Aims of programme

The emphasis of the inpatient stay is on rehabilitation. In other words, improving quality of life, participation in everyday activities and learning how to manage your condition long-term. It will not cure your CRPS. The programme involves working with a team of health care professionals who have specialised knowledge of CRPS, in particular Physiotherapists and Occupational Therapists. During your hospital stay we will work with you to develop a tailored rehabilitation programme based on your individual needs and personal goals.

SECTION 1: INFORMATION ABOUT THE PROGRAMME

The inpatient programme takes place at the Royal National Hospital for Rheumatic Diseases (RNHRD), Bath in the CRPS therapy department and the hydrotherapy department.

How long does the programme last?

Generally most patients stay two weeks but sometimes for one. The programme duration is dependent on your individual needs. Patients are asked to arrive either on a Sunday or Monday depending on their therapy appointment times. If asked to arrive on a Monday please allow at least two hours before your first therapy appointment to enable the nursing and medical staff to complete your admission details with you.
What will I be doing each day?

- During Monday to Friday you will attend daily sessions of physiotherapy, hydrotherapy (where appropriate) and occupational therapy (OT). Each therapy session lasts approximately 20-45 minutes. The duration and number of sessions is flexible and depends on your needs.

- The first couple of days will allow us to closely assess your condition and give you time to get used to the ward and hospital. Thereafter therapy sessions start in earnest and your daily programme will be “posted” onto the Patient Information board on the ward.

- Between therapy appointments it is important that you practice the various exercises and techniques which you will be taught in therapy (this does not include hydrotherapy). Practising outside of formal therapy, is vital for your ongoing self-management. Also, research suggests that LITTLE and OFTEN is most beneficial.

- Group sessions are run twice a week and cover issues that are relevant to most people with CRPS. For example our Pain Consultant will talk about medications and other groups will be facilitated by your OTs, Physiotherapists and a Psychologist.

  “Having my daily programme of activities posted on the ward noticeboard helped me to remember where I was supposed to be each day”.

- Some people who are struggling to cope with the emotional side of CRPS, which is impacting on them fully participating in the rehabilitation programme, may find an individual session with our psychologist helpful. A referral can be arranged.

- During your stay you will have the opportunity to meet other people with CRPS. On the first Monday afternoon we have a group welcome session so that you can be formally introduced to each other and we
can give you more information about the programme. Up to six people usually attend the programme.

- Once a week, usually on Friday mornings, the CRPS team see all patients on a ward round. This allows the team to focus on you and your CRPS and provides you with the opportunity to ask any questions.

What happens at the weekends?

There are no therapy sessions at the weekends and you may, if you wish, choose to go home. If a second week of the programme has been arranged you will be asked to return on the Sunday evening, or, if you live locally and can arrive in time for your first therapy session Monday morning. Patients who stay can take the opportunity to enjoy the leisure facilities in Bath. Whether you stay on the ward or go home, it is important that you continue with your therapy programme as advised by your therapists. For this reason, if you have a long and tiring journey to get home, it may be sensible to stay in Bath.

What can I expect from each component of the programme?

The programme is centred on therapeutic rehabilitation, which includes physiotherapy, hydrotherapy, occupational therapy and psychology. **Medical involvement is minimal but you may be seen by our consultant pain physician during your stay.**

During the therapy sessions you will be encouraged to look at your affected limb and to move it, which you may find challenging. It is likely that you will have started to move or hold yourself differently as a result of your pain and we will work with you to identify and correct this. All of our therapy and nursing staff use a ‘hands off’ approach, and encourage self-management because we want you to feel confident in continuing your rehabilitation when you leave the programme.
1. Physiotherapy

Our physiotherapists will work towards re-educating normal movement of your whole body as well as your affected limb. This may be challenging if you have been using compensatory movement strategies for some time, but left uncorrected, this can exacerbate your symptoms further. General reconditioning activities may also be introduced as appropriate.

A variety of interventions will be utilised according to your specific problems/needs, which will be established during your admission assessment. The physiotherapy you receive during your stay may seem different to what you have previously experienced and some of the treatments may seem unusual. We use these treatments to target unhelpful changes which occur in your musculoskeletal system and nervous system caused by pain and CRPS.

Physiotherapy includes land and water-based (hydrotherapy) treatments (so please bring swimwear and a dressing gown). Many patients find hydrotherapy very helpful and when unable to attend, this can be disappointing. Unfortunately the pool is occasionally out of action for cleaning purposes and sometimes the person themselves is out of action! When a patient has vomiting and diarrhoea this means that hydrotherapy is not feasible until two days post episode for this patient.

2. Occupational Therapy

Our Occupational Therapists (OTs) will ask you to think about the impact that CRPS has had on your life, especially on those activities that mean the most to you. These may include activities such as coping at work or with domestic tasks, managing your personal care, communicating with

“It felt like I was being taken a step backwards, but in fact I was learning how to use my limb properly.”
people who are important to you, continuing to enjoy leisure activities, using relaxation techniques or improving your sleep.

OT will introduce you to a wide range of strategies which will help treat CRPS with the aim of restoring your level of function. Treatments are varied, but may include desensitisation, mirror visual feedback, energy conservation, and using everyday tasks as opportunities for continuing your rehabilitation. Your treatment will be specific to your needs and all interventions will show you how to manage your condition independently once you leave the programme.

3. Psychology

We know that good physical rehabilitation rarely happens if a person is distracted and concerned by other issues, or feels that everything has got on top of them. CRPS can be a chronic, life changing condition and these types of emotions are entirely normal. All of the team will be sensitive to listening to these concerns but sometimes specialist expertise is best to address these types of problems if they are interfering with your rehabilitation progress. For this reason we have a Psychologist as a key member of the team, who is trained to listen and discuss with you these aspects of your life.

“This is a good opportunity to talk about things which you may not have discussed even with your family, partner etc”.

4. Nursing staff

On admission the nursing staff will discuss your nursing needs with you and, if required, develop a care plan for the duration of your stay. Like the therapists, the nurses encourage independence but are happy to assist
you as your needs require. The hospital operates a self-medication programme and it is likely that you will remain responsible for your medication. Please ensure you bring enough of your medication to last the duration of the course.

“The pain increased in the first week, but by the second week this had levelled out. The pain hasn't gone but I've got the movement starting to come back, so the pain is something I have to accept and live with”.

What should I expect to gain from the programme?

Often, patients and their families and friends believe that the inpatient stay will solve all of their problems, relieve their pain and return the patient to their former self. Unfortunately, this is an unrealistic expectation. Rather, we hope to help you improve your function by teaching you exercises and strategies to manage your condition more effectively, and in so doing over time, reduce the impact of the pain. Clearly this is only possible if you actively participate.

“My hope, when I heard that I was able to come for treatment, was that if I got just one little thing out of it then that would be more than before, but I actually came out with so much. I think when you come in you've got to be positive and everything you're told to do you have to try, even though it's very hard or painful some days”.

What can I do to get the most out of the programme?

We cannot emphasise enough the importance of fully participating in your treatment and contributing to your treatment plan. We will encourage you to continue the exercises, desensitisation and use of your arm/leg in
everyday activities, at all times during your stay and, most importantly, once you return home.

At times progress may seem slow but try to remain positive. You may wish to involve your family and friends in supporting you to continue your treatment at home. Please let us know if you would like someone to join you during a therapy session to learn how to do this. You can also contact the team here or your local health professionals if you require any further guidance once you return home.

“Well worth every minute but the overall criteria when you come in is that you have got to be positive”.

SECTION 2: INFORMATION ABOUT THE HOSPITAL

Staying at the RNHRD

Patients are accommodated on the two general rheumatology wards at the RNHRD. Male and female wards are separate as are toilet and washing facilities. Meals take place in a patient dining room.

Hospital wards are busy places and can be noisy at times but the staff try their best to keep the environment as peaceful as possible. The hospital is located right in the heart of the city centre so there may be external sources of noise arising from a busy city environment, including during the night time.

As hospitals are often warm it is suggested that you may prefer to wear light casual clothing which is suitable for exercise and sensible footwear (low heeled, lace-up shoes or trainers). Wearing layers is recommended as you will be moving from warm to cooler areas within the hospital and during the therapy sessions you might get warmer.

Please note the hospital is a smoke free environment and smoking, or use of e-cigarettes is actively discouraged during your stay.
What can I do to prepare for my stay?

During your outpatient assessments with the CRPS team you may be taught some exercises, desensitisation techniques or agree some goals. It is very important that you regularly practice your exercises, follow desensitisation advice and try to achieve set goals before you begin the programme. It is also a good idea to think about what goals you would like to work on during your stay.

What happens when I return home?

Depending on your clinical need we are able to make referrals to local therapy services to support you in continuing your treatment programme. Once again we cannot stress enough the importance of practicing in all that you have learnt when you go home.

A follow-up appointment with the team, including physiotherapy, occupational therapy (and in some cases psychology) will be arranged for you approximately three months after discharge.

“...The most important thing is to take everything you have learnt and continue to improve when you get home. With busy lifestyles it is sometimes hard to fit it all in, but it’s worthwhile and I have continued to improve slowly”.

“The programme is holistic and has helped me to put the routine back into my life”.

Is there any research being done on CRPS?

Research into the causes and treatment of CRPS is ongoing worldwide. At the RNHRD we have a multi-disciplinary research team studying a wide range of projects aimed at giving us a better understanding of this complex condition.
One project, using laboratory and clinical investigations, is concerned with trying to identify the mechanisms involved in triggering and maintaining CRPS. Another is exploring how those with CRPS perceive their affected limbs. Alongside this work we have also pioneered the use of a new therapy (mirror visual feedback), which aids some people to reduce their pain whilst exercising their affected limb. You may be invited to take part in some of these studies whilst you are a patient with us, although participation is voluntary.

In addition to research, we ask people to complete a number of questionnaires before they attend the programme and at various time points after the programme. The reason we ask you to complete the questionnaires is to measure any changes over time. Your co-operation in completing these questionnaires is greatly appreciated.

“There is the possibility of being asked to take part in various research projects whilst an ‘in patient’ these I found very interesting and sometimes helpful”.

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Frequently asked questions?

- **What do I need to bring with me?**
  Plenty of comfortable clothing: The hospital can be warm, so layers are recommended. Two swimming costumes/ trunks for hydrotherapy.
  Don’t forget to bring your usual medication.

- **Does the hospital have Wi-Fi?**
  No, there is no Wi-Fi available within the hospital.

- **Can I leave the hospital early on the day of discharge due to train time bookings, or any other arranged transport?**
  Yes, you can leave at a specific time but please note you may miss therapy sessions. Please advise the CRPS team upon arrival so that they can arrange your time table accordingly.

- **Do I have a secure locker?**
  Yes, a secure locker is provided.

- **Do I have to bring my own towels?**
  The hospital provides you with towels, but you can bring your own if you wish.

- **Do I have to stay in the hospital at all times?**
  Outside of therapy times (usually 9.00-4.30pm) you are free to come and go as you please. Please note the hospital doors are locked at 9.30pm.

- **Does the hospital provide me with food?**
  Yes, whilst you are an inpatient your food is provided for you.

- **Can I use my mobile phone within the hospital?**
  Yes, you can use you mobile phone, but please be considerate to others, particularly during the doctors ward rounds and quiet periods such as at night time.

Please note the hospital culture is that of respect and consideration to others at all times. The Trust operates a zero tolerance policy on physical or verbal abuse, aggressive or threatening behaviour.
Further Information can be obtained from:

If you have any questions about any of the information in this leaflet please contact:

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Please contact the Patient Advice and Liaison Service (PALS) on 01225 825656 if you would like this information in different format.

We value your feedback.
Your comments, suggestions, praise and complaints will help us to improve the standard of our services.
Please contact PALS to feedback your views on the hospital
Tel: 01225 825656 or email ruh-tr.PatientAdviceandLiaisonService@nhs.net