



Oak Centre for Children and Young People

Patient Information



Contents

Introduction

The role of the therapists The role of the Physiotherapist The role of the Occupational Therapist (OT)

Staying in hospital

Younger children JIGSAW therapy group School age children The hospital school Physical education (PE) group

Challenges you may face 10

3

7

17

20

How to promote play Everyday activities Advice for everyday activities Ways to manage fatigue Ways to manage anxiety

What happens after leaving hospital?

General advice

Contact numbers Resources



Introduction

During their time at hospital, children may be in bed for long periods due to the side effects of their cancer treatment such as surgery, chemotherapy, radiotherapy or due to their particular type of cancer. This may result in children being less active.

The aim of this booklet is to provide parents with information on how to keep their child active and independent throughout their hospital stay, as appropriate for their age.

The role of the therapists

The therapists will work with you and your child to help minimise the effects that illness, treatment and a long hospital stay can have on your child's development, movement and participation in daily activities.

The therapists will provide assessment and treatment of your child's abilities at various stages throughout their hospital stay.

Assessment and treatment can take place at the ward, the therapies room, the therapy department, the play room or the school room.

The role of the Physiotherapist

Physiotherapists help by providing advice about movement and exercise as well as manual therapy and education for those affected by injury, illness or disability.

The aim of physiotherapy is to restore and maximise function through a variety of treatment techniques.

Physiotherapy can help to:

- Increase muscle strength
- Maintain flexibility of joints
- Improve co-ordination and balance
- Assist with clearing chest secretions.

The role of the Occupational Therapist (OT)

An OT can support your child to maximise their ability in the activities that are important to both you and them.

An OT will assess your child's ability to do their everyday activities such as playing, games, washing, dressing, feeding and school work.

This may involve providing:

- Play and activity programmes to promote development
- Adaptive equipment to support independence
- Advice on positioning in activities and at rest to improve function and comfort
- Strategies to manage fatigue and tiredness
- Advice and strategies to manage anxiety.



Staying in hospital

Children of different ages have different needs. Being in hospital can make it difficult for your child to play, move and learn as they would usually do at home.

At the Oak Centre for Children and Young People there are different activities available to help support your child's needs and to maintain some normality in their routine whilst in hospital.

Younger children

For younger children, the most important activity is play.

Play is how children develop all the necessary skills to become independent and to develop physically, cognitively and socially.

Play may need to be adapted for your child whilst they are not feeling their best. The OT and physiotherapist can support your child to continue to play throughout their stay and provide you with advice about how to promote good play.

JIGSAW therapy group

JIGSAW is a pre-school group held once a week in the therapies room.

The team running JIGSAW includes an OT, physiotherapist, speech and language therapist and the psychological support team.

The hour long session includes fun activities such as soft play, interactive play and musical games.

You will be invited to attend with your child.

School age children

For older children, it is important to encourage them to continue doing their activities and hobbies of interest.

Encourage them to bring their favourite games and hobbies to hospital. These activities will help to maintain good activity levels, add to the day to day routine on the ward and may help with maintaining social and emotional wellbeing. This can be particularly useful during times when children have to be in isolation.

The hospital school

The Oak Centre for Children and Young People has a school room that is open during term time from 10am-3pm.

Children are able to continue with their academic studies as well as take part in group activities such as music, art, cooking and parties.

A team of teachers work on the unit and can liaise with your child's school and the therapies team.

As therapists, we actively encourage school attendance to give structure to your child's day.

Physical Education (PE) group

The PE group is held together with the teaching staff.

The session runs for an hour each week in the therapies room.

All primary school aged children are welcome to attend.

Sessions run on a rolling program which includes ball skills, balance, coordination, dance and other physical activities dependent on the ages and abilities within the group.

Adaptations are made to ensure all children who want to are able to participate.

Challenges you may face

The following section explores specific difficulties your child may experience and provides basic information to help you to support your child's needs. Remember you can always ask to see an OT or a physiotherapist to assess your child's needs.

How to promote play

Play for your child may be difficult in hospital, especially when they are feeling unwell and tired. Here are some ideas for how to promote play for your child (age dependent).

Younger children

- Younger children spend time playing on the floor at home. Although this is difficult in the hospital environment, try to allow them to spend time playing on the floor wherever possible (a mat can be placed on the floor to sit on). Try playing teddy bears picnics, driving toy trains and cars or building with blocks or lego, and using sensory toys. These provide noise, light or tactile sensory input to your child, so are ideal for when they are unwell or tired.
- Bubbles can be fun, relaxing and pleasing to watch.
 Blowing them encourages deep breathing, chasing them promotes moving around and popping them encourages arm movement.
- Balloons can be used for throwing, catching, batting or kicking. This will help maintain or develop ball skills and maintain movement and muscle strength in a fun way.
- Singing and moving action songs and sensory songs are fun and encourage movement, interaction, sensory experiences and listening skills.
- Bubbles, balloons, singing and moving can all be done sitting or in bed if needed.

Older children

- For older children, baking, Wii, and arts and crafts can be motivating and easily adapted for their movement and fatigue levels. Ask the OT or physiotherapist if they feel your child would benefit from these activities.
- Try board games, puzzles, construction toys (such as Technic Lego, K'nex, Goldieblox). If these are age appropriate for your child, they are great activities which require little energy and take lots of time.
- Learn a new skill, for example magic or circus tricks, card games, knitting or sewing or jewellery making.



Everyday activities

As a parent, it is natural to want to help your child as much as possible. You may want to help wash, dress or feed them more than you would otherwise.

It is very important to encourage your child to keep doing as much for themselves as possible. Even a small amount of independence in washing and dressing, brushing teeth and eating will be beneficial.

Try to make activities fun and allow your child to have some element of choice during the activity.

Keeping up with everyday activities can help to:

- Maintain your child's abilities and promote their development
- Help your child to feel they have some independence and control, improving their motivation and mood
- Provide some structure and routine to your child's time in hospital.

Advice for everyday activities

Some of these strategies will require assessment or specific advice from an OT or Physiotherapist – the profession to ask is indicated in brackets.

Hand problems:

- If hands are sore or tired, try resting them on small beans bags, playing in warm water, having them massaged or doing stretches to relax them (OT)
- Use easier to grasp toys, loop handled scissors, pencil grips, chunky pens and adaptive cutlery and crockery for eating (OT).

Getting dressed:

- Choose clothing with fewer fastenings (OT)
- Handy aids can help your child to dress independently (OT)
- A special seat can be put in the shower or bath or a frame can be put around the toilet for easier access (OT)
- Try doing table top activities with your child standing or lying on their tummy for a change in position. This can be useful if the muscles used in sitting get tired (OT & PT)
- Walking aids can be provided as required (PT) or a wheelchair/buggy for longer distance mobilising or for more significant mobility problems. (OT)

Ways to manage fatigue

The treatments your child receives can make them feel tired and lack energy. Being less active can weaken the muscles and make your child feel more tired.

- Try to create a consistent daily routine on the ward if and when possible, for example going to bed and getting up at the same time each day.
- Fatigue can make it more difficult for your child to concentrate for long periods. Try to do 'little and often' and give them rest breaks in between activities.
- Make activities a bit easier when your child is very tired. Do things sitting down rather than standing, use a buggy/ wheelchair to take them to groups or school so they save their energy for the actual group and get family involved in playing with the child to keep even simple play fun.

- There is evidence that exercise can help to reduce the symptoms of fatigue, so if possible, it is important to encourage your child to exercise, move or play a little each day. If you would like specific exercises, please ask to be referred to the physiotherapist.
- Try to be realistic in your expectations of your child there are some days when your child may need more rest and may not be able to do as much as other days. Try to make allowances where needed.

Ways to manage anxiety

Spending long periods of time in hospital can cause a great deal of anxiety to both you and your child. This can affect your child in many different ways such as reduced appetite, less willingness to engage, disinterest in activities, behavioural changes and difficulty in sleeping.

The OT can:

- Teach relaxation techniques
- Provide strategies to promote positive thinking
- Teach calming breathing exercises
- Provide advice for using distraction techniques.

The Play Team can also help you and your child to cope with anxiety, especially anxiety directly associated with medical procedures.



What happens after leaving hospital?

What happens after leaving hospital?

When your child finishes treatment, they may still feel tired and may not be as strong as before. It will take time to return to their normal routine and activities.

It may take time to build up stamina again, but it can help to eat a good balanced diet and introduce activities gradually.

Hopefully your child will soon be able to attend nursery or school and join in sport and other activities in and out of school.

Sport and exercise are important as they can help maintain levels of fitness, maintain a healthy weight, improve sense of wellbeing and self-confidence and can improve a sense of belonging. Exercise can also enhance good sleep patterns, decrease pain and increase appetite.

If treatment has left your child with any ongoing issues, they may need follow-up by The Royal Marsden physiotherapy or OT team. They may also be referred to a local service or community service.



General advice

General advice

- Build activity and exercise into your child's daily routine this may need to be built up slowly.
- You may need to pace activities. Incorporate a warm-up, do little and often and do activities as a family.
- Be aware of blood and platelet counts. Low haemoglobin (Hb) may cause tiredness and breathlessness. Low platelets may increase the risk of bleeding.
- Take care with infection. If your child has an infection or a temperature, they should not do more than their daily routine.
- Ensure a balance between activity and rest.
- If your child feels unwell or has a new pain, seek advice before allowing him/her to resume sport and exercise.
- Make sure that your child drinks enough while exercising.
- For children that have had brain tumours, it is important to take all possible precautions to prevent a bump to their head.
- If your child has a central line, ask for advice in relation to swimming or other water sports.

Contact details

For any queries or issues, please contact us on the numbers below.

Physiotherapy department 020 8661 3098

Occupational Therapy department 020 8661 3090

Resources

Children's Cancer and Leukaemia Group www.cclg.org.uk

CLIC Sargent www.clicsargent.org.uk

Macmillan Cancer Support www.macmillan.org.uk

Teenage Cancer Trust www.teenagecancertrust.org

Notes and questions

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This booklet is evidence-based where appropriate and where evidence is available.

Details of the references used in writing this booklet are available on request from: The Royal Marsden Help Centre Freephone: 0800 783 7176 Email: patientcentre@rmh.nhs.uk

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Should you require information in an alternative format, please contact The Royal Marsden Help Centre.

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The Royal Marsden publishes a number of booklets and leaflets about cancer care. Here is a list of information available to you.



Diagnosis

- A beginner's guide to the BRCA1 and BRCA2 genes
- CT scan
- MRI scan
- Ultrasound scan
- Lynch Syndrome



Supportive care

- Eating well when you have cancer
- Lymphoedema
- Reducing the risk of healthcare associated infection
- Support at home
- Your guide to support, practical help and complementary therapies



Treatment

- Central venous access devices
- Chemotherapy
- Clinical trials
- Radiotherapy
- Radionuclide therapy
- Your operation and anaesthetic



Your hospital experience

- Help Centre for PALS and patient information
- How to raise a concern or make a complaint
- Making your stay with us safe
- Your health information, your confidentiality

Please visit **www.royalmarsden.nhs.uk/patientinformation** where several patient information booklets are available to download.

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