Preparing paediatric patients (up to 16) for proton beam therapy at The Christie

Information pack for professionals

Dear colleagues

Proton beam therapy at The Christie is part of a national service and we recognise that patients already have good support in place with professionals at their primary treatment and/or radiotherapy centre.

Our aim is for children and their families to be reassured and well informed about coming to The Christie. We value your knowledge and assessment of any individual needs of patients and families and appreciate as much information as you are able to share with us before they come for assessment.

This information pack will tell you about proton beam therapy and what the pathway will be like for UK patients coming to The Christie in Manchester. We are really keen to hear from you as children and young people transition to our team at for this part of their treatment and look forward to collaborating with you all.

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Proton beam therapy assessment visit

Paediatric patients will be seen in clinic on a Monday or Thursday and will be staying in Manchester for their assessment visit which is approximately a week long. Families normally arrive in Manchester the day before they are due to be seen in clinic. During their assessment visit they will have the following appointments scheduled in:

- Clinic visit – including Key worker introduction, clinical consultation, blood test and observations by one of the paediatric nursing team
- Individual education/play preparation session with the health play specialist (HPS) team
- Anaesthetic assessment if applicable – this will be done once the decision has been made regarding GA/awake pathway by the team here at the Christie. Please be clear with families about this when discussing proton beam therapy.
- Pre-treatment education and safety screening
- Cannulation for contrast unless they have a central line
- Immobilisation
- CT and MR scans (all paediatrics will have both and usually back to back)
- Other people they might meet: Clic Sargent social worker, Teenage Cancer Trust youth support co-ordinator and teachers

If patients require chemotherapy during their proton beam therapy they will also attend ward 84 at Royal Manchester Children’s Hospital

Families travelling to Manchester for proton beam therapy will be provided with accommodation and transported to the centre for their appointments.

Key workers

The key worker team consists of specialist radiographers and paediatric nurses. Every child having proton beam therapy at The Christie will have a named key worker. Their role is to provide support, advice and co-ordinate the patient’s care. The key worker will be the first point of contact for the patient even before they visit The Christie.
Meet the health play specialist team

The proton beam therapy centre has a team of highly experienced, registered health play specialists forming part of the paediatric team. They have a wide range of skills and experience with children young people and families in radiotherapy, oncology and further afield.

Their role is to prepare children and young people for all aspects of planning and proton beam therapy and support them throughout their treatment in order to make it as positive experience as it can be.

Children will be allocated an individual preparation session with a member of the team who will work with the child and make a plan of support for their time at The Christie. They will also contribute to the team assessment regarding whether children will proceed with their treatment awake or need GA.

Play preparation

We have a dedicated play room specifically designed for our HPS team to see patients individually and prepare them for proton beam therapy. It is also used throughout treatment for children needing some individual support or therapeutic play.
We use a range of resources and therapeutic techniques in our sessions with children to help them to understand their pre-treatment and treatment pathways. As a centre we have also produced a range of booklets for children illustrating what they will experience during proton beam therapy. All patients will get an age appropriate printed version during their assessment visit but pdf copies can be accessed via the website (see below). The books feature our Proton Panda mascot chosen by former patients receiving protons abroad.

All patients can decorate their masks if they need one (please ask if you are not sure) as this can be very therapeutic and make them much more fun to wear. This forms a really valuable part of their preparation. If children are excited and feeling positive about having a mask made, it helps them to feel more comfortable wearing it. If you are doing some preparation work then it would be great to help them design their mask and they can bring their ideas with them.
Pre-treatment stages

Here are some of the types of immobilisation currently used for protons at The Christie. If you feel that children or families need to know exactly what will happen to them before they come for their assessment visit please discuss this with us first so all patients get the correct information as the method of immobilisation will only be confirmed when they come for assessment. The HPS team will then prepare children and young people appropriately and support them throughout their pre-treatment pathway.

Left to right: neck rest, head mask, head and shoulder mask, vac bag and arm shuttle. All proton masks will cover the face without cut-outs as shown below.

Permanent marks/tattoos – are normally (but not always) required and we will discuss this with them if appropriate.

The standard pre-treatment pathway for paediatric patients is to have their immobilisation, CT and MRI scans on the same day. This is quite a long day for them but we will make sure they feel fully supported throughout. It is a good opportunity for us to build a rapport with them as parents and carers are not permitted in any pre-treatment or treatment appointments. Patients can choose the colour of the ambient lighting in the scanner rooms and have music or a story playing.

Patients can also choose a theme (for example the jungle or seaside) which projects on the walls in the scanner rooms.
Patients will need to lie on the treatment couch throughout their treatment and the robotic arm moves the couch into place. The radiographers will then ensure the patient is in the correct position which needs to be very precise. Patients need to stay completely still throughout while X-ray and cone beam images are taken to confirm their position and then for treatment delivery. The nozzle on the machine which delivers the treatment may come quite close but will not touch them.

The treatment session will be less than an hour per day but often shorter. Due to the imaging bay being inside the gantry (on the right in the picture above) the health play specialist and radiographers can be next to the patient during set up and imaging, just leaving for the treatment itself which is a few minutes long. Patients can listen to music or stories during set up and treatment and we can plan other relaxation or distraction techniques as needed.
**Paediatric facilities**

We have an outdoor play area in the centre and two paediatric waiting areas (one on the treatment floor and one in the clinic area)

We are planning a range of activities and workshops that all patients and families can join in with as we want it to be a positive shared experience for everyone. Daily play will be available for all children attending the centre and all families are encouraged to get involved.

**Family support**

We have a dedicated complementary therapist working 4 days per week offering support to families and carers for stress, anxiety and other emotional issues. The therapies range from clinical hypnotherapy, neuro linguistic programming, aromatherapy and HEARTs touch therapy (gentle over clothing massage for relaxation).

All young people under the age of 24 who are receiving proton beam therapy treatment will be eligible for CLIC Sargent support and there is a social worker based in the centre.

Please speak to your local CLIC Sargent team for information on how to refer and further information about possible ways CLIC Sargent may be able to support your families.

For more information about how CLIC Sargent uses your information, please read our privacy policy. [https://www.clicsargent.org.uk/content/privacy-policy](https://www.clicsargent.org.uk/content/privacy-policy)

We also have a great team of volunteers who help families feel very welcome and a fabulous clinical support work team.
Teenage and young adult support

The Teenage Cancer Trust Youth Support Coordinator will work with any patients aged 13-24 years, providing support pre-treatment, during treatment, and post-treatment (for up to 2 years). This support will include one-to-ones, peer support groups, off-site activities and practical help and advice.

For any patients who do not have a Teenage Cancer Trust youth support coordinator at their referring centre, this support will continue post-treatment with patients also invited onto a range of national Teenage Cancer Trust residential once they are 6 months post-treatment. Those patients who already work with a Teenage Cancer Trust Youth Support Coordinator at their referring centre will continue to be supported by them once they have finished their treatment here at The Christie.

The Christie school

All children of school age who are receiving proton beam therapy will be offered teaching in our classroom on the ground floor. We liaise with each child’s own school and support them in their learning when they are well enough to do so.

With treatment schedules in mind, teachers will work with parents and Christie staff to arrange times to attend daily classroom sessions. We will also facilitate independent study and revision sessions in our learning space.

Pupils can generally expect a mix of one to one and small group sessions. IT resources and internet are provided.
Paediatric day unit – nursing, anaesthetic and recovery teams

Paediatric patients requiring general anaesthesia (GA) for their proton beam therapy will be admitted to the day unit and looked after by a dedicated paediatric team including nurses, clinicians and a dedicated anaesthetic and recovery team. As well as induction rooms, there is a recovery area and 4 bedded day unit. This adjoins the paediatric waiting area where they can play before their treatment and afterwards once they have fully recovered from their anaesthetic.

The paediatric nursing team consists of a paediatric lead nurse, paediatric nurse clinicians, ward manager and paediatric nurses. The paediatric day unit cares for all children under the age of 16 years. The nursing team will see children daily if they require general anaesthetic for their radiotherapy treatment and also routinely see children who have their radiotherapy treatment awake. They support patients and families including planning scans, treatments, clinic appointments, blood tests and medical reviews. They work closely with all members of the team to deliver holistic family centred care.
Patient information – where can children and families find out more about coming for proton beam therapy?

The Xploro® app uses augmented reality and games to help young patients understand hospital environments and processes including proton beam therapy. This will be available on all app stores from September 2019 and is primarily aimed at children aged 7-12.


Our website (using the above link) has a range of information and updates about the proton beam therapy service at The Christie and may be more appropriate for older children, teenagers and families. It also has a link to you tuber Gracie’s video about her treatment to show other proton beam patients what the experience was like.

For children needing more information before coming please direct them to the panda books which are on the website as pdfs and ask them to come with any questions which we’ll be happy to answer when they get here. Once we have assessed them for the relevant pathway (GA or awake treatment) we will give them their own printed copy of the right booklet.

Contacts

For any enquiries regarding paediatric patients please contact our clinical support workers on the main desk and you will be transferred to the appropriate person:

0161 918 7577

If you have any questions about preparing or transitioning patients to the health play specialist team at The Christie please contact us on the above number or via secure email: chn-tr.pbt.hpsteam@nhs.net Appendix 1 is a pro-forma which we would really appreciate your support in completing and attaching to any correspondence for our team to review.

*Please ensure that any correspondence meets GDPR regulations and any identifiable patient information is sent via a secure route (nhs.net recommended)
## pro-forma for The Christie health play specialist (HPS) team

<table>
<thead>
<tr>
<th>Procedure</th>
<th>Any further details, distraction or support strategies used</th>
</tr>
</thead>
<tbody>
<tr>
<td>CT Scan</td>
<td>awake GA/sedation</td>
</tr>
<tr>
<td>MRI Scan</td>
<td>awake GA/sedation</td>
</tr>
<tr>
<td>Needles/cannulation</td>
<td>manages Finds challenging</td>
</tr>
<tr>
<td>Observations and saturation monitoring</td>
<td>manages Finds challenging</td>
</tr>
<tr>
<td>Central line/portacath access</td>
<td>manages Finds challenging</td>
</tr>
</tbody>
</table>

**Please comment including any recommendations for reasonable adjustments**

- **Does the child have any additional needs?** Please specify any confirmed diagnosis or EHC plan
  - yes
  - no

- **Any physical/mobility issues**
  - yes
  - no

- **Does the child have any specific procedural fears or anxieties?**
  - yes
  - no

- **Does the child have the capability to safely stay in a room alone without getting distressed?**
  - yes
  - no

- **Can the child keep still easily when necessary (preferably lying down)?**
  - yes
  - no

- **How is their concentration span?**
We want to make this experience as positive it can be for children, young people and their families. Please let us know anything else about the child/young person and their family to help us support them during their proton treatment? Any likes, dislikes, ways you have connected with them and what we can do to make it easier. What would make them feel welcome and supported?

Any further comments regarding their resilience and ability to cope with new and unfamiliar procedures or engagement with healthcare professionals:

Referring centre contact details

Name:
Job title/role:
Hospital:
Telephone number:
Secure email:

* Please email the completed form to chn-tr.pbt.hpsteam@nhs.net ensuring that any correspondence meets GDPR regulations and any identifiable patient information is sent via a secure route (nhs.net recommended)