

PEG TUBE FEEDING INFORMATION FOR PARENTS



Children's Health Ireland
at Temple Street



Children's Health Ireland
at Crumlin



Children's Health Ireland
at Tallaght

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INTRODUCTION

This booklet was developed by the staff of CHI at Temple Street and CHI at Crumlin to answer some questions you might have about PEG feeding. Our booklet explains PEG feeding tubes and how to care for your child's tube at home. We also explain what to expect when your child comes into hospital for the procedure.

What is a PEG feeding tube?

PEG stands for

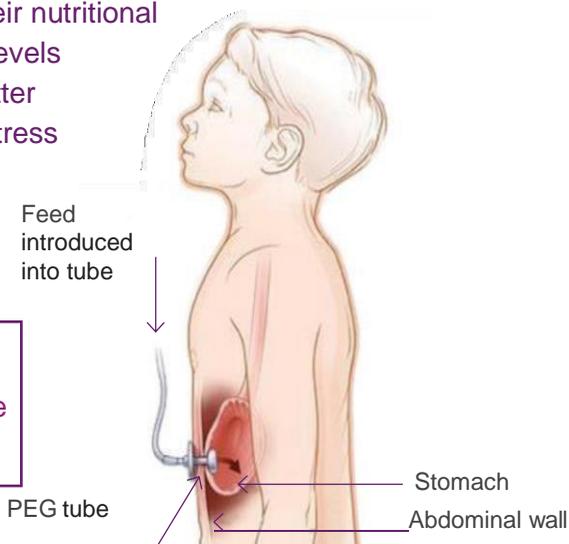
PERCUTANEOUS	ENDOSCOPIC	GASTROSTOMY
placed through the skin	using a scope to see the stomach	an opening into the stomach

Your child can receive special liquid food (feed), fluids and medications through the tube directly into the stomach by passing the mouth and throat.

There are other types of gastrostomy feeding tubes. A PEG tube is the preferred type for children having their first gastrostomy tube.

Why does my child need a PEG feeding tube?

It can be difficult for children, parents and their families to make the decision to have a PEG tube placed. However, when children are unable to meet their nutritional requirements for their activity levels and growth, they can enjoy better health and it can remove the stress associated with eating.



The opening on the tummy where the PEG tube enters the stomach is called the 'stoma'.

Common reasons why a child may need a PEG feeding tube:

- Your child may continue to eat normally and only need the PEG for extra calories and nutrients ('top-ups') when your child is not able to eat enough food to meet his/her nutritional needs.
- A PEG allows extra water to be given if your child can not drink enough fluids/liquids.
- A PEG allows precise measurements of special diet or medications to be given.
- A child may have an 'unsafe swallow'. If a child's swallowing is weak, there is a risk of choking and aspirating and so is unable to eat or drink safely (i.e. food enters the lungs during swallowing).
- Some children can continue to eat thickened food / fluids and only need the PEG for extra nutrition.
- Other children are at high risk for aspiration of oral food/fluids and a PEG may be advised for all feeding.
- If your child has had a Nasogastric Tube (NGT) for a long time, then a PEG may be recommended to reduce the distress associated with passing NGT frequently.

Will my child always need the PEG tube?

This will depend on your child's underlying medical condition. As your child's medical condition improves, he/she may be able to reduce the use of the PEG and eat normally. If your child has an unsafe swallow, the PEG tube may be needed in the longer term.

How is a PEG inserted?

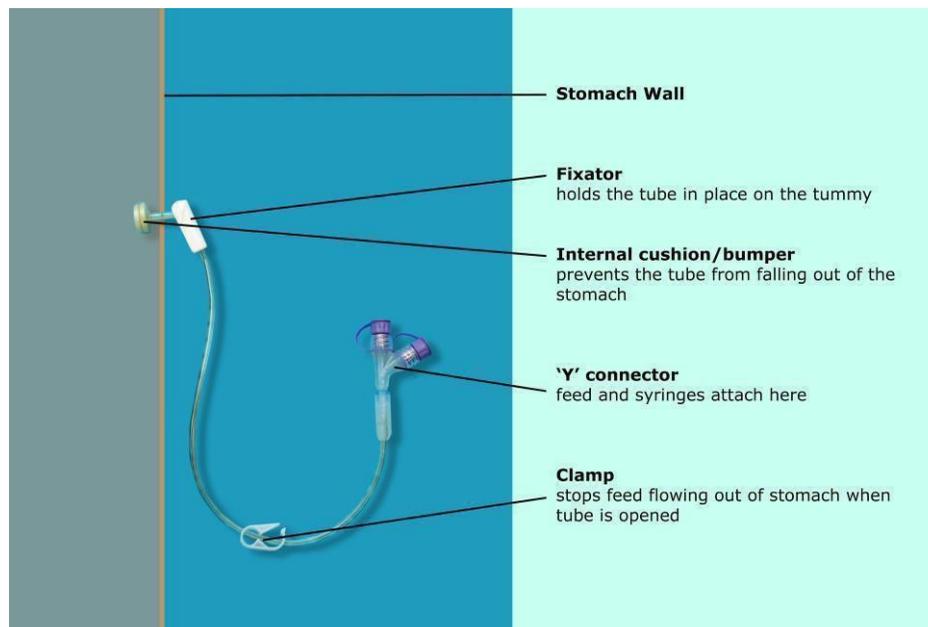
A PEG is inserted in theatre under general anaesthetic when your child is asleep.

1. The PEG is inserted using an endoscope. An endoscope is a long narrow tube with a camera and light at the end of it. It is passed through the mouth and throat into the stomach. The doctor will use the endoscope to place the PEG in the stomach and secure it in place.
2. In a smaller number of children, the PEG may be placed surgically. The doctor will make an opening into the stomach and place the feeding tube through the skin into the stomach. The stomach is then stitched closed around the tube.

How long will the PEG last?

The PEG is manufactured from special plastic (polyurethane) which can last up to three years. When the tube is old, it will be removed under anaesthesia and another PEG or a 'button' type tube can be inserted through the original opening. If your child no longer needs any feeding tube, then the PEG is removed under anaesthetic and the opening (stoma) is allowed to close by itself.

PEG tube description:



PLACEMENT OF THE PEG TUBE

What happens *before* the operation?

You will meet with your child's surgical team before the operation. They will discuss the surgery; explain the procedure and you will sign the consent form. The team will explain the estimated length of stay and post-operative feeding regime, as this may vary from child to child.

What happens *after* the operation?

When the surgical team is satisfied with your child's progress, feeding will start through the tube for the first time. Your child will be seen by the dietitian and your child's feed will be started slowly at first and increased gradually as tolerated. If your child eats normally, a light diet can be given once the team allows.

How long will my child be in hospital?

Usually between three and five days is sufficient to monitor your child's tolerance of the feeding regime and for you to become familiar with the pump and feeding.

FEEDING MY CHILD

How do I feed my child?

Every child is different. The amount or type of feed your child receives is specific to them and will depend on your child's weight, height, activity level, medical conditions and your home circumstances.

Your dietitian will discuss a suitable feeding regimen with you. Depending on your child's tolerance and activity level, you may need to make adjustments to their feeding regimen from time to time. During a period of illness, if your child is not tolerating their feeding regimen, please contact the dietitian for advice.



Children are fed using a combination of 'continuous' and /or 'bolus' feeding.

Continuous Feeds

The feed is given slowly over a number of hours using a plastic feeding set and a special pump. The pump can be carried in a backpack or placed on a stand.

Bolus Feeds

The feed can be given at intervals throughout the day; the feed can be given via the pump or by gravity through a syringe. If your child is not prone to vomiting or retching and only requires small top-ups of feed, you can give the feed slowly with a syringe.



How should I position my child when giving a feed?

When you position your child correctly, it will allow the feed to settle in their stomach and should make feeding more comfortable for them.

- When feeding your child, the ideal position is at an angle of at least 30 degrees unless otherwise specified by your healthcare professional.
- If this is not possible, the head of the bed should be tilted. Your child should remain in this position during the feed and for up to 30–60 minutes after tube feeding.

Feeding my child through the tube

There are many types of special liquid feeds that can be given to your child through the PEG tube. Many feeds used are pre-prepared and ready to use. Some feeds have to be made by mixing a number of powders and liquids together. It is very important that only the feed advised by your dietitian is put down the tube; do not put anything else down the tube unless advised by your team.

How should I store and handle the feed?

STORAGE

Pre-packed Feeds

- Ready-made feeds in cartons, packs or bottles can be stored in a dry cool place away from sunlight, if they are unopened.
- Check the shelf life on all products to make sure they are in date.
- Do not use feed from any damaged cartons or bottles.
- You do not need to keep the unopened, pre-packed feed in the fridge.

Special Feeds

- You can make the amount your child will require for one day. They can then be divided into bottles of the amount needed at each feed (your dietitian will discuss this with you).
- Feeds are stored immediately in the refrigerator in a covered jug or bottle, ready to use. Any feeds that are open in the fridge (cartons/bottles/special made-up feeds) should not be kept any longer than 24 hours.

HANDLING

- Wash your hands before starting to set up the feed.
- Avoid touching any internal part of the feed container and giving set with your hands.
- You should throw away opened packs/bottles of feed after 24 hours.
- You should change giving sets every 24 hours or as directed by the dietitian.
- Use only sterile or cooled boiled water for flushing.
- Before using, check the expiry date and seal on packs/bottles of feed.
- Always gently shake the bottle or pack before you use it.

Venting

- Children who are prone to vomiting, retching or a lot of wind may benefit from 'venting' or releasing air from the stomach prior to feeding. You can also vent the stomach at other times if your child has symptoms. For more information, contact your dietitian or clinical specialist nurse.
- Attach a large syringe with the plunger removed, to the 'Y' on the PEG, and hold it up to allow air to release. You can also 'aspirate' or draw back on the syringe to release air. Some feed will also be aspirated. You can return this feed to the stomach after the air has been released.
- Children with severe vomiting or reflux may benefit from using a 'Farrell Valve' during feeds – ask your ward nurse or the gastrostomy/enteral nutrition nurse specialist for more information.



Maintaining my child's feeding skills

Some children who are on tube feeds can still eat food. Your child's medical team / speech and language therapist will discuss this with you. They will advise you about how much your child can eat and which consistencies your child can have.

What can I do if my child cannot eat?

It is important to promote pleasurable experiences or sensations around the mouth. Here are some ideas:

- Encourage your child to put objects such as teething rings or soothers in his/her mouth.
- Gentle massage around your child's face and mouth.
- Encourage messy play with food items.
- Use flavoured lip balms to keep your child's lips moist.
- Introduce food smells.
- Include your child in family mealtimes.
- Offer tastes – your child's medical team will advise you if it is safe to offer your child food tastes. Offer any food tastes just before or during your child's tube feed. These will help your child to associate the smell, taste and sight of food with the feeling of hunger being satisfied.

ORAL HEALTH

Maintaining your child's oral health

Children who are tube fed may be taking little or no food by mouth but they still need their mouths to be cleaned. Cleaning will make your child's mouth feel more comfortable and can reduce the build up of tartar and plaque bacteria which can cause gum disease and chest infections. Brushing and massaging around the mouth and cheeks can improve muscle tone, saliva flow and desensitise the mouth.

- Try to introduce tooth brushing from an early age, ideally as soon as the first tooth comes through.
- A very small, soft headed toothbrush or finger brush should be used to clean the teeth. A Superbrush or Curved Collis toothbrush are good alternatives.
- Try to brush your child's teeth with them sitting upright and with their head tilted forwards.
- Teeth should be brushed twice a day (morning and bedtime).
- Use a pea-sized amount of fluoride toothpaste and water for children over two years of age. A non-foaming toothpaste may help.
- Use only water for brushing teeth of children under two years of age unless advised otherwise by your dentist.
- Try to brush both gums and teeth using small circular motions.
- If your child bites/clamps down on the toothbrush leave it there as a mouth prop and use a second toothbrush to clean the other areas you can reach.
- If your child has a tendency to hold food in their mouth, then it's a good idea to check after eating that their mouth is clean. Your dentist will liaise with the paediatrician on how best to manage oral care.

Ask your dentist / pharmacist about various types of toothbrushes and non-foaming toothpaste



Fingerbrush

Dr.Barnam's Superbrush

Collis Curved brush

A visit to the dentist is recommended within the first year of age. Regular visits every 4-6 months will help prevent dental problems and your dentist can advise and help with tooth cleaning and fluoride application if appropriate.

LOOKING AFTER THE PEG TUBE

How do I give medications through the tube?

- The medication should be in a liquid form if possible.
- Most tablets can be dissolved in water to make them safe to give via the PEG tube.
- If a tablet is to be crushed, make sure it is crushed finely and dissolved/dispersed completely in warm water.
- When your child starts on any new medication, check with your local pharmacist for a liquid version if possible.
- Remind any doctor or pharmacist that your child will be receiving medication via a PEG tube.

When giving medications through the tube

- Stop the feed and close the clamp on the feeding set.
- Give the medication in a syringe through the feeding tube.
- Or through the opening at the end of the feeding set.
- A nurse will demonstrate this to you before discharge.
- Flush the tube, using a syringe, with a minimum of 10ml of cooled boiled water before and after giving each medication.

NEVER mix medication with the tube feed.

NEVER mix medications together.

Flush the PEG tube with water BEFORE and AFTER giving medications.

How do I look after the PEG tube?

Always wash your hands with liquid soap and water before you touch the PEG tube. You will receive training from the ward nurses on how to care for your child's feeding tube.

After surgery:

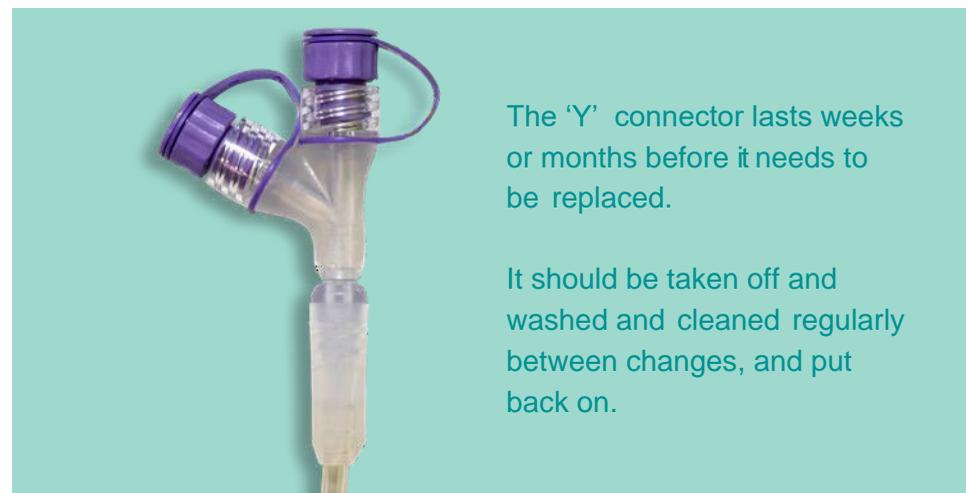
- There will be a dressing on the stoma around the PEG tube for the first week after surgery.
- A little oozing on the dressing is normal.
- The nursing staff may change the dressing each day and will show you how to do this at home for the first week after surgery.
- The PEG tube is not moved or turned for the first 72 hours post-surgery.

Daily Care:

- You will be shown how to rotate or turn the tube while in hospital – this is done once a day at home.
- After the first week, there is no need for a dressing unless there is a continuous ooze. A slight crusting around the stoma in the morning is normal.
- Wash and dry the stoma twice a day with mild soap and tap water.
- Look at the stoma site and surrounding area daily for signs of infection/irritation.
- The clamp on the tube should be placed in a new position every day to avoid weakening the tube.

Weekly Care:

- The fixator is opened for the first time between 4 and 12 weeks after surgery.
- Once the fixator has been opened, the inside is cleaned, and the tube is repositioned on the tummy.
- You will be shown how to do this.
- The fixator is opened once a week at home.



Positioning the tube



Tape the tube to your child's tummy as shown to the left to prevent it dragging on the stoma. Mepitac (a low-allergy tape) will be on your prescription for home.

Some parents prefer to use a belt or wrap to keep the tube secure.

You may have to try a few designs to find a suitable one.

SUPPLIES

Where do I get my supplies?

- The feeding pump which you will receive prior to discharge is supplied by Healthcare 21. You will also receive an initial supply of feeding sets and supplies from Healthcare 21.
- Your liquid feed will be supplied by your pharmacist.
- A prescription for all your supplies will be sent to your public health nurse before discharge.
- There is a table with Healthcare 21 items and code numbers on page 22 of this booklet.

OTHER ACTIVITIES

Baths and swimming

Your child can shower one week after surgery and can have a full bath and return to swimming after 4 weeks.

Physiotherapy and daily activities

When your child has recovered from the operation and is not needing any pain medication they can resume their normal activities. The PEG will not restrict physiotherapy or 'tummy-time'.

School

Your child can return to school whenever you are happy with their tolerance of the feeding regimen. If your child needs feeding with the PEG during school hours, contact your school principal so training can be organised for school staff and your child's special needs assistant.

Travel and holidays

Your child's PEG feeding requirements will not prevent you from travelling or going on holidays like any other family. It will require a bit more organisation and planning, but help is available.

For feed, contact your supplier to help transport your feed supplies. Contact the company as soon as you are planning your holiday for further information. Please call:

Nutricia Homeward at 1800 22 1800 · Abbott at 1800 22 1166

HOME NURSING/RESPIRE

Nurses who work with home care agencies, Jack & Jill and respite facilities usually are very familiar with PEG feeding tubes. CHI at Temple Street and CHI at Crumlin run training days for nurses caring for children with PEG feeding tubes. Your home nurses can contact the hospitals directly if they have any queries regarding the PEG tube.



www.benik.com

www.carealine.com

www.comfizz.com

www.p1h.it

www.ostomysecrets.com

COMPLICATIONS ASSOCIATED WITH PEGTUBES

Are there any complications associated with PEG tubes?

Your surgical team will discuss the benefits and risks associated with the operation to insert the PEG tube.

In CHI at Temple Street, the gastrostomy nurse specialist looks after children with different types of feeding tubes; in CHI at Crumlin, the enteral feeding nurse specialist looks after children with feeding tubes. In CHI at Tallaght, your dietitian and clinical nurse specialist looks after children with feeding tubes.

Don't hesitate to contact your nurse before and after surgery with any queries you may have. Contact details are located at the end of this booklet.

Troubleshooting common problems with PEG tubes

Infection around the stoma is not very common. If you suspect an infection – a large area of redness with pain and a temperature – you should visit your GP; an antibiotic is usually necessary.

Skin irritation and oozing around the stoma is very common but treatable and manageable. Antibiotics are not needed.

Remember:

Slight ooze in the first week or so after the operation is normal.

Crusting around the tube in the morning is normal.

PROBLEM	TREATMENT	PREVENTION
Oozing or a discharge of yellow/green fluid from the stoma	More frequent cleaning of the stoma Antibacterial dressings	Regular washing and drying of the stoma
Pink or red tissue growing around the stoma (overgranulation tissue)	Antibacterial dressings	Prevent the tube from moving in the stoma (Some children are just more prone to developing this tissue)
Tube blockage	'Push & pull' with warm water, flush open the fixator and massage the blockage If the measures above fail contact the hospital nurse specialist or the hospital surgical team for further advice	Flushing carefully before and after feeding and medications
Tube falling out This rarely happens with new tubes as they are very secure, but can occur easily when the tube is much older and it is tugged or snagged on buggies, cots etc.	The stoma can close very quickly if there is no tube in place Attend your local hospital Emergency Department as soon as possible In the Emergency Department any type of hospital catheter/ tubing should be inserted immediately to keep the stoma open. An anaesthetic is not necessary	Keep the tube safe by taping it to the tummy and secure it under clothing

FINAL CHECKLIST BEFORE DISCHARGE

- Giving medication and feeds
- Preventing tube blockage
- Cleaning and care of stoma site
- Troubleshooting/emergency care
- PEG tube care/Replacing 'Y' adapter
- Know where to get your supplies
- Practice opening the fixator on the model

USEFUL NUMBERS



CHI at Temple Street
Gastrostomy Nurse Specialist
Mary Walsh / Ann Finlay
Tel: (01) 878 4356 ·
E-mail: mary.walsh@cuh.ie, ann.finlay@cuh.ie
Dietitians: (01) 878 4442
Ask to speak with your surgeon's team (01) 878 4200



CHI at Crumlin
Enteral Nutrition CNS
Renagh Tomlinson
Tel: (01) 428 2656 · E-mail: renagh.tomlinson@olchc.ie
Dietitians: (01) 409 6809
Ask to speak with your surgeon's team (01) 409 6100



CHI at Tallaght
Clinical Specialist Dietitian
Tel: (01) 414 2000 or
Stephanie Kelly - Clinical Nurse Specialist
Tel: (01) 414 3640
Ask to speak to your surgeon's team: (01) 414 2000

USEFUL PARENT SUPPORT

There are many hundreds of children in Ireland with different types of feeding tubes. Support and contact with other families is available from:

- Facebook: Ireland NG and PEG feeding page
- www.pinnt.com (UK)
- www.oley.org (USA)
- www.feedingtubeawareness.org (USA)

My surgeon	
My dietitians	
My speech & language therapist	
My public health nurse / home nurse	
My pump company	
My appliances office	

MY CHILD'S FEEDING REGIMEN

Feed name	Total volume each day	Rate & duration

CODE NUMBERS FOR YOUR HEALTHCARE 21 ITEMS		
PRODUCT	CODE NO	SUPPLIER
Kangaroo Joey Enteral Feed and Flush Pump	383400	Healthcare 21 (Mon-Fri 9am-5pm): 1890 777 444 (Emergency Out of Hours 5pm-9am and Weekends): 1800 911 921
3-in-1 Feed Only Set	777503	
3-in-1 Feed and 1000ml Flush Set	777506	
3-in-1 Feed and 3-in-1 Flush Set	777408	
1000ml Feed and 1000ml Flush Reservoir Set	668104	
500ml Reservoir Set	666064	
1000ml Reservoir Set	666106	

Additional Codes	
Description	Code
<i>Corflo peg adapter repair Kit 12Fr ENFit connectors</i>	<i>50-6112</i>
<i>Corflo peg adapter repair Kit 16Fr ENFit connectors</i>	<i>50-6116</i>
<i>Mepilex Border Lite dressing 7.5cm x 7.5 cm</i>	<i>281200</i>
<i>Mepitac tape PH indicator strips</i>	<i>298300</i>
<i>Reusable Home Syringes available from Technopath</i>	
<i>5ml ENFit Low dose reusable home syringe 100</i>	<i>ELDISO-5H</i>
<i>10ml ENFit reusable home syringe 100</i>	<i>EISO-10H</i>
<i>3ml ENFit Low dose reusable home syringe 100</i>	<i>ELDISO-3H</i>
<i>20ml ENFit reusable home syringe 100</i>	<i>EISO-20H</i>
<i>60ml ENFit reusable home syringe 50</i>	<i>EISO-60H</i>
<i>Bottle Adapter 1 -12mm – 15mm with ENFit 100</i>	<i>BAISO1</i>
<i>Bottle Adapter 2 -14mm – 16.5mm with ENFit 100</i>	<i>BAISO2</i>
<i>Bottle Adapter 3 -17mm – 20.5mm with ENFit 100</i>	<i>BAISO3</i>

CHI AT TEMPLE STREET

The canteen is available:
 Mon – Fri 7.30 am – 6.00 pm
 Sat – Sun 8.00 am – 10.30 am

There are vending machines with meals, snacks, tea & coffee available outside the canteen.

Shop: There is a Spar shop nearby on Temple Street
 ATM: There is an ATM in the Spar shop on Temple Street

Temple Street is a smoke free hospital; smoking is prohibited on hospital grounds.

Parents Accommodation:

Rooms available for parents to stay: (01) 878 4300/(01) 878 4200

Disability Changing Facilities:

There are changing facilities for older children with a bench and hoist available in The Gill Unit, 2nd Floor, Out Patient Department and The King Unit, 3rd Floor of NEW OPD.

Please ensure you bring your child's sling for use with the hoist.



Transport:

Parnell Luas stop is the closest to the hospital via the Green Line.

The following buses pass near the hospital:

Bus Stop	Number	Route
Dorset St.	11	Wadelai Pk to Sandyford Business District
	16	Dublin Airport to Ballinteer (Kingston)
	13	Harristown to Grange Castle
	40 / 40B / 40D	Charlestown Shopping Centre to Liffey Valley / Parnell St to Toberburr / Parnell to Tyrrelstown
	122	Drimnagh – Cabra
	41	Lower Abbey St to Swords Manor
	33	Lower Abbey St to Balbriggam
	747	Heuston Station to Dublin Airport
	120	Parnell to Ashtown Rail Station
	38 / 38A	Burlington Rd to Damastown
Mountjoy Sq.	46A	Phoenix Park to Dun Laoghaire
	46E	Blackrock Station to Mountjoy Sq.

CHI AT CRUMLIN

The canteen is available:
 Mon – Fri 8.00 am – 2.00 pm

Oasis Café (opposite the canteen)
 Mon – Fri 7.30 am – 10.00 pm

Jelly Bean (beside OPD)
 Mon – Fri 7.30 am – 5.00 pm

Three vending machines are located behind Emergency Department, behind the canteen and at second cross roads on main corridor.

Shop (located at the main entrance ground floor)

Mon – 8.30 am – 8.00 pm
 Fri Sat 10.30 am – 7.00pm
 Sun 9.30 am – 8.00pm

ATM is located opposite Jelly Bean behind Emergency Department.

CHI at Crumlin is a smoke free hospital; smoking is prohibited on hospital grounds.

Chapel is located on the ground floor.

Parents Accommodation:

Rooms available for parents to stay: (01) 409 6622/E-mail: parents.acc@olchc.ie

Transport:

Bus waiting times are available on screen outside the Emergency Department. The following buses pass near the hospital:

Number	Route
27	Clare Hall to Jobstown
56A	Ringsend Road to Tallaght (The Square)
77A	Ringsend to Citywest
122	Ashington to Drimnagh Road
123	Walkinstown to Marino
150	Hawkins St to Rossmore
151	Docklands to Foxborough



CHI AT TALLAGHT

Canteens and Coffee Shops

The hospital canteen is called the Phoenix and provides a variety of hot meals.

Mon – Fri 7.00 am – 3.00 pm

The Baxter Storey Coffee Shop (main atrium) Mon – Fri 7.30 am – 9.30pm

The Volunteer Coffee Shop

Located in the reception area of the main entrance hall. It is staffed by volunteers

Mon – Fri 7.30 am – 4.00 pm

Tea and coffee-making facilities are available in CHI at Tallaght.

ATM is located in main foyer beside AIB.

TUH is a smoke free hospital; smoking is prohibited on hospital grounds.

Chapel is located on level 1.

Transport:

The hospital is accessible on the red Luas line.

The following buses pass near the hospital:

Bus Stop	Number	Route
Tallaght Hospital	27	Clare Hall to Jobstown
Tallaght Hospital/Belgard Road	54A	Pearse Street to Ellensborough/Kiltipper Way
Tallaght Hospital/Belgard Road/The Square	65	Poolbeg Street to Blessington/Ballymore
Tallaght Hospital/Belgard Road/The Square	77A	Ringsend Road to City West



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